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Poly Cystic Ovarian Syndrome in India: A Socio-cultural Perspective

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Important Abbreviations and Terms

Menstrual Cycle (MC)

Oral Contraceptive Pills (OCP)

Poly Cystic Ovarian Syndrome (PCOS)

Oral Contraceptive Pills (OCP)

Hyperandrogenemia: a medical condition characterized by excessive levels of androgens (male sex hormones such as testosterone) in the female body and the associated effects of the elevated androgen levels.

Oligomenorrhea: Infrequent (or, in occasional usage, very light) menstruation. More strictly, it is menstrual periods occurring at intervals of greater than 35 days, with only four to nine periods in a year.

Primary Amenorrhea: the failure of menses (periods) to occur by age 16 years

Socio-economic Status (SES): an economic and sociological combined total measure of a person's work experience and of an individual's or family's economic and social position in relation to others, based on income, education, and occupation.

Hyperandrogenemia: a medical condition characterized by excessive levels of androgens (male sex hormones such as testosterone) in the female body and the associated effects of the elevated androgen levels.

Abstract

This study examines the ways in which cultural determinants affect the health-seeking, diagnosis and treatment process of women with Poly Cystic Ovarian Syndrome (PCOS) as well as the underlying socio-cultural causes of the illness. Often coined as a "lifestyle disease", PCOS is becoming a growing concern of physicians and women alike as its prevalence is on the rise with no signs of slowing down. Lifestyle, stigmas/taboos, PCOS's effect on identity, and quality of life are all areas that are examined throughout this paper. A mixture of patients' and doctors' perspectives on PCOS were gathered throughout a three-week time period in Jaipur, India. Questions were tailored to extract information that could further the understanding of the socio-cultural aspect of PCOS and its etiology. Furthermore, this study seeks to understand how India's social and cultural climate affect the health-seeking, diagnosis, and treatment of women with PCOS and how these factors contribute to its increasing prevalence. The findings revealed that unhealthy lifestyle, diet, lack of exercise, stigmas, and insufficient awareness impact the health outcomes of women who suffer from PCOS.

Introduction

Socio-cultural determinants play a predominant role in the health outcomes of women in general, and the rising prevalence of PCOS in particular. Lack of preventive measures as well as low awareness about PCOS has given rise to the exponential increase in PCOS all over the world. An increase in biological studies pertaining to PCOS in the recent past has brought forth new insights which were hitherto not available. This has allowed doctors to treat PCOS better than ever before, yet a large piece of the puzzle is still missing. There are still gaps in the understanding of the socio-cultural perspective of a rampantly spreading illness. It is important to understand the socio-cultural components of illness in order to ensure not only proper treatment, but also prevention. Awareness surrounding PCOS in India is alarmingly low even among educated women from a higher socioeconomic status. Therefore, this study, through interviews with patients and doctors from both public and private hospitals, seeks to understand why so few women are aware of PCOS as well as the social and cultural reasons for its increasing prevalence.

What is Poly Cystic Ovarian Syndrome?

In an age of exponential upsurge in chronic illnesses in India, many experts are investigating how to best deal with this serious public health problem. Ranging from reproductive disorders to diabetes, chronic illness affects every aspect of people's lives. These illnesses are difficult to diagnose as well as treat due to their complex nature and multitude of symptoms. One such illness, Poly Cystic Ovarian Syndrome (PCOS), a chronic endocrinal disease that affects only females of child-bearing age, has become an increasing health concern

in the lives of Indian women. Not only can PCOS cause a myriad of uncomfortable symptoms, but it may also lead to serious and chronic diseases such as infertility, heart disease, and even ovarian cancer, all of which are difficult to treat (Choudhary et al.). Early diagnosis of PCOS is critical in order to relieve symptoms and prevent long-term health consequences.

Due to an increase in research on PCOS, the causes of this illness have become better known as researchers have discovered that PCOS and diabetes are often comorbid (Choudhary et al.). According to many recent studies, weight-related illnesses have sky-rocketed in India due to rapid urbanization, easy access to unhealthy food, and lifestyle changes. These lifestyle changes include a lack of adequate exercise, prolonged use of technology, and the rising consumption of unhealthy food. The unfortunate effect of these changes is an increase in the number of women with weight issues and chronic illnesses that accompany weight gain.

Furthermore, PCOS should be at the forefront of public health concerns due to the fact that it is widespread and affects from 2.2% to as high as 26% of women globally (Choudhary et al.). Therefore, all doctors, no matter the specialty, should be able to recognize the signs and symptoms of PCOS. In addition, the patient should be able to undergo a sonography, or ultrasound, examination as doctors have proved that this is one of the most important steps in the final diagnosis of PCOS. Seven out of seven patients that were interviewed for this study underwent a sonography as the final step in the diagnostic process. As a further step, researchers also recommend that the patient's insulin levels should be checked because PCOS and insulin resistance are often comorbid. If left unchecked, insulin resistance can lead to adult metabolic syndromes and ultimately to the development of type 2 diabetes (Choudhary et al.).

PCOS has an unclear etiology due to its many risk factors and somewhat recent entrance into medical history in 1935 (Sirmans and Pate). These risk factors include type 1 and 2 diabetes,

gestational diabetes and a family history of obesity. Oligomenorrhea, amenorrhea, and prolonged erratic menstrual bleeding are key symptoms of PCOS and often lead women to initially seek treatment. However, 30% of women with PCOS have normal menstrual cycles, which further indicates that PCOS has a tricky diagnostic process (Sirmans and Pate). According to the Rotterdam criteria, the most widely accepted diagnosis guidelines, one must have two out of the following symptoms to be diagnosed with PCOS: presence of oligomenorrhea after two years of menarche (first occurrence of menstruation) or primary amenorrhea at the age of 16 years, polycystic ovaries on the ultrasound along with ovarian size of more than 10cm, and hyperandrogenemia, or androgen excess, should be present (Sirmans and Pate). Doctors consider a score of 8 for hirsutism, or unwanted male-pattern hair growth on a woman's face, chest, and back, and severe acne as positive for hyperandrogenemia (Sirmans and Pate).

Moreover, a primary symptom of PCOS is an imbalance in hormone levels, which is believed to be the root cause of the irregular menstrual cycles. Over 80% of women who have excess androgen are also diagnosed with PCOS (Sirmans and Pate). These hormonal imbalances lead to the development of several small collections of fluid (follicles) which fail to regularly release eggs (Sirmans and Pate). Women found to have external symptoms such as hirsutism and irregular menstrual cycles are then examined more closely via ultrasound. If the patient has multiple cysts on her ovaries, her diagnosis of PCOS will be confirmed. This leads to the question of what exactly are the root causes of PCOS, and how do Indian women, particularly in Jaipur, grapple with being diagnosed with a reproductive disorder?

Methodology

Who was interviewed:

This study is the culmination of seven personal patient interviews, four personal interviews with gynecologists, and one personal interview with an endocrinologist. Personal interviews were a vital component of gaining insight into the social determinants of PCOS from both the patient and doctor perspective. Patients and doctors were interviewed with a mixture of qualitative and quantitative questions from a pre-made questionnaire prepared by the researcher. The qualitative questions were left open-ended and up to the interviewee's interpretation for maximum insight into the interviewee's way of thinking. There were no restrictions placed on the age of patients to be interviewed. However, all patients interviewed, besides one, were under the age of 26. The last patient interviewed was 48 years old. The time that had lapsed between the interview and the diagnosis of PCOS varied considerably. This ranged from the patient having been diagnosed only five minutes prior to the interview to having had PCOS for ten years. Often, the longer the patients had been dealing with PCOS, the easier it was for them to open up about their experiences. In contrast, women who had just been diagnosed with PCOS had not been given sufficient time to come to terms with their illness which may have affected their answers. Patients came from a variety of socioeconomic backgrounds ranging from low socioeconomic status (SES) to high SES. Three patients were treated and interviewed at Gangori Hospital, a public hospital in Jaipur, India. The remaining four patients attended treatment at private gynecological clinics. All names were changed in order to protect privacy.

Three of the gynecologists who were interviewed, Dr. Acharya, Dr. Gupta, and Dr. Patel, are employed at Gangori Hospital. In addition, Interviewee Dr. Chhabra, also a gynecologist,

works at a private gynecology clinic. The endocrinologist, Dr. Bali, is employed at a private endocrinology clinic. The endocrinologist can play an important role in the treatment of PCOS because patients with PCOS often consult an endocrinologist for conditions relating to weight. These conditions range from weight control to metabolic syndromes, which are often found to be comorbid with PCOS (Sirmans and Pate). All doctors were female except for the endocrinologist.

Type of Hospital

In India, treatment at private hospitals is exponentially more expensive than at public hospitals. Therefore, private hospitals cater to patients from the upper-middle to upper class. In contrast, public hospitals usually serve people from low to middle class socioeconomic strata. Normally, people seeking treatment at public hospitals are more likely to be coming from more conservative households. People who have a higher education are likely to come from better off economic backgrounds, and therefore seek treatment at a private hospital. It was assumed that given the higher socioeconomic strata, patients interviewed at the private hospitals would be more informed about PCOS.

Study Location

The researcher chose Jaipur, India as the location for this study due to its diverse population and easy access to both public and private hospitals. By conducting this study in Jaipur, the researcher was able to interview patients from diverse socioeconomic and cultural backgrounds. The assortment of patients, doctors, and treatment centers used in this study ensured that diverse points of view were gathered to obtain the most accurate information possible. Therefore, this data is not biased toward one group of people, but rather a unique range of stories from women and doctors stemming from all walks of life.

Cultural Connotations: Illness vs. Disease

Reproductive disorders are multi-faceted illnesses and each individual reacts to his/her diagnosis differently. Despite an increase in awareness and a decline in stigmatization, women's reproductive health has always had a complicated background, especially in conservative-leaning countries such as India. Every society not only experiences reproductive health biologically, but also culturally. On one hand, an illness is the overarching perception individuals have of their ailment which can be influenced by culture, societal norms, and a variety of other social determinants (Krishnakumari et al.). On the one hand, a disease is defined as "an abnormal condition of an organism which interrupts the normal bodily functions that often leads to feeling of pain and weakness, and usually associated with symptoms and signs" (Krishnakumari et al.). The chief difference between diseases and illnesses is that diseases exist regardless of whether or not they are culturally recognized, while illnesses do not exist until they are culturally recognized (Krishnakumari et. al). In fact, how the patient reacts to his/her biological symptoms is what characterizes the illness. Multiple studies have shown that environmental factors shape the pathogenesis of PCOS (Brady et al.). Analyzing not only the biological aspect, but also the cultural aspect provides for a holistic approach to further understanding PCOS.

Furthermore, PCOS is not just a biological condition. It is also defined as a metabolic, hormonal, *and* a psychosocial disorder that impacts patients' quality of life (Brady et al.). Women with PCOS are at a higher risk of developing disorders such as anxiety, depression, and a decreased quality of life due to the large amount of stress this illness may cause them (Brady et al.). Its symptoms affect all aspects of a woman's life from her marriage to self-confidence. Therefore, it is vital to examine the ways in which this disorder affects patients' lives from first

hand encounters. Throughout this paper, the experiences of patients suffering from PCOS will be the primary focus. The researcher will attempt to uncover what the illness means to the patient, and how that affects her subsequent treatment and lifestyle.

Symptomology & Stigmas

From the patient:

"In marriages, it (PCOS) can make problems because it is very hard for a woman to bear a child. At that time, everyone kept it as a secret. I didn't know who had it or didn't have it because no one talked about it." – Ranu, 23

An extremely important component of Indian culture is the ability to bear children. It is a deeply-rooted belief that a woman's value directly correlates to her ability to produce children. Often, when this is affected, a woman's identity is also negatively affected. Throughout numerous doctor interviews at both private and public hospitals, each one reiterated that women, and especially married women, are deeply concerned about their fertility. Due to this adamant concern, irregular menstrual cycles are what often initially spur women to seek treatment. While, according to patients and doctors, PCOS does not carry any defined cultural stigmas or taboos that would prevent a woman from seeking treatment, it does have a reputation of causing infertility as it is the leading cause of infertility among women (Brady et al.). Dr. Chhabra, a private gynecologist, stated that, "The public doesn't know about PCOS. There is no cultural problem, but people are very concerned about menstrual disorders, acne, hirsutism. Those things impact the child's future. Their marriage, that's why they think about it" (Dr. Chhabra, personal communication). Patients and doctors do not necessarily define PCOS as having a stigma, but it

is clear that it negatively affects the patients' lives. Dr. Chhabra even went as far as to say, "any disease that has a negative impact on the marriage market is seen as bad" (Dr. Chhabra, personal communication). Dr. Acharya, Gangauri Hospital, explained that the more uneducated individuals were, the more likely they were to see the diagnosis as something detrimental. When asked about how husbands may view their wives condition, she explained that more educated men will likely not have as negative of a reaction, "but for a lay person who doesn't know anything about this, then he will take it to another level. He will say, "My wife is not conceiving" so it will become a big issue within the marriage and negatively affect it" (Dr. Acharya, personal communication). Many doctors stressed that while patients often panic upon first receiving their diagnosis, the doctors make sure to counsel and educate women about PCOS in order to curb any further distress. By changing their lifestyle and taking their medication (if necessary), then most, if not all, of the symptoms will go away. Unfortunately, not all patients follow the treatment plan given to them, and sometimes the treatment guidelines are not properly transacted to the patient as discussed in subsequent sections.

Effects on Identity

From the patient:

"Having PCOS actually negatively impacts you mentally. I mean your body isn't in your control." –Navya, 26

"I feel shy in front of my husband because of the hairs on my chest. That's why I came to the doctor to discuss my problem."- Kyra, 21

Two points of view were gathered from interviews: one being from the doctor and the other from the patient herself. Four out of the four gynecologists as well as the endocrinologist interviewed all agreed that PCOS had a negative effect on a woman's self-esteem. The factors that contributed to the worsening self-esteem included low confidence due to physical appearance, worry about fertility, and a woman's marriage prospects being affected by her illness. When Dr. Acharya, a public gynecologist, was asked about how PCOS may impact a woman's self-esteem she explained, "It is negative. Most of the women have symptoms of hyperandrogenism. You've got pimples, you've got fat and your skin is very oily and you don't have periods regularly. It always affects your mental health" (Dr. Acharya, personal communication). Another doctor spoke similarly, "PCOS is associated with psychological problems. People go into depression because of their hair growth and their appearance" (Dr. Chhabra, personal communication). Hirsutism is often described as one of the most disturbing effects of PCOS and can cause a great deal of emotional stress on the patient. Furthermore, a study on how PCOS affects quality of life states that "Women with PCOS who experience hirsutism have often expressed that they feel "unfeminine," "freakish," "weird," and "different,"

(Brady et al.). One patient agreed with these statements, saying she even felt embarrassed for her husband to see her body due to the large amount of hair on her chest (Kyra, personal interview).

On the other end of the spectrum, hair loss is also found to be a frequent symptom among PCOS patients. A patient stated,

> "I used to have patches on my body. It wasn't unusual for me. But I started shedding hair from the top of my head. I started getting bald patches because of PCOS so that was really traumatizing. I don't think it's necessarily PCOS but the things that come along with that. I have some friends who started growing facial hair and some hair on their chest and that is very traumatizing" (Navya, phone communication).

The use of the word traumatizing conveys how difficult it can be for patients to deal with the external symptoms of PCOS.

Additionally, other patients said that PCOS caused mood swings, fatigue, weight gain, and a decline in libido and that PCOS "slowed down their bodies" (Navya, phone communication). If a patient already feels depressed, then it may be even more difficult for her to start exercising or eating healthily which is an incredibly important component in the treatment of PCOS. The patient continued to say that, "I did not feel very active, I wasn't sexually aroused, and things like that. I was very moody" (Navya, phone communication). Weight gain was an issue that all seven patients touched upon as something that greatly bothered them about having PCOS. Weight is almost always a concern for women due to the value that modern society has placed upon it. Being overweight is often accompanied by feelings of discontent towards oneself as expressed by all the patients interviewed. One patient described "I was gaining weight and all so I was going through a lot of things like tension" (Richa, phone communication). In general, women who experienced only one symptom of PCOS seemed to be more optimistic and at peace

with their illness. One woman who only experienced irregular menstrual cycles (MC's) later spoke to friends who dealt with hirsutism and acne. She said that if she would have had those symptoms along with the concern of irregular MC's, it would have deeply affected her self-esteem and in turn, her sense of self (Navya, phone communication). Ranu, a patient who has experienced irregular menstrual cycles, hirsutism, mood swings, and acne, said that she was "so irritated, frustrated, and tense" when she was diagnosed in 2014 (Ranu, personal communication). She felt as though her symptoms would never improve. She commented that once she found out just how prevalent PCOS was from speaking to her mom and friends, she did not feel as alone or distraught. Another patient spoke similarly, stating that she felt comforted once her doctor explained that many women are going through the same situation, and to not feel discouraged. Dr. Chhabra, private gynecologist, said counseling is a huge part of the diagnosis process. However, more needs to be done to prevent patients from feelings of isolation which can foster mental health issues such as anxiety and depression.

Delayed Health Seeking & Lack of Awareness

From the patient:

"Actually, most of the people do not know about PCOS. If my mother knew about PCOS I would have gone to the right treatment in the first place" – Navya, 26

Delaying treatment for reproductive disorders is not uncommon in India and happens for various reasons. In a study done on health seeking-behavior of 315 women from Amritsar slums, it was found that 53% of them had one or more health problems (Gill KP et al.). Only 25.2 % of women sought treatment for their ailments and only 19.3% out of these women sought treatment

from qualified health professionals (Gill KP et al.). Women belonging to the upper caste were found to be 2.8 times more likely to seek treatment than those from a lower caste. Similarly, literate women were 3 times more likely to seek treatment. This study further demonstrates that health seeking behaviors are prone to the influence of class factors which may delay visiting the doctor and/or compliance with treatment.

Socio-economic status can determine how quickly one seeks treatment as well as awareness of PCOS. Five out of five doctors interviewed stated that the majority of women who sought treatment had not heard of PCOS prior to being diagnosed. Additionally, six out of the seven patients interviewed had never heard of PCOS prior to their diagnosis. One patient responded that she had heard of PCOS through casual discussions, but had minimal information about the topic. One doctor also stated that women now "talk to each other more frequently" and will learn about the illness through their friends (Dr. Patel, personal communication). One patient commented that she had friends who were diagnosed with PCOS which is how she first heard of it, but did not know much about the illness until she was diagnosed (Anaya, personal communication).

In a study of PCOS in Bhopal it was found that lack of awareness (78.4%) was a risk factor strongly associated with developing PCOS (G. Mahesh et al.). The lack of awareness surrounding PCOS is quite startling considering this study was completed in an urban area, although according to Dr. Chhabra, this is not an uncommon occurrence. However, urban women have a higher chance of possessing prior knowledge about PCOS due to increased access to the internet. Women who have internet access are able to see that they may suffer long-term consequences as a result of delaying treatment. Therefore, they will naturally come in sooner than women who do not have access to this information. She also brought up the point that the

general population is unaware of PCOS and that most women discover what it is through research on the internet, especially if they are having menstruation and infertility issues. Women who are most likely to have prior knowledge are those coming from a higher socioeconomic background due to their ability to look their symptoms up on the internet. However, almost all of the women interviewed had not heard of PCOS prior to their diagnoses despite some patients having displayed symptoms since puberty. Alarmingly, this means that women are not aware of PCOS no matter their socioeconomic status or their location in an urban area.

This topic was further explored by speaking to Dr. Gupta, a gynecologist from a public hospital. She stated, "The people who are educated read the internet then come to us. But that person stays in private hospital. Only 1% of people will come well-read because this is a public hospital. Not very many educated people come to us" (Dr. Gupta, personal communication). Dr. Gupta's words demonstrate that although most women do not know about PCOS prior to being diagnosed, women from a lower socioeconomic background have an even higher chance (99%) of not knowing what it is. When Navya, a patient who was mistreated and misdiagnosed, was asked about whether or not she had heard of PCOS prior to her diagnosis she stated, "Actually, most of the people do not know about PCOS. If my mother knew about PCOS I would have gone to the right treatment in the first place" (Navya, phone communication).

When women experience the external symptoms of PCOS such as hirsutism and acne, they are more likely to seek treatment from beauty parlors first and when that does not work they will come to a doctor for treatment (Dr. Chhabra, personal communication). Usually, due to an underlying imbalance in hormones, these symptoms are not treatable without the help of a gynecologist. After unsuccessful treatment at a beauty parlor, the stylist will then suggest that the woman should get her hormones checked by a doctor. This is when the patient will initially come

in for a consultation (Dr. Chhabra, personal communication). Aditi's story with PCOS began when she developed incredibly painful facial acne at the age of 36. Her first thought was to consult a dermatologist as she had never heard of PCOS and therefore did not know its symptomology. After switching between four dermatologists with no success in curing her acne, it was finally suggested that she should visit a gynecologist and have her hormones checked. This is how she came to know that she had been suffering from PCOS all along. When asked about how PCOS affected her self-esteem, she stated "Initially when the breakouts happened I was a little socially scared to go out because my face looked bad. Once I started taking medication and exercising it was not so much an issue" (Aditi, personal communication). For five months, Aditi unintentionally delayed seeking the correct treatment due to her unawareness of PCOS. Yet, Aditi credits her external symptoms, rather than her internal ones, as the motivating factor to change her lifestyle. "I was more worried about my breakouts than my PCOS or missed periods. That was physically appearing on my face. It was troubling and hurting. It was really bad. The physical appearance mattered to me more at the time" Aditi explained (Aditi, personal communication).

When asked about why one sought initial treatment, doctors and patients gave varied responses. According to Dr. Chhabra, private gynecologist, urban women suffer much more from external symptoms of PCOS due to their lifestyle (Dr. Chhabra, personal communication). This can play a large role as to why they seek treatment in the first place. In contrast, rural women are more likely to seek treatment due to menstruation irregularities and infertility issues. However, a majority of the patients from urban areas expressed that irregular menstrual cycles were their main cause of concern. According to Dr. Chhabra, the rural population normally seeks treatment after they begin having menstruation problems (adolescents) and/or infertility issues (usually in

their late 20's). Irregular menstruation scares women into seeking treatment because they are taught that it could be a sign of infertility (Dr. Gupta, personal communication). In an interview with Dr. Chhabra, a private gynecologist, she stated that almost all women will attempt to treat themselves with home remedies before coming into her clinic, although rural women were much more likely to only consult traditional or home remedies like homeopathy, a type of alternative medicine. Therefore, they were more prone to delaying coming in for treatment much longer than urban women.

Family was a theme that frequently came up from both doctors and patients. Often, the family is worried about the daughter being infertile as the ability to bear children is a prominent part of Indian culture as discussed earlier in the paper. It plays a large role in many Indian women's identity within the family. When asked if women delay seeking treatment, Dr. Chhabra commented,

> "It's difficult to say, you know, PCOS comes in as a slow process. It does not happen overnight. If menstrual issues remain a problem then patients seek treatment. Some people are very scared. Sometimes the parents are very concerned because the adolescent girl is not getting her period so they get worried, then they bring her in for a consultation. Otherwise, if the symptoms are mild they wait 5 or 6 months. If there is hirsutism, then they are more concerned and seek treatment earlier. Infertility is very variable. Some come even after 3 months. if they are not able to conceive, then they come. Others come after 3 years" (Dr. Chhabra, personal communication).

Dr. Acharya, a public hospital gynecologist, stated that sometimes mothers tell their adolescent daughters to wait before rushing to seek treatment. These women and girls are most at risk (Dr. Acharya, personal communication). She went on to say that in India it can sometimes be difficult

for children to open up to their mothers about reproductive issues and even when they do they feel uncomfortable doing so. However, seven out of seven patients stated that their mothers, as well as their families, were supportive throughout the treatment seeking, diagnosis, and treatment process.

Additionally, unmarried adolescents do not come to the gynecologist as frequently, if at all, when compared to married women, who are actively trying to conceive. These young women may not be diagnosed until they are married, which can cause issues with fertility and within the marriage (Dr. Acharya, personal communication). According to Dr. Patel, a startling 30% of PCOS cases are accidentally diagnosed due to lack of awareness and knowledge (Dr. Patel, personal communication).

Lifestyle as a Cause of PCOS

From the doctor:

"Obesity is a big issue in all girls. In my opinion, the first cause of PCOS is obesity. It affects everything."- Dr. Patel, Public Gynecologist

From the Patient:

"She (doctor) suggested that I do something like exercise or cycling. Sometimes I don't exercise because I am a student and I don't have time." – Tanya, 25

Every single patient and doctor who was interviewed conveyed that lifestyle was one of the main etiological causes of PCOS. When speaking to doctors, they expressed frustration due to their patients not taking life-style change seriously enough. A variety of factors have contributed to a decline in the quality of lifestyle among urban Indian women. Issues that

gynecologists are concerned about include easy access to unhealthy foods which range from traditional Indian sweets to western fast food, little to no exercise, unhealthy sleep patterns, and too much time focused on academics. Both doctors and patients expressed frustration when speaking about the obstacles that must be overcome in order to fully change one's health régime in a sustainable way. When asked about cultural causes for unhealthy lifestyles, Dr. Patel, a gynecologist from Gangori Public Hospital stated

> "They (children) get up late in the morning and spend prolonged hours in front of the internet and their mobile phone. This is the most important reason. They are not taking healthy diet. They don't want to play outside or do household work. If a child is asked to bring this water or make some tea or fold their bedsheet, they just don't want to do it. They are basically very inactive. School pressures also don't allow children to grow up naturally" (Dr. Patel, personal communication).

This response reflects much of the frustrations which the other gynecologists and endocrinologist articulated. Many of these unhealthy habits are byproducts of an urban, modern lifestyle. Women living in urban areas are able to rely on easy modes of transportation such as rickshaw and Uber which results in walking less than rural women. According to Dr. Chhabra, a private gynecologist, "In urban areas it's all the same. In rural areas, it's a little less. Their activity is reduced but the access to fast food is not there. They have to walk because of the rural setting. In an urban setting, it's all across the globe. Addiction to chips and fast food is prevalent". Currently, PCOS is not as large an issue in rural areas as it is in urban areas, but it is important to point out that this may be quickly changing. While rural women are at a lower risk for developing PCOS since they still incorporate more physical activity into their daily lives than

urban women, studies show that they are also beginning to suffer from the effects of an unhealthy diet.

In an epidemiological study of many rural Indian villages, it was found that

> "Participants identified three primary factors that have catalyzed dietary changes leading to rising prevalence of diabetes. First was the increasing presence and influence of "government shops," the local term for state-mandated fair price shops operated through the Public Distribution System (PDS). Second was an increasing availability of 'new' foods at low prices at local food stalls and shops. And third was a shift in agricultural patterns due to the financial incentives of commercial crop production" (L. Matthew et al.).

The PDS is an Indian government sponsored initiative that includes chains of shops which distribute basic food and non-food commodities to disadvantaged citizens at subsidized rates ("Public Distribution System"). Some say this program has catalyzed the shift away from traditional diets, which include more reliance on locally grown food, while the "new" urban diet consists of fast foods that are not considered healthy. Though diabetes is usually not initially found when diagnosing PCOS, patients with PCOS are at a higher risk for developing it later in life or during pregnancy in the form of gestational diabetes.

Furthermore, an epidemiological study of 502 urban and 566 rural women found that the prevalence rate of PCOS was 8.9% and 1% respectively (Bharathi et al). The overall prevalence was 6%. 40% of urban and 16.6% of rural women with PCOS were also obese (Bharathi et al.). The lower prevalence of obesity in rural areas is attributed to many factors, some of which are diet and level of physical activity. Rural women perform more manual labor than rural women and are more likely to eat nutritious, home-cooked food. Junk food consumption was double in

urban areas (Bharathi et al.). Moreover, startling statistics about the increasing rates of diabetes in India have emerged in recent years, one being that "A review of studies in rural India conducted by Misra and colleagues (2011) found that prevalence increased from 1.9% in 1994 to upwards of 12% in 2009," (Little et al.). Despite PCOS currently being considered a rare illness in rural areas, as urban lifestyle habits continue to spread to these regions, there is a higher potential for an increase in PCOS, and therefore there is need for more education and preventive care. It also displays the need to re-examine urban lifestyle and ways that are detrimental to one's health so that timely corrective measures may be taken.

A prevailing theme in doctor's responses when asked about the prevalence of PCOS, is that PCOS is most common in women from higher socioeconomic status. In Dr. Acharya's words,

> "I think that PCOS is more common in people of a higher socioeconomic strata. It's not very common in India in lower class because they do much of the physical activity. Even the females in the house do much of the housework so PCOS is not so common"

A study that examined how socioeconomic status may affect the risk of developing PCOS found that there was "a strong association between low childhood socioeconomic status and PCOS, primarily among women with high SES in adulthood," (Merkin et al.). This somewhat supports Dr. Acharya's claim in PCOS being more rampant among women from higher socioeconomic strata. However, this study is not specific to India which has its own unique social determinants that must be considered. Due to a lack of studies in this area, especially in India, it is difficult for researchers to pinpoint the exact correlation between SES and PCOS.

Chronic Illness and PCOS

Women with PCOS are found to be at a much higher risk of developing other chronic illnesses. When doctors were asked about how at risk PCOS patients were for developing diabetes, they responded that while most women who are first diagnosed with PCOS do not have diabetes, they are at a much greater risk for developing gestational diabetes and type 2 diabetes later in life (Dr. Gupta, personal communication). PCOS patients are also more at risk for developing other disorders such as high cholesterol, hypertension, and cardiovascular problems (Dr. Chhabra, personal communication). According to Barbieri and Ehrmann, "Insulin resistance and hyperinsulinemia can occur in both normal-weight and overweight women with PCOS. Among women with PCOS, up to 35 percent of those who are obese develop impaired glucose tolerance ("prediabetes") by age 40 years, while up to 10 percent of obese women develop type 2 diabetes. The risk of these conditions is much higher in women with PCOS compared with women without PCOS". These startling statistics demonstrate that women with PCOS are pre-disposed to developing additional life-style related chronic illnesses. Patients with PCOS should be continually monitored for these illnesses.

However, no patients expressed concern about developing diabetes or hypertension in the long-term. They appeared more worried about PCOS's immediate effects like irregular periods, infertility and hair growth. However, women were concerned about being overweight as they felt unattractive. Obesity and its side effects are something that must be addressed in order to prevent the prevalence of PCOS from continuing to rise. In Dr. Patel's words, "Obesity is a big issue in all girls. In my opinion, the first cause of PCOS is obesity. It affects everything" (Dr. Patel, personal communication).

Treatment Compliance

From the patient:

"Most people are still popping pills for no reason. They don't know why it is happening. They end up taking the same medications life long and then they stop suddenly. Eventually their ovaries increase in size and then then the next big news you have is that you can't conceive"

-Navya, 23

Treatment does not work unless the patients are willing to actively participate in their treatment plan. Unfortunately, PCOS is an illness that usually demands a complete lifestyle change in its sufferers. Upon interviewing, it was found that seven out of seven patients were recommended to change their diet as well as start exercising, but seven out of seven patients also felt they had difficulty following these instructions for a variety of reasons. Furthermore, five out of five doctors felt as though most of their patients struggled to change their lifestyle in order to decrease symptoms of PCOS. Dr. Chhabra and Dr. Bali, an endocrinologist, thought that about 50 percent of their patients actually followed through with their directions to eat healthier, exercise regularly, and lose weight. Dr. Chhabra spoke of a patient who was 90 kilograms and overweight. This patient was having treatment for secondary infertility, or the inability to become pregnant or carry a baby to term after previously giving birth ("Secondary Infertility"). Dr. Chhabra asked the patient why she had not lost weight and the patient replied that she had just now stopped eating fast food. This was supposedly 6-7 months after Dr. Chhabra had first recommended she eat more healthily. Dr. Chhabra stressed that this was just one example of many in which women refused to comply with their treatment recommendations. When asked if patients were taught about nutrition in school, doctors agreed that adolescents were educated, but

simply did not adhere or take their diet seriously enough. They attributed this to too many temping, unhealthy food options (KFC, McDonalds, etc.) as well as negative influence from their peer group (Dr. Chhabra, personal communication).

India is increasingly producing some of the best academics, doctors, scientists, and IT specialists in the world. It is no secret that completing a higher education and finding a good job are primary focuses of many Indian youth. Aside from personal pressures, parents are also pushing their children to be successful. Many doctors conveyed that in today's society, one's health is simply no longer a priority. Both patients and doctors commented that education and careers were at the forefront of one's concerns and it is easy to let health become a secondary priority.

Ranu, a woman who has been suffering from PCOS since 2014, spoke about how difficult it was to be diagnosed with the disorder when she was just a 19-year-old, first year nursing student. She admitted that at first, she struggled with changing her lifestyle due to the amount of pressure she was under. After a year, she managed to bring her weight down, but has recently struggled with trying to keep it off and along with that, the symptoms of PCOS are once again presenting themselves (Ranu, personal communication). In her words, "Just because of the lifestyle we are all running to work and towards our goals so it's very hard to focus on your own self. That's why it's hard. I was in college at that time, my first year. I was so tired and I had to look after my health" (Ranu, personal communication). In contrast, Anaya, a 22-year-old who was diagnosed with PCOS just a month ago, said that her inability to change her life-style was chalked up to laziness that PCOS itself had caused (Anaya, personal communication).

Aditi, whose story began with acne, was first prescribed oral contraceptive pills (OCP's) by her gynecologist. However, Aditi credits the clearing up of her acne to the weight she lost

through joining a gym and changing her diet. 12 years later, all of Aditi's symptoms have dissipated without the need for oral contraceptive pills. Only occasionally (about once or twice every 2-3 years), if she has a flare up, her gynecologist will put her back on the OCP's. "The major reason I feel like I controlled my disorder was because of weight loss. That really plays a big role in aggravating my PCOS" (Aditi, personal communication).

Throughout the interviews, a topic that came up frequently was the disconnect between doctor and patient regarding treatment plans. Patients spoke about their frustrations with not being given correct treatment by their gynecologists. Navya had to visit several gynecologists before finding one who treated her in a way that worked for her (Navya, phone communication). The first gynecologist she received treatment from diagnosed her symptoms of irregular menstrual cycles and hirsutism as merely adolescent stress and potentially a deficiency in an essential nutrient. No further tests were performed to find the root cause of her symptoms. After speaking to another gynecologist, she was given a sonogram which confirmed that she had PCOS. She was then prescribed hormone pills to regulate her symptoms as well as to regulate her levels of estrogen and testosterone. This gynecologist relayed very little information about the importance of lifestyle change to Navya, which she had little knowledge about at the time. Navya conveyed that,

> "It's very difficult to find the right treatment. So I kept on changing my gynecologist because they used to give me contraceptive pills and I had to take it for 21 days. I did not feel very active. I wasn't sexually aroused and things like that. I was very moody. It actually, I think it used to give my body a false alarm that everything was fine, and I used to have my period. But as soon as I stopped taking those medicines I was back to square one" (Navya, phone communication).

Due to her dissatisfaction with the failing treatments, Navya switched to another gynecologist who insisted she also take oral contraceptives. Navya described this as the "primary treatment" that every gynecologist claimed would undoubtedly cure her of PCOS. What these doctors failed to realize is that what works for one patient, may not work for another. From Navya's point of view, "popping pills" is not a sustainable way to treat PCOS. Finally, she met with Dr. Rajeev who explained the importance of lifestyle change and that pills may be helpful in the first month of treatment to regulate hormones, but exercise and weight-loss would be the most maintainable and healthy way in which to keep the symptoms at bay. The following words from Navya show the importance in the need for more awareness and increased communication between doctors and patients:

> "Most people are still popping pills for no reason. They don't know why it is happening. They end up taking the same medications life long and then they stop taking it. Eventually their ovaries increase in size and then then the next big news you have is that you can't conceive" (Navya, phone communication).

Navya's experience demonstrates a need for increased communication between patient and doctor. Patients must be informed that OCP's are often not a long-term solution to treating PCOS, and that a variety of other methods that modify lifestyle habits such as exercise and diet are just as important, if not more so.

In contrast, Diya, felt her treatment plan of oral contraceptive pills (OCP's) has worked well for her. Her gynecologist described the importance of exercise and diet, and that hopefully she would one day be off the pills and able to manage PCOS symptoms through diet and exercise alone. Currently, she is not taking any pills for PCOS and has no symptoms, although she does

follow a rigorous exercise schedule which has resulted in a large amount of weight loss since first being diagnosed ten years ago.

Additionally, doctors are beginning to recognize that PCOS is a growing concern and that they should be more knowledgeable in its symptomology in order to avoid misdiagnosis and unnecessary stress on the patient. A study states, "The doctors believe that the heritability and lifestyle adaptations as major causes for the development of PCOS…from the patient's point of view, the patients feel that the delayed diagnosis and unsuccessful treatment are very stressful" (Bharathi et al.).

There is a change in the eating habits. That does affect PCOS. There is a belief among the girls and women that because of the irregular cycles and missed periods that they are experiencing increased weight but we first council them that it is the other way around. You must reduce your weight then the cycles will automatically become regular.

Barriers to Compliance

From the patient:

"It's a little bit hard in our society (to walk around) …where I am living, Badi Chaupar, nearby there, the people around me are a little bit conservative. They're like "oh my god she is walking alone! What's that?" It's so ridiculous" – Ranu, 26

As previously stated, the two main treatments for PCOS are Oral Contraceptive Pills and lifestyle change which includes a healthier diet, exercise, and ultimately weight loss. Due to obstacles such as stigmas surrounding women exercising and/or taking pills, it can be difficult for the patient to comply. While urban areas are usually more liberal when compared to rural areas, there are still "less educated, more conservative areas" (Ranu, personal communication).

Ranu, a Jaipur native, was told that the most important action she could take to lessen her symptoms of hirsutism, acne, and weight gain was to exercise and change her diet. According to her, however, this is sometimes easier said than done. As a working student from a middle-class family, Ranu found herself unable to afford a gym membership. When she explained her predicament to her gynecologist, she was told that joining a gym and completing strenuous workouts was not necessary. All she needed to do was incorporate "brisk walks" into her daily routine. Usually, this means choosing to walk from one place to another versus using an auto rickshaw. However, Ranu felt as though the parts of Jaipur she must navigate through are "more conservative", and at times she feels ostracized for walking around alone as a woman. She spoke of her experiences, saying that "It's a little bit hard in our society (to walk around) …where I am living, in Badi Chaupar, nearby there, the people around me are a little bit conservative. They're like "oh my god she is walking alone! What's that?" It's so ridiculous" (Ranu, personal communication). Moreover, Dr. Chhabra agreed that this gender based barrier may begin as early as one's childhood. "Boys love to play, they may run after kites, but then it's not very safe for sending girls to play outside. It's very restrictive" she said (Dr. Chhabra, personal communication).

Another problem with treating PCOS is some women will not follow through with taking their medication. Dr. Chhabra stated that due to certain taboos around women taking medicine, they will halt their treatment altogether without telling their doctor. She said,

> "People who have hyperthyroid will sometimes stop the medication and then later they will tell me in secret that I've stopped taking the medication because I got married. Then of course people don't want to say the girl has any flaw whether it's a menstrual problem or thyroid problem" (Dr. Chhabra, personal communication).

Along with PCOS, hyperthyroidism is currently one of the most common endocrinal disorders in women, and may also cause polycystic ovaries. As discussed earlier in the paper, women who have health issues, especially endocrinal ones, can sometimes be seen as not as desirable on the marriage market. This can trigger women to go as far as quitting their medication, sometimes by the influence of their own mothers. At times, pills themselves are seen as bad or harmful due to miseducation or traditional beliefs which can be common in lower socioeconomic households and communities. Once again, this demonstrates the essential need for more preventative education on PCOS to combat any taboos having to do with treatment.

PCOS in Healthy Weight Patients

PCOS is a tricky and frustrating illness for not only patients, but also the doctors and scientists who research it. Studies have shown that there is an obvious connection between weight gain, the propensity to gain weight, and developing PCOS. However, it remains unclear as to why this does not account for all women being diagnosed with PCOS. Many women who develop PCOS are not overweight and therefore its direct etiology remains unknown. A cross-sectional study of 170 Indian women of reproductive age who were experiencing irregular menstrual cycles participated in the following study. The women were extensively tested and examined in order to confirm a PCOS diagnosis based on Rotterdam criteria. The study found that the prevalence of PCOS in its patients was 41%. Further broken down, 16% were married women and 25% were unmarried women. Menstrual irregularities (40%) were found to be prevalent among the women as was obesity (38.5%) (Choudhary et al.). However, many women that were diagnosed with PCOS were not obese. This study points out that “The condition (PCOS) however is not uncommon in non-obese, or underweight women, we found 14% of

subjects were normal weight" (Choudhary et al.). Therefore, while there is a strong connection between obesity and PCOS, not all women with PCOS will be obese, making its complete etiology still unclear.

When doctors were asked about the cause of thin women developing PCOS, their answers ranged from genetics to lifestyle to simply not knowing. Dr. Acharya, who's sister suffers from PCOS, believed that even if a woman is thin, she may still be leading an unhealthy lifestyle. At first glance, her sister does not look like she would have PCOS due to her thinness, which is often associated with good health. However, her sister still eats junk food, has an erratic sleeping schedule, and does not regularly engage in exercise. Regarding her sister, Dr. Acharya stated,

> "Actually, she is an engineer. When you see her you cannot say she has PCOS. But she eats all the junk food, she orders pizza. She is not eating healthy food. So when she was diagnosed she started exercising and cycling. And she got a sonography and now there are no cysts so I told her that just by changing only lifestyle you can change so much."

