

'Anxiety provoking.' Commonly misdiagnosed, disease targeting women in spotlight

Samantha Lapinsky was officially diagnosed with PCOS at 26 years old. Experts are looking to rename PCOS, arguing that the new name better reflects the condition's impact on the body.

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Contributed by Samantha Lapinsky

Samantha Lapinsky was officially diagnosed with Polycystic Ovary Syndrome or PCOS a year after her first symptoms appeared.

At 26 years old, Lapinsky said she gained more than 50 pounds within six months, despite never changing her fit lifestyle or how much she was eating. Then came the other symptoms, such as unwanted facial hair growth, adult acne and enlarged ovaries. She also lost four pregnancies within three years, all at varying stages of gestation.

And yet, despite the ongoing challenges, Lapinsky said getting an official diagnosis took time since she didn't showcase all of the symptoms typically associated with PCOS. That back-and-forth with testing and changes to her body left her in a lot of "pain and emotional suffering."

"It's not a cut-and-dry disease, where you're always going to have all four symptoms; that's just not the case," she said. "It's just one of those things where you have to check all the boxes in order for a doctor to be willing and confident enough to say that you have it, so I think the frustration also involves not getting the proper treatment right away."

About one in eight women – or around 170 million people – globally are diagnosed with PCOS, and despite how common the disease is, many face delays in getting a diagnosis or misdiagnosis as a result.

However, after a 14-year international collaboration among experts and patients, researchers are proposing a new name for PCOS that they say better reflects the condition's complex metabolic and reproductive effects.

What is PCOS?

PCOS was first described in the 1930s, but its exact cause remains under investigation. Symptoms vary person to person, but it's most commonly associated with irregular periods and excess production of androgen hormones that can cause unwanted acne and hair growth.

Fluctuating hormones affect weight and reproductive, metabolic and mental health. PCOS can also increase a person's risk of developing other chronic health issues if left improperly managed, like Type 2 diabetes, heart disease and stroke.

It is typically diagnosed through a combination of blood tests, ultrasounds and physical exams after patients report one or more of the traditional symptoms.

Treatment is highly individualized, based on what symptoms patients are looking to address, said Dr. Ilana Ressler, an OB-GYN and reproductive endocrinologist with Illume Fertility.

Most PCOS symptom management is done through major lifestyle changes – like improving diet, exercise and sleep – that address the underlying metabolic dysfunction. Other options include using insulin-resistant medications or hormonal birth control. The goal, Ressler explained, is to treat patients beyond just correcting their menstrual patterns.

“If conception is not desired at that time, then really the question becomes – what are the main symptoms that someone is experiencing?” she said. “Is it that they're having irregular cycles, and that's really their only symptom of the condition? Or are they having severe acne, as well as hirsutism? So, that's how it's decided.”

What does the name mean?

The name “polycystic ovary syndrome” specifically refers to the number of follicles found around the ovaries that help manage egg development and ovulation.

These follicles, mistakenly called “cysts,” can typically be seen on ultrasound. If a patient has over a certain number of follicles in at least one ovary, then it's considered polycystic ovarian morphology, one of the possible diagnostic features of PCOS.

Clinical and research experts, however, have long said that the term “PCOS” is a misnomer that doesn't accurately reflect the whole-body metabolic impact of the condition.

The ovarian follicles are not considered the underlying cause of the disease, but rather a symptom of the hormonal imbalance, said Dr. Irinia Magidina, chair of the obstetrics and gynecology department at St. Mary's Hospital. And yet, follicles have traditionally been included in the diagnostic criteria.

“Some women have this classic picture where they have the irregular cycles, they have the evidence of elevated androgens or hirsutism, but not all women have these little follicles on their ovaries, and it doesn't have to be present in order for the diagnosis of PCOS to be made,” Magidina said.

Over the years, diagnostic criteria have been updated to reflect how the condition varies from person to person, but the name kept its focus on the polycystic ovarian issue, which Magidina said has led to delayed or missed diagnosis.

“It's really a multi-system, full-body metabolic condition,” she said. “And not just an ovary problem.”

Calling it PCOS, Magidina added, also likely limited the treatments available, noting that there are not many FDA-approved treatments for PCOS and the metabolic dysfunction it causes.

What is it like to live with PCOS?

In the years since her diagnosis, Lapinsky said the most unpredictable of her symptoms are the irregular periods. Some days, she said, her period is “right on track,” while other times she’ll go months without it.

“It’s anxiety-provoking, because you don’t really know what’s going on with your body,” she said. “Obviously, it makes you feel like your disease isn’t being controlled, but this is just part of it.”

Lapinsky, who is 33, said managing her weight is also difficult with insulin-resistant PCOS. She said she needs to follow a low-carb diet, which she described as a “modified keto,” to see any weight loss and lower her risk of developing diabetes in the future.

Some day-to-day symptoms, like oily skin, persistent exhaustion and hunger, can also be traced back to fluctuating insulin levels, which in turn impact self-esteem.

“I feel like people don’t really understand how physically and emotionally exhausting it can be, because symptoms are always minimized,” she said.

What changed?

Following more than a decade of international collaboration and research, global experts proposed renaming PCOS to Polyendocrine Metabolic Ovarian Syndrome (PMOS).

Neither diagnostic practices nor treatment will change with the new name, but Ressler said the hope is that the new description better reflects how the condition impacts the whole body, not just the reproductive system.

“I think that this new name is much more appropriate, and hopefully will drive focus on what is actually involved in the condition,” said Ressler, noting that the new name could also help bring women’s health to the forefront of medical research after years of historical underinvestment.

To Magidina, the new name describes the condition in a way that “implies what has to be done.” There are also wider implications, including the potential for the renaming to open the door to new research opportunities and better insurance coverage.

The new name is being adopted over the next three years, said Magidina, as it’s incorporated into the professional organizations, treatment research and medical education.

“In the last 40 years, look at how far we’ve come in diabetes treatment, but how far have we come in PCOS treatment?” Magidina said. “Maybe now will be the era where we really start to think about it differently, treat it differently, and really start to make gains in women’s health.”

What do patients think?

The name change is validating, Lapinsky said.

“These symptoms are real. The anxiety, the inflammation, the weight gain, the hair issues, the fatigue, the insulin issues. I think, for years, the main ‘PCOS’ just did not cover all of the things that come with it,” she said. “It almost like it minimized what was actually happening in our bodies, and it's so important that people get ahead of all these other risks and diseases that can develop later in life,”