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HEALTHCARE

# Silent epidemic: the health catastrophe India is not talking about, and why that should change

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Women across age groups are silently enduring this largely overlooked disorder.

## Synopsis

Polycystic ovary syndrome, or PCOS, a complex metabolic and endocrine disorder affecting women across age groups, has silently acquired the level of an epidemic. While the medical world is not on the same page regarding its actual diagnostic criteria, pharmaceutical research has been negligible. What are the reasons behind this, and why aren't people talking about it?

“I feel exhausted all the time.”

Cheryl (name changed on the condition of anonymity), a 30-year-old artist from New Delhi, was suffering from heavy menstrual bleeding, hot flashes, and chronic fatigue. All of that prompted her to consult a gynaecologist in 2016.

The diagnosis came soon enough. Cheryl had **polycystic ovary syndrome** (PCOS). She would have to deal with some of these symptoms all year, rather than just seven days a



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month. She felt helpless.

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In India there are **millions of women** who have similar symptoms. Some have been diagnosed. Many haven't.

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According to a **report in The Hindu**, one out of five women in India may be suffering from it. A few back-of-the-envelope calculations based on **numbers** from the 2011 census, and limited to women in the menstruating age, that projection works out to a mindboggling 60 million women. For comparison, India has an **estimated** 80 million people suffering from diabetes, a condition that frequently figures in conversations. **Globally**, one out of 10 women suffer from it.

Like Cheryl, women across age groups are silently enduring this largely **overlooked disorder**. "A two-month menstruation left me severely anaemic and unable to engage in routine activities," says Ishika Ramakrishna, a 28-year-old doctoral fellow at the Centre for Wildlife Studies in Bengaluru.

When Ramakrishna was diagnosed with PCOS in 2007, it jolted her. Her symptoms and diagnosis have been an arduous grind. "I've been on and off medication since I was diagnosed," she says, "from having to pop multiple pills a day for six months to short bursts of medication for a month, or sometimes just to manage particularly out-of-whack menstrual cycles."

So, why are people not talking about it? Aren't they scared? And why is research for solutions so muted?

The answers don't make for happy reading.

### **Inside the diagnosis**

PCOS is a complex condition in which ovaries, the organ that produces and releases eggs, produce unusually high levels of male sex hormones, androgens. These hormones, while naturally present in women in small amounts, can wreak havoc with the female body in higher levels.

According to Johns Hopkins University, the exact reason for PCOS is unclear. Genetics, environmental toxins, and lifestyle patterns are some of the known factors that contribute to the development of this condition, but the lack of research makes estimating change over time difficult.

"Many women with PCOS have insulin resistance. This means the body can't use insulin well. Insulin levels build up in the body and may cause higher androgen levels. Obesity can also increase insulin levels and make PCOS symptoms worse," the university's page observes.

Insulin is a hormone that regulates blood-sugar levels. When insulin levels rise, the ovaries produce and release androgens. Women with this condition frequently have irregular menstrual cycles, missed periods, unpredictable ovulation, infertility, excess facial and body hair, acne, obesity, and a host of other health issues.

Due to a lack of ovulation, they develop small cysts — fluid-filled sacs — in their ovaries. However, despite the “polycystic” in the name, which indicates the presence of cysts, many women who have been diagnosed with this condition do not develop cysts.

**"We cannot say how much of this [PCOS] is associated with ultra-processed foods, or endocrine-disrupting chemicals, or air pollution... Until some of those aetiological questions are answered, we can't say there's a public health intervention needed."**

*— K Srinath Reddy, honorary distinguished professor, Public Health Foundation of India*

A report published in the scientific journal Nature in April 2022 says that the global prevalence of PCOS is estimated to be between 8% and 21%. Despite the high prevalence, it remains a low-priority topic for researchers in the world. Although it can occur at any

age starting with menarche (the first occurrence of menstruation), the majority of cases are diagnosed between the age of 20 and 30.

Worse still, the medical world is not on the same page regarding the actual diagnostic criteria. This is influenced by the fact that the diagnostic accuracy of the disorder can change by age group, region, ethnicity, lifestyle, and certain underlying secondary disorders.

According to a study published by US-based National Center for Biotechnology Information (NCBI), 71% of the women with PCOS lived in urban areas, while 29% lived in rural areas in Haryana.

#### **A long list of problems**

Suffering from PCOS is just the start. Previous studies suggest that women with PCOS are at a higher risk of getting diagnosed with mental health problems such as anxiety, depression, eating disorders, and body-image issues.

“I was in therapy to manage my stress and anxiety,” says Ramakrishna. Her mental health is intricately linked to her menstrual cycles, with anxiety peaking during premenstrual syndrome days, affecting both her work and personal life. “Increased levels of anxiety, stress, and overthinking can throw my cycle off balance by delaying it or causing prolonged, excessive bleeding,” she says. “The unpredictability of both is exhausting to keep up with.”

Another study published by NCBI also indicates that women with PCOS must be screened for anxiety and depression, as they experience psychological distress due to multiple risk factors and a range of metabolic changes like hormone fluctuations, obesity, inflammation.

Due to **insulin resistance**, it is difficult to lose weight despite exercising. As doctor Duru Shah, director of Gynaecworld, a women's health and fertility centre in Mumbai and president and founder of The PCOS Society, India, says, "they are unable to lose weight as effectively as those who do not have PCOS".

A **New York Times article** published in 2020 said women with PCOS commonly have insulin resistance that leads to high insulin levels and an increased **risk of diabetes** and heart disease.

Professor K Srinath Reddy, honorary distinguished professor of the Public Health Foundation of India and former head of the cardiology department at AIIMS, New Delhi, tells ET Prime that the vascular risk is high due to high blood pressure, high lipid levels, and an increased tendency towards glucose intolerance. "For all of these reasons, blood-vessel damage is increased, as are the chances of having heart attacks and strokes."

### **The hidden epidemic**

In India, where health awareness is low, PCOS has become so widespread that it has silently acquired the level of an epidemic. It is known to affect the quality of life and is often underdiagnosed. "We have an understanding of what happens in the body after PCOS is detected, but we don't know what causes it," says Shah.

Shah emphasises that prevalence is difficult to determine in India unless the entire population of a particular area is tested. She has seen a steady stream of patients in different stages of the condition, asserting the need to create more awareness for diagnosis and treatment.

Her analysis is on point, as highlighted in a **study published in the medical journal Lancet**, which reports that rapid changes in lifestyle over the last decade may have influenced the prevalence of PCOS among women in the reproductive age group in China. Furthermore, due to differences in diagnostic criteria and participant-selection criteria, estimates of absolute prevalence vary significantly across populations and even within studies from the same population.

Timely diagnosis could help in better management of the condition and allows early detection of various comorbidities such as diabetes, high blood pressure, cardiovascular disease, endometrial cancer, sleep apnoea, depression, anxiety, and eating and somatisation disorders.

Living with PCOS can be a constant battle. "It took me some time to accept that my body, both inside and out, has changed," says a 29-year-old management consultant from Hyderabad, requesting not to be named. "I'll have to make adjustments every day to keep my symptoms under control."

Despite the extensive nature of this disorder, pharmaceutical research has been negligible.

At present, there is no medication for PCOS approved by the US Food and Drug Administration. However, the type of treatment depends on whether or not a woman wishes to have children. The treatment varies because no two PCOS cases are alike.

## PCOS: symptoms and management

### Symptoms

- Missed periods, irregular periods, or very light periods
- Ovaries that are large or have many cysts
- Excess body hair, including the chest, stomach, and back
- Weight gain, especially around the belly
- Acne or oily skin
- Male-pattern baldness or thinning hair
- Infertility
- Skin tags on the neck or armpits
- Dark or thick skin patches on the back of the neck, in the armpits, and under the breasts

Source: [hopkinsmedicine.org](https://hopkinsmedicine.org)

### Management

#### For women planning to have children

- A change in diet and physical activity
- Medication to cause ovulation
- Medication to treat other symptoms like body-hair growth and acne

#### For women not planning to have children

- Birth-control pills
- Diabetes medication
- A change in diet and physical activity
- Medication to treat other symptoms like body-hair growth and acne

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Currently, **erratic symptoms** are commonly treated with several approved drugs, such as oral contraceptives to regulate menstrual cycle, clomiphene citrate for ovulation induction, and metformin to lower blood glucose levels by balancing insulin levels.

These are typically “off-label” drug uses, which means that regulatory agencies have not approved the drug for the indication, but doctors use them at their discretion based on real-life experiences and mutual sharing of such case histories.

The **global PCOS treatment market**, which was valued at USD3.41 billion in 2021, is expected to reach USD5.26 billion by the end of 2030, growing at a compound annual growth rate of 5.13% during the forecast period.

There have also been conversations around traditional or herbal medicine, but this has been backed up by very little clinical evidence. In a **study published in ScienceDirect**, the data collated from in vivo and **small clinical trials** indicates that herbal treatment might be of some benefit to women in managing symptoms. However, it hastens to add that “the current literature should be enhanced with better study design, with more clinical relevance and patient data”.

### What next?

An **Indian Council of Medical Research** study, which started in August 2021, has included approximately 9,000 women. With the goal of evaluating national prevalence, comorbidity burden, and variation in efficacy of standard therapeutic modalities, ICMR’s study could be the first of its kind. The result of this study is awaited.

More large-scale studies and a multidisciplinary approach are needed to get deeper insights into this disorder.

Historically, women's health research has been neglected and underfunded. There have been gaps in understanding this multifaceted disorder due to the often patriarchal nature of medical research. The social stigma attached to certain symptoms like infertility add to the gravity of the situation.

OZiva, a brand of plant-based wellness products, conducted a **survey** with 2,756 participants across India in September 2022, and the results revealed that more than half of the women polled were judged for being overweight, having facial hair and acne, and having difficulty in conceiving.

Another critical aspect that requires additional research attention is how genetics and environmental toxins are linked with the prevalence of PCOS. "We cannot say how much of this [PCOS] is associated with ultra-processed foods, or endocrine-disrupting chemicals, or air pollution," says Reddy, and "until some of those aetiological questions are answered, we can't say there's a public health intervention needed."

Reddy suggests a healthy diet, physical activity, and adequate sleep are important measures that should be advocated to lower the risk of diabetes and cardiovascular disease, and "they become even more applicable in this [PCOS] condition".

While these issues remain in the realm of doctors and a few research labs, millions of women, like Cheryl and Ishika, continue to suffer as a result of the silent and debilitating condition.

*(Graphic by Sadhana Saxena)*

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