This suggests that unhealthy lifestyle and diet are not only affecting overweight or obese people, but also women who appear to be thin and healthy. It is extremely important that thin women who are diagnosed with PCOS are also educated about the importance of changing their lifestyle to lessen the symptoms of PCOS.

Summary of Findings

The purpose of this study was to determine how India's social and cultural climate affect the health-seeking behavior, diagnosis, and treatment of Indian women with Poly Cystic Ovarian Syndrome and how these factors contribute to its increasing prevalence. The term "illness" is often used interchangeably with disease, yet they are wholly different. When one experiences an illness, especially a prevalent one such as PCOS, it is critical to recognize that it is more than just a physical health ailment. As shown in this paper, PCOS is a dynamic disorder that affects many aspects of the lives of women who suffer from it. Furthermore, social and cultural determinants shape the way women diagnosed with PCOS view their illness. This in turn directly affects their treatment and health outcomes. Unfortunately, doctors often disregard the socio-cultural determinants of PCOS which prevents patients from receiving the best care possible. Due to lack of research in the socio-cultural aspect of this disease, it was vital that both doctor and patient perspectives were gathered to ensure a holistic understanding of PCOS.

Through the seven personal patient interviews and five personal doctor interviews, it was found that poor lifestyle choices, lack of awareness among patients as well as doctors, and social stigmas are likely factors that precipitate PCOS. Almost none of the women interviewed knew about PCOS prior to their diagnosis which increased the chances of women delaying treatment seeking. Once treated, all of the women interviewed had problems with changing their lifestyle, which is one of the main treatments for PCOS. They found it difficult to exercise and eat healthily for a variety of reasons which include social stigmas, easy access to unhealthy food, and rigorous life schedules due to their pursuit of higher education and/or jobs. In the words of Dr. Acharya, "PCOS is a group of symptoms, the whole body is involved." Therefore, every

aspect of PCOS, including the socio-cultural ones, must be examined by doctors when treating PCOS. With increased awareness, more studies, and preventative care, the prevalence of PCOS will decrease, which would represent a remarkable step in improving health outcomes of Indian women suffering from PCOS.

Study Limitations

The aim of this study was to further the understanding doctors and researchers have of PCOS and its etiology from a socio-cultural perspective. Since this topic is still quite new to the medical field, and the fact that it has not been adequately researched from this perspective, the researcher found it somewhat difficult to find secondary literature to further support this study's claims.

The information collected from personal patient interviews has proved invaluable in understanding women's perception of PCOS. However, any reproductive disorder can at times be difficult to talk about because the issue of reproductive health is shrouded in secrecy in the Indian context. Additionally, women would sometimes feel uncomfortable answering questions and/or did not know exactly how to articulate their feelings and experiences. At times, the researcher found it difficult to find patients willing to speak about their illness. Furthermore, when the researcher completed interviews at the public hospital, language often became a barrier in fully understanding the patient. The researcher remedied this by recording and carefully transcribing each interview, however, there may have been information that was still lost in translation. The researcher was also unable to make sure that the interviews could be conducted in privacy as close relatives or attendants were sometimes present with the patient. This may

have affected the truthfulness of some responses. This study highlights the gaps in the holistic management of PCOS and is also indicative of the need for further studies on the subject.

Recommendations for Further Research

As shown through this study, the socio-cultural aspect of PCOS must be further examined through additional research. Further questions the researcher would like to ask are, "What are the causes of PCOS in healthy weight women and how are these cases different than those of overweight women with PCOS?" and "What are the long-term effects on the mental health of women diagnosed with PCOS?". Due to the newness of PCOS in the medical field, few studies have been done on its long-term effects on women's health. An additional study, similar to this one, but with a larger sample size of patients and doctors, would prove helpful in solidifying this study's conclusions. If these questions are answered, the knowledge of PCOS, especially from a socio-cultural perspective, would be significantly increased. In turn, health outcomes of Indian women with PCOS would improve, and the prevalence of PCOS would decrease.

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Doctor Questionnaire:

1. How prevalent do you believe PCOS is?
2. Why might the prevalence of PCOS be on the rise?
3. How many of your patients are urban?
4. How often do you treat PCOS? What percent of your cases is it?
5. Do you find certain disorders to be comorbid with PCOS? Which ones and why do you believe this is?
6. How is PCOS culturally viewed? Does its cultural connotation vary from person to person or is there one overall trend in how PCOS is viewed within Indian culture?
7. What causes women to initially come in for treatment?
8. For how long do patients usually have symptoms before they come in? If they delay coming in, why is that?
9. How knowledgeable are women about PCOS prior to diagnosis?
10. How do patients react to their diagnosis? What are their thoughts towards treatment plans? Positive, negative, mixture?
11. What is the general timeline of treatment? How often must patients have check-ups, are they willing to come back? How important is long-term treatment to PCOS?
12. How does PCOS affect the way patients view themselves in terms of self-esteem? (view themselves differently)
13. What causes women who are not overweight to develop PCOS?

Patient Questionnaire:

1. How old are you?
2. Are you married?
3. Where do you live? (rural vs urban)
4. Had you heard of PCOS before your doctor told you about it?
5. When were you diagnosed with PCOS?
6. Does anyone in your family have PCOS?
7. What caused you to come to the doctor?
8. How were you diagnosed with PCOS?
9. Did you delay seeking treatment and if so why?
10. How do you feel about your illness? Do you view yourself differently? (relieved with diagnosis, effects on self-esteem, change of identity, etc.)
11. What did your doctor tell you when you were diagnosed with PCOS?
12. How did that affect how you feel about your illness? What went on in your mind when your doctor disclosed that you are suffering from PCOS?
13. Do you feel as though you understand your illness?
14. How does your family feel about your diagnosis?