

Beyond the Ovaries:
Renaming a common yet neglected hormonal condition could be the key
to unlocking better care for patients

by

Lily Stewart

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Authored by: Lily Stewart
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Certified by: Rachel E. Gross
Thesis Advisor

Accepted by: Seth Mnookin
Director, Graduate Program in Science Writing

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ABSTRACT

PCOS is a common hormonal condition found in 10 to 19 percent of people with ovaries. It frequently causes irregular periods and ovulation and is one of the most common forms of female infertility. However, the effects do not stop there. People with PCOS are at higher risk for a slew of health complications: insulin resistance, sleep apnea, depression, and anxiety. They are also more likely to develop metabolic syndrome—a combination of high cholesterol, high blood pressure, diabetes, and high waist-to-hip ratios. Together, many of these symptoms are risk factors for fatty liver disease or heart attacks and strokes.

Despite the commonness and potential seriousness of the condition, many patients go undiagnosed, and those with diagnoses frequently go under-treated. The reasons for this are aplenty. PCOS's cause is unknown. It has no known cure. It looks different from patient to patient. Its research is underfunded. Physicians do not learn much about it in medical school.

But one reason at the root of it all, some experts say, is how tightly this condition has been intertwined with reproduction and fertility. Over the past decade, researchers and physicians who specialize in the condition have been pushing for everyone to recognize PCOS for what it is: a full-body endocrine syndrome with wide-reaching effects on health and quality of life. And one way to combat these is to change something fundamental about the condition: its name.

Thesis Advisor: Rachel E. Gross

Title: Thesis Advisor

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What Andrea remembers most about trying to get pregnant is the isolation. At age 26, she had spent the past two years moving through three fertility doctors. She'd endured expensive rounds of ovulation-inducing medications, ultrasounds, and injectables, but nothing took. No one else she knew seemed to be struggling. "It was very, very emotionally debilitating to me," she said. "Emotionally, financially, and socially." Andrea had always suspected she'd need a little extra help trying to get pregnant thanks to a certain diagnosis: polycystic ovary syndrome (PCOS). She just hadn't realized how much.

Andrea had received the diagnosis in her teens after going to her doctor for her irregular periods. Her doctor prescribed her birth control pills to regulate her bleeding and told her not to worry about the condition until she wanted to have children. She dutifully took her pills throughout her late teens into her 20s, up until when she and her husband began trying to start a family. Andrea remembered the diagnosis when she was first trying to conceive and went to her gynecologist for help, but that gynecologist assured her not to worry too much yet.

Andrea's fourth doctor was more blunt. He thought PCOS was a critical factor in her struggles and recommended more intensive treatments. If it was taking her so much time and money to get pregnant, maybe it was a bigger deal than she'd always been told.

The fourth doctor referred Andrea to a support group for other people with PCOS, who he said would understand what she was going through. She leapt at the chance, and each week, she joined the group virtually over a chatroom. People from all across the country shared their experiences trying to get pregnant with PCOS, many of which sounded eerily like Andrea's. They understood the pain, frustration, and confusion Andrea had endured the past few years. Finally, her isolation started to dissipate.

Then, they started talking about how PCOS affected the rest of their lives. Suddenly, the stories she was hearing from other members started to make other parts of her life click. Andrea had a new realization: Her condition went far beyond her reproductive system.

Andrea had always struggled with her weight. She had dieted her whole life, yet even while eating a cup of yogurt, a protein-devoid salad, and a chicken breast every day, the weight wouldn't come off. Hours of step aerobics didn't help, either. While she saw others praised for their willpower, her hard work never showed. Then there was the dark hair that stuck out against the pale skin on her legs, abdomen, and bikini line. It bothered her so much that she took out a special credit card to cover laser hair removal, zapping away the hair.

While she had plenty of hair where she didn't want it, she was losing it where she did. The hair on her head grew patchy and thin, so she refrained from wearing ponytails, taking care to style her hair in ways that hid the hair loss. "You learn tips and tricks. Thank god for professional hair people," she laughed.

Andrea had always accepted these traits as just something she had to live with—"It's hard being a girl," she said. But all of these experiences, she learned through her support group, traced back to her PCOS. Since she had only ever conceived of PCOS as a fertility disorder, it had taken her nearly 12 years to notice its reach across her body.

Though Andrea was diagnosed almost forty years ago, her story isn't too different from many of the 10 to 19 percent of people with ovaries who have PCOS today.

PCOS is a hormonal condition in which the ovaries can produce elevated levels of androgens, which are hormones like testosterone typically found in higher levels in people without ovaries. These elevated levels can make it harder for people to ovulate, leading to irregular periods and difficulty getting pregnant—a potentially devastating symptom that those familiar with PCOS are well aware of.

However, the effects don't stop there. PCOS impacts a number of body systems outside of the ovaries. People with PCOS are at higher risk for a slew of health complications: insulin resistance, sleep apnea, depression, and anxiety. They're also more likely to develop metabolic syndrome—a combination of diabetes, high cholesterol, high blood pressure, and high waist-to-hip ratios. Together, many of these symptoms are risk factors for fatty liver disease or having a heart attack or stroke. That's a whole lot more than just having trouble getting pregnant—which can be devastating, as can these other symptoms.

It can take many patients over two years and three doctors to get a diagnosis for PCOS. (That's if they're lucky: It's estimated that at least half of all people with PCOS never get diagnosed.) But even having a diagnosis doesn't mean that all of these non-reproductive symptoms get addressed.

The reasons for this are aplenty. Researchers don't know exactly what causes PCOS, nor how to cure it. It looks different from patient to patient. Its research is underfunded. Physicians don't learn much about it in medical school.

But one reason at the root of it all, some experts say, is how tightly this condition has been intertwined with reproduction and fertility.

As Andrea found out, PCOS doesn't stay put in the ovaries. Yet, PCOS's categorization as a reproductive disorder has meant that these other impacts frequently go ignored in the lab and in the doctor's office, meaning many patients end up with chronic conditions like diabetes—which affects about half of all PCOS patients. Over the past decade, researchers and physicians who specialize in the condition have been pushing for everyone to recognize PCOS for what it is: a full-body endocrine syndrome with wide-reaching effects on health and quality of life. And some believe that one way to combat poor care is to change something fundamental about the condition: its name.

Not Just a Name

With the word “ovary” so prominent in the name, it's no surprise that most people get their PCOS diagnoses from their gynecologists, typically after presenting with irregular cycles or difficulty getting pregnant. The impression many patients get is that this condition mainly affects their ability to conceive.

One of the first (and sometimes only) treatments most patients end up receiving is a hormonal birth control pill prescription. Birth control pills are great at minimizing the risk of endometrial

cancer, which is five times greater in people with PCOS than in the general population. For Andrea, managing this risk was critical. After witnessing a family friend pass away after a brutal bout of endometrial cancer, she didn't want to take any risks. Outside of her two eventual pregnancies, she stayed on the pill from her teens up until she was 51.

For the 40 to 80 percent of PCOS patients who have high levels of androgens, the pill can also help balance out some of the symptoms they cause. Androgens are important hormones that regulate bone, muscle, and sexual health, but at elevated levels, they can cause hard-to-treat acne, balding on the head, and increased body and facial hair growth, as Andrea knows intimately.

However, the pill can't treat all components of PCOS. Even for androgen-induced symptoms like balding and acne, it doesn't work for everyone.

These symptoms can decimate a patient's body image. Andrea described going on vacation with her husband and having to make sure she packed her tweezers and a magnifying mirror so she could take care of the hair that inevitably popped up on her face. The last thing she wanted, she said, was to be on a romantic getaway and feel less feminine. "I know it's cosmetic, but it definitely affects your self-esteem," she said.

Plus, androgens aren't the only hormone that PCOS influences. The condition also tampers with the body's balance of insulin, a key hormone that regulates blood sugar.

PCOS is intertwined with insulin resistance, which is found in about 50 to 80 percent of patients, independent of age, body composition, and weight. It occurs when the pancreas doesn't produce enough insulin to help process food into energy, requiring the production of more and more insulin. If left untreated, it can progress to diabetes—which is why people with PCOS are four times more likely to develop it than their non-PCOS counterparts.

PCOS's ovary-centered name and reputation say nothing about metabolic dysfunction, so many patients might never guess it would be relevant. Andrea had no idea that the reason she struggled to lose weight was due to her insulin resistance until she had already spent years agonizing over restrictive diets and exercise regimens. "What I didn't know, and nobody explained it to me, was that it was never going to work for my body," she said. "I was out of whack," she emphasized.

This insulin resistance doesn't originate in the ovary; researchers think it might come from differences in muscle, bone, and fat cells. However, it can majorly alter ovarian function. The more insulin resistant someone is, the higher their androgen levels tend to get, making it harder for their body to ovulate. It's a messy web that appears to be the reason PCOS is associated with so many other serious conditions like metabolic syndrome, elevated cardiovascular risk, and even mental health risks like depression, anxiety, and eating disorders.

While nutrition and exercise can help ease insulin resistance, lifestyle tips tend to be vague since research into PCOS hasn't found any one specific diet or style of exercise that best eases symptoms. Even more, only some patients receive that general lifestyle advice, and even fewer receive medications that help manage their blood sugar.

After Andrea gave birth to her first son at 28, her gynecologist prescribed her metformin, an insulin-sensitizing drug that makes it easier for cells to metabolize sugars. Up through her late 40s, this medicine helped keep her blood sugar steady and prevent progression into diabetes.

Yet, clinicians often don't fully address the metabolic component of PCOS—and all its associated risks—in the clinic. Plus, there's a disparity in care depending on which specialty of physician—primary care, gynecology, or endocrinology, typically—a patient sees. Andrea Dunaif, the Chief of Endocrinology, Diabetes, and Bone Disease at Mount Sinai, expressed her frustration at the “large number” of physicians who don't know how to diagnose and treat PCOS thoroughly. This is especially true, she said, of PCOS's “orphan area” of metabolic complications.

When patients can't find a provider who addresses the whole-body effects of PCOS, the consequences can be severe. Katherine Sheriff, an internist and Chief of Women's Health at Jefferson Health, sees it every day. A woman will come in with diabetes, a history of irregular periods, and high cholesterol. She'll be at high risk for a stroke or heart attack over the next five years, and she'll have experienced decades of mental health difficulties. “It's the hardest thing to see,” Sheriff said. “And it's easily preventable.”

Julie Snyder, another patient, had never even heard of PCOS until she was 42. By that point, she had already developed metabolic syndrome. Her cholesterol and blood pressure were high, and she was on the verge of developing type 2 diabetes. She now has her symptoms under control, but she feels that starting metformin and other treatments in her 30s could have saved her from years of confusion and shame. “Never knowing what to expect year after year after year after year is taxing,” she said.

In Sheriff's view, these consequences stem from the arbitrary separation of women's health from the rest of medicine. The way she sees it, too many providers outside gynecology get a bit squeamish when it comes to periods and ovaries, believing it to be out of their purview.

Dawnkimberly Hopkins, a women's health nurse practitioner and nurse scientist, has experienced this firsthand. As a clinician herself, she knows how to self-advocate in the doctor's office and bring up her PCOS diagnosis. Outside of gynecologists and endocrinologists, she says the only doctor who has brought up her PCOS diagnosis without prompting was a sleep doctor, who knew that patients with PCOS were predisposed to obstructive sleep apnea. Outside of that encounter, she's had to fight to not roll her eyes when other clinicians question why she takes metformin or what her PCOS has to do with anything.

“As long as we have those silos where OB/GYN is over here and everything else is over here,” Sheriff said, gesturing with her arms spread wide, “we will not make progress with PCOS because it's consigned to OB/GYN.”

A Condition Rooted in Gynecology

PCOS's categorization within gynecology dates back to its earliest years as a condition. In 1935, Irving Stein and Michael Leventhal, two Chicago gynecologists, noticed that seven of their

patients all experienced irregular or absent periods. When the physicians conducted small exploratory surgeries to take a look at what was going on, they found the patients to have enlarged, bumpy ovaries. Researchers referred to these ovaries as polycystic because they looked like they were dotted with lots of tiny cysts. Along with missing periods and polycystic ovaries, five of the seven patients also complained of excess body hair.

The physicians reported this cluster of irregular menstruation, polycystic ovaries, and hyperandrogenism, which would become the trinity of features that still dominate PCOS diagnostic criteria today. Stein was an early leader in the field of fertility, so he turned his attention toward how these symptoms affected patients' abilities to get pregnant. He published so much on the condition that, by the 1950s, people had begun referring to this collection of symptoms as Stein-Leventhal syndrome, the earliest version of PCOS's name.

However, not everyone agreed on what to call this group of symptoms. By the early 70s, the name started to shift organically. Researchers began using both polycystic ovarian disease (PCOD) and polycystic ovary syndrome (PCOS) as part of a move toward using names based on characteristics of a disorder rather than the people who discovered it. According to Ricardo Azziz, a reproductive endocrinologist and expert on the history of PCOS, for a few decades, Stein-Leventhal, PCOD, and PCOS were used interchangeably.

Researchers started to identify PCOS's link to insulin resistance as early as the 80s, right around when Andrea was first diagnosed. But by then, PCOS had already become known as a primarily gynecological condition in the broader medical imagination, and insulin-related symptoms got overlooked—including in the name.

Around the late 90s, when metabolic research started to pick up, some scholars in the field began publishing their thoughts on PCOS's name, raising a few main complaints. First, using three separate terms was confusing for patients, clinicians, and researchers alike. Second, it didn't address anything but one symptom: cysts on the ovaries. And that continued focus on cysts on the ovaries wasn't just narrow: It was inaccurate.

Whenever a person ovulates, a handful of follicles on their ovaries swell in preparation to release an egg. Eventually, the biggest follicle bursts to release the egg. For people with PCOS, the egg can get stuck, so the follicles stay enlarged and look like little cysts all over the ovaries. These follicles don't fit the specific medical definition of a cyst. They also aren't dangerous and don't need to be removed, which, according to Dunaif, can be misleading for patients. Even more, patients don't need to have polycystic-looking ovaries to get a diagnosis, and plenty of people have them even if they don't have PCOS.

In 1995, Rogerio Lobo, a reproductive endocrinologist, pointed out that while PCOS went by several names, none of them were particularly accurate. In his opinion, something new like hyperandrogenic chronic anovulation (HCA) would better encapsulate the condition's traits. If people wanted to use one of the three existing names, though, he wrote, everyone should at least stick to PCOS, since the categorization of a syndrome fit the condition better than a disease. While a disease usually has a known cause and set of treatments, a syndrome simply refers to a

collection of symptoms. Since the cause of PCOS wasn't (and isn't) known, syndrome was more accurate. While HCA didn't catch on, more people started to favor PCOS over the other two names, though some researchers and physicians continue to publish and diagnose using all three monikers.

Andrea noticed this shift in her own medical experiences around the same time. At an appointment with a new primary care doctor, she remembers filling out a form and noting that she had PCOD, which was the term used during her diagnosis. She recalls a nurse correcting her, saying that they didn't call it that anymore. What, Andrea wondered, was up with that? Even though physicians might have had some more clarity and cohesion from the term PCOS, patients on the other side of the picture were still in the dark.

Though a move toward a unified use of PCOS was helpful for consistency in research, teaching, and diagnosing, not everyone was satisfied with the term. For the next decade, the consensus was that everyone knew the name was wrong, but no one knew what to do about it.

Campaigning for a New Name

Around 2010, Helena Teede, a research endocrinologist at Monash University in Melbourne, had an idea. When she was doing clinical work, she always saw the most tears while diagnosing and treating her patients with PCOS. They were exhausted, she recalled, from going to physician after physician, desperate for clarity and relief.

Moved by their plight, Teede decided to campaign for a new name that would get the condition and its sufferers the recognition and resources they deserved. She reached out to representatives from medical associations and PCOS nonprofits. When she surveyed patients and clinicians, she found that the majority of respondents supported a name change, building momentum for further campaigning.

“You cannot reduce one in eight women down to their ovaries,” she said. “It does a great disservice to call it something based on how it was historically discovered.”

She wasn't the only one who thought something needed to change. In 2012, the National Institutes of Health (NIH) recognized that the field of PCOS research was fighting some major problems: Three different sets of diagnostic criteria existed. People still used different names. Research was severely lacking.

The institute gathered a panel of clinicians to review the existing literature on PCOS and come up with a plan. The first recommendation in their report: change the name.

“We believe the name ‘PCOS’ is a distraction and an impediment to progress,” the authors concluded, suggesting an “expeditious” switch to a new name. The name wasn't just incorrect, they said. It impeded education and funding, cheating patients out of quality care.

Dunaif is one of many PCOS researchers who has struggled to procure funding for her projects. She believes some of this struggle comes from PCOS's name. “Everyone agrees that cancer is

important, heart disease is important. But cysts in the ovaries?” Dunaif shrugged. “Your elevator pitch is really hard.”

Relatively, diseases like cancer and Alzheimer’s have continued to draw increased funding even as overall NIH funding contracts. While it’s important to fund these conditions, the gap is frustrating for people researching and suffering from chronic and lifelong conditions—including PCOS—for which money has become more competitive.

Poor funding is also a deterrent for young researchers who might be interested in PCOS, said Dunaif: “Why torture yourself?” The combination of little money and few researchers poses a hurdle to high-quality PCOS research.

Women’s health research receives disproportionately little funding, and PCOS is no exception. In a 2017 study, Azziz compared the amount of NIH funding PCOS received compared to conditions that have similar prevalence and morbidity in the US like rheumatoid arthritis, tuberculosis, and lupus. He found that PCOS receives anywhere from 8 to 17 percent less funding than these conditions of similar impacts, a difference of hundreds of millions of dollars.

Researchers like Teede view this disparity as a direct result of the name. In the US, almost 70 percent of PCOS’s research funding comes from the National Institute of Child Health and Development, an organization that funds research centered around reproductive health, child health, and disability. Yet, according to Azziz, PCOS isn’t a strategic priority of the organization, and it receives little funding from other institutes (like those that study diabetes or heart health) despite its strong ties to those organization's priority areas.

“Whenever there is money to study PCOS, it’s basically around infertility,” Sherif said.

This categorization affects medical education, too. Most health care students receive little training related to PCOS, and when they do, it’s mostly reproductive, Sherif added.

Sherif tries her best to confront this gap in knowledge, especially for other internists like herself. When she gives talks at teaching hospitals across the country, she likes to bring a simple presentation, during which she presents two patients. The first is a young woman in her 20s with lots of body hair, irregular periods, trouble conceiving, and difficulty losing weight. When she asks attendees what the diagnosis would be, she says it’s a simple answer for almost everyone in the audience: classic PCOS.

Then she presents a woman in her 40s with kidney damage, metabolic syndrome, sleep apnea, and balding, and asks them the same question. Her audience is usually stumped, Sherif said. She recalls people coming up to her after she first gave the presentation 30 years ago. They were shocked to learn what unmanaged PCOS could look like. Sherif says she still gets the same responses now.

If any of these doctors had run into Andrea around the time the NIH released their recommendations, when she was in her early 40s, they would have seen a woman with two

children, insulin resistance, and hair loss. No longer did she fit that classic image of PCOS, making it easier for her to slip under the radar—and for her to ignore the condition herself.

“Looking back, I question if they even understood it,” she said of the physicians who never explained her treatments or diagnosis. She remembers one of her doctors telling her PCOS might subside after she had her two sons. It didn’t. Her cycles were still unpredictable if she didn’t take her birth control. Her body hair persisted, becoming harder to treat as her hair grayed and resisted laser treatment. She kept taking higher doses of metformin until she reached perimenopause, when it stopped managing her symptoms, sending her into another saga of medical frustration.

“I wish I was a little bit more assertive and maybe had gone to an endocrinologist sooner,” she said. “I do have that regret.”

Rebranding a Misunderstood Condition

Researchers like Teede, Dunaif, and Azziz have all proposed new names for PCOS, hoping to ensure better and prevent decades of frustration for patients like Andrea.

However, finding a name that’s specific enough to be useful while broad enough to fit patients’ varied experiences is no easy task. PCOS can look completely different from patient to patient, and what affects someone might not affect another. Some patients might have severe insulin resistance while others don’t. Some might have trouble conceiving while others get pregnant without even trying.

Among all the name suggestions that came and went, a frontrunner emerged from Teede’s surveying efforts: metabolic reproductive syndrome (or, reproductive metabolic syndrome). This name captured the two biggest components of the disorder and, according to Teede’s survey, was a hit with both patients and clinicians.

Building on the momentum for what felt like an imminent name change, Teede gathered PCOS researchers, physicians, and advocates at an international summit in 2015 to discuss their options. However, upon meeting, it became clear that even though metabolic reproductive syndrome had seemed promising, not everyone approved. The summit ended in the same state it began: with PCOS intact. At that point, efforts to change the name slowed to a pause.

For some, this pause was a welcome outcome. Not everyone even agreed that changing the name was the way to go—just yet, at least. Among them were doctors who treated PCOS patients, like Sherif.

Though Sherif wishes the name had changed decades ago, she thinks it’s too late to change the name now. She agrees that consistency in research and education is important. But to her, a self-described gender-equity militant, the bigger issue is that medicine needs to stop thinking that a diagnosis with the word “ovary” in the name could never affect anything other than reproductive health.

“Someone needs to go right up to the American Heart Association and say: ‘Yo!’” she said. “That’s what has to change. It’s the attitude.”

The biggest opposition, though, is from some patient advocacy groups. Sasha Ottey directs PCOS Challenge, the country’s most prominent PCOS advocacy group—of which Sherif and Azziz sit on the medical advisory board. A PCOS patient herself, she founded the group in 2009 after her own confusing PCOS diagnosis experience. Like Andrea and so many other patients, she was handed birth control, a pamphlet, and orders to come back when she wanted to get pregnant. When she turned to online resources, she was disappointed to find that everything prioritized getting skinny or pregnant.

Unsatisfied with her experience, Ottey founded PCOS Challenge, which now boasts over 50,000 members. PCOS Challenge lobbies representatives on their annual PCOS Day of Advocacy, and they’ve even snagged a meeting with the FDA to talk about new drugs for PCOS. To advocates like Ottey, these steps show that major organizations are starting to recognize PCOS as a condition worthy of investment.

Changing the name, in Ottey’s opinion, would squash all the progress. Plus, it would kill the existing branding—of both the condition and PCOS Challenge as an organization. More importantly, it wouldn’t guarantee an immediate increase in funding and education. It’s possible that nothing would change at all. “We’re the ones doing the actual work in the government, in public health policy. We’re struggling to get recognition around this condition,” Ottey said.

Another major concern has been finding a name that isn’t stigmatizing for patients. Teede’s surveying efforts have sought to understand what feels most stigmatizing. She has found that some patients find “ovary” to be an embarrassing term, while other resist “androgen” or “hormonal.” Most are comfortable with the word “reproductive,” but Ottey explained that that isn’t always the case in cultures where a woman’s ability to reproduce remains critical to her social and economic security. When patients from all across the world aren’t included in the surveying process, what’s stigmatizing in one culture could get overlooked in favor of another.

“One of our biggest pushbacks is just the lack of intention in this process,” said Ottey.

Additionally, PCOS’s cause is still unknown. Some advocates fear that changing the name now would be premature, leading to another change down the road. Waiting for the discovery of the condition’s origin would be the right time for a change, according to Ottey—even it’s unclear if or when that day might come.

Even if experts picked a new name tomorrow, it could take years—decades even—to go into full effect. Not one single organization oversees or dictates what goes on with PCOS. Instead, a handful—the Androgen Excess and PCOS Society, American College of Obstetricians and Gynecologists, Endocrine Society, European Society of Endocrinology, American Society of Reproductive Medicine, etc.—exert authority over the condition, so all parties would need to collaborate to make an official, documented change across the world.

Then, to fuel integration into medical school, continuous education for practicing clinicians, and patient education venues, there'd need to be money. Lots of it. The process would require focus and intention, detachment from egos, and a single, motivating goal: improving the lives of patients with PCOS.

What the Future of PCOS Care Could Look Like

This improvement doesn't necessarily need to wait for a new name to get started. Even though the name hasn't changed, medicine is slowly moving toward the same conclusion: PCOS is a multi-organ condition that requires multidisciplinary treatment.

According to Sherif, a complex, multiorgan condition like PCOS requires collaboration between specialists to treat all symptoms and risks. In her view, an ideal team might include a primary care physician, gynecologist, endocrinologist, dermatologist, therapist, dietitian, and more, depending on a patient's symptoms and risk factors.

Some clinics like this already exist. The University of California, San Francisco is home to the Multidisciplinary Clinic for Women with PCOS. If Andrea had been able to visit this clinic when she'd first sought care for her PCOS, she'd have had a totally different experience.

She'd be asked to arrive at the clinic prepared with blood tests gauging her hormones, and she'd fill out extensive questionnaires about her diet, sleep habits, exercise routine, and family history.

At her first appointment, she'd have two hour-long meetings with a reproductive endocrinologist and then a dermatologist. Afterwards, the clinic's reproductive endocrinologist, dermatologist, psychologist, and dietitian would convene to discuss her goals and history. She'd then return to the clinic to meet with the endocrinologist, psychologist, and dietitian for half an hour each. She'd also be asked about her interest in enrolling in any of the clinic's ongoing studies regarding PCOS.

Then, she'd leave the clinic with copies of a thorough treatment and lifestyle plan tailored to her individual needs. The plan would involve recommendations for her primary care provider, along with prescriptions and any necessary referrals, like to a bariatric surgeon or hepatologist.

Accessibility is, of course, a barrier to multidisciplinary care at clinics like these. Not everyone lives nearby, and just like other forms of PCOS care, these centers might be too costly for some patients. But, there are ways to make quality PCOS care more accessible even far from a dedicated clinic. Telehealth and strong referral networks can widen access to a multidisciplinary team, which must be the goal for comprehensive PCOS care.

Plus, resources for providers are starting to get better. Teede and a coalition of providers and advocates from across the world have banded together to release evidence-based guidelines for diagnosing and treating PCOS that providers can use to provide more thorough care—though the guide notes that overall research quality for the condition is still quite low.

Experts involved in PCOS's naming campaign hope the problem of research quality might subside sooner than later. In Azziz's opinion, it's only a matter of time and careful planning until PCOS gets a rebrand.

The past year has brought about a resurgence of interest in renaming PCOS. Teede has rekindled the movement, undertaking another survey she hopes to publish later this year. Of the preliminary responses, about 90 percent of patients continue to support a new name, suggesting that the interest remains. This most recent survey also brought up a new name idea: prevalent cardiometabolic ovarian syndrome. Essentially, PCOS would still be PCOS, but the letters would stand for something new. A compromise, it seems, to use something medically accurate while easing the issue of confusion.

Or, as Azziz joked, they could simply give it the KFC treatment: use PCOS as a set of letters that no longer mean anything specific. "We really just need something that rolls off the tongue," he said. "And has good branding."

The current poor branding still plagues Andrea, who is now 55 and officially post-menopause. About a year away from retirement at the New York City middle school she's worked at for three decades, she's ready to devote her time to volunteering at a local animal shelter and spending time with her own two pet bulldogs. Instead, she feels like she's still fighting her PCOS symptoms, now with the addition of all the changes of post-menopause life.

With the reputation of a reproductive condition, PCOS isn't widely recognized beyond a person's reproductive years. When Andrea tried bringing up what she viewed as persisting symptoms of her PCOS to her endocrinologist, she felt that the doctor totally dismissed her concerns. She's found solace in yet another online PCOS support group—a Facebook group intended for those in menopause—but it's no substitute for research that could help answer her questions about whether and how her PCOS lasts after menopause.

More research is suggesting that PCOS could be a lifelong condition with potential cardiometabolic and psychological consequences beyond reproductive years, long after ovulation ceases. Some research into the genetics of the condition is even suggesting that ovaries aren't necessary to experience all the effects of PCOS since it seems the male relatives of people with PCOS may also experience elevated cardiometabolic risks. Only high-quality research could ever provide answers to these questions, but according to Teede, without a new name, it'll be hard to study whether (and how) an assumed-to-be fertility disorder affects people who don't ovulate: "No one will fund that research," she said dryly.

Andrea is just one of millions of PCOS patients throughout the country who continues to battle substandard care. A condition with a far reach beyond the ovaries requires more than just fertility treatment, but people continue to get lost in the cracks because of the zoom-in on reproduction. Whether through a specific name change or a multifaceted rebrand, everyone who cares about the condition can agree on one thing: Approaches to PCOS need a makeover.

And after four decades of frustration, Andrea just wants change: “They can call it Mickey Mouse disease if I can get the right treatment and insurance is willing to pay for it.”

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Interviews

Azziz, Ricardo. Reproductive endocrinologist, researcher, and executive. Zoom interview. March 12, 2024

Christ, Jacob. Reproductive endocrinology fellow at the University of California, San Francisco. Zoom interview. Zoom interview. March 18, 2024.

Douglas, Crystal. Nutrition scientist and dietitian at the University of Texas Medical Branch. Zoom interview. January 31, 2024.

Dunaif, Andrea. Endocrinologist at Mount Sinai Health System. Zoom interview. March 11, 2024.

Hopkins, Dawnkimberly. Women's health nurse practitioner, researcher, and patient. December 6, 2023.

Iyer, Tara. Family medicine physician at Brigham and Women's Hospital. Zoom interview. January 22, 2024.

Lantz, Emily. Nutrition scientist at the University of Texas Medical Branch. Zoom interview. January 31, 2024.

Levinson, Ashley. Patient, advocate, and influencer. December 4, 2024.

Mahalingaiah, Shruthi. Reproductive endocrinologist at Massachusetts General Hospital. Zoom interview. January 29, 2024.

Noble, Robin. Gynecologist at InterMed. Zoom interview. January 23, 2024.

Ottey, Sasha. Patient and director of PCOS Challenge. Zoom interview. March 14, 2024.

Pierce, Courtney. Patient and advocate. Zoom interview. September 29, 2023.

Renner, Sandra. Patient. Zoom interview. January 27, 2024.

Rothbort, Andrea. Patient. Phone interview. January 25, 2024.

Sherif, Katherine. Internist at Jefferson Health. Zoom interview. February 21, 2024.

Snyder, Julie. Patient. Zoom interview. February 7, 2024.

Tay, Jillian. Endocrinologist at Monash University. Zoom interview. May 9, 2024.

Teede, Helena. Endocrinologist at Monash University. Zoom interview. December 13, 2023.

Tuckman, Allison. Patient. Zoom interview. January 23, 2024.

Williams, Stacey. Psychologist at East Tennessee State University. Zoom interview. September 29, 2023.