

More awareness, education needed to better treat polycystic ovary syndrome

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Researcher Donna Vine led a survey of women with polycystic ovary syndrome that shows a need for more clinician and patient education and awareness of how to treat the condition. Credit: Vega Studios

By the time she was 15, Sarah Chambers knew something wasn't right with her body.

"I was late getting my first period, I'd only have a couple a year, and I

had [facial hair](#), but I got told it was teenage hormones."

So she waited, hoping the embarrassing symptoms would fade as she matured—but they didn't. It wasn't until, frustrated and pressing for more answers a few years later, the young Alberta woman first heard her doctor make passing mention of something called polycystic ovary syndrome.

The condition, PCOS for short, causes the ovaries to produce abnormally high levels of male hormones, which are usually present in [women](#) in only small amounts.

"The doctor said don't worry about it, and didn't explain (the condition) to me," Chambers, now 32, recalls. "I was like, OK, and so I went home and Googled it and I started crying. Because it was me and everything I was dealing with."

PCOS the most common hormone disorder in [adolescent girls](#) and women globally, affecting about one in 10 across their lifespan, and is a leading cause of menstrual dysfunction and infertility.

When she got a formal diagnosis of PCOS at 19, the confirmation brought Chambers some relief, and she was told treatment for the condition could be more fully explored when she was ready to get pregnant.

But what she wasn't told at the time was that PCOS often goes hand in hand with health risks like [heart disease](#) and diabetes.

It took another two years, when she started rapidly gaining weight for no apparent reason, for Chambers to be told she was prediabetic. Then, at age 27, her cholesterol started climbing, and it wasn't until she took part in a University of Alberta clinical trial that she found out it was related

to PCOS.

All of it came as a shock.

"I didn't think I'd have to worry about any of that stuff in my twenties at all," Chambers says. "I remember thinking, I'd just had a baby, I shouldn't be at that point in my life."

More awareness and education needed

Chambers isn't alone in her rocky experience navigating the condition, according to [results from a recent survey](#) of 300 Canadian women diagnosed with PCOS, about half of them from Alberta.

The findings from the Alberta participants show that it took 34% of the women more than two years to get a diagnosis of PCOS, and 60% had to visit more than one health-care provider before a final diagnosis.

On top of that, 75% of the respondents weren't told about the health risks linked to PCOS. And following their diagnosis, 23% of the women were found to have high blood cholesterol and 25% were either prediabetic or diabetic.

Those numbers show a need for much more awareness in the health-care system in treating the disorder, says U of A nutritional scientist Donna Vine, who conducted the survey under PCOS Together, a research program she leads for women with the condition.

"There seems to be a lack of patient and clinical education about the long-term medical risks associated with this disease, and as a result, these women may just be treated for their reproductive and fertility issues, and not treated for other health risks, like cardiovascular risk," says Vine, a professor in the Faculty of Agricultural, Life &

Environmental Sciences and member of the Women and Children's Health Research Institute.

With little information provided about her condition, Chambers spent years trying to glean everything she could about PCOS from the internet.

"For a good chunk of those years it was me on my own trying to learn everything, but when you start looking for information, you walk into this storm and you're trying to pick out what's going to help you and trying to understand it. It was frustrating."

More education about PCOS and its many related health risks can help clinicians fully treat their patients rather than targeting only one symptom at a time, Vine says.

"Given what we have learned, if a cardiologist sees a female patient they should also ask for a menstrual-reproductive history. The minute you establish that patient has PCOS, they can immediately be put in a different risk category and checked for other symptoms, along with knowing there may be a range of other health concerns that need to be addressed."

'These women can't do it on their own'

Beyond the doctor's office, patients with PCOS need to be referred to specialists to help them manage their various risk factors, adds Vine.

The first line intervention in PCOS is improving nutrition and lifestyle. One of the most important ways to do that is through referral to nutritional counseling, she suggests.

The survey showed that 96% of the women diagnosed with PCOS reported being overweight or obese, and 38% said a lack of knowledge

about [healthy eating](#) was a major barrier to them losing weight or managing their weight.

At the same time, more than 80% said they weren't referred to a registered dietitian or other specialist to help them manage their health.

"I very much had to tackle that aspect on my own," says Chambers, adding that after her diagnosis, she asked about seeing a nutritionist, dietitian and endocrinologist, but felt "brushed off."

"I left my appointment feeling like my PCOS wasn't serious enough for referrals or extra help."

That gap needs to be closed, Vine says.

"These women can't do it on their own, but need specialized intervention to help monitor their diet and exercise, to be on the right medication to lower their testosterone and insulin levels, to get an approach to help them really target all of their symptoms."

The high testosterone and insulin levels patients are living with already make them metabolically resistant to losing weight and increases [health risks](#) that come with PCOS, Vine notes.

Women with PCOS who want to become pregnant face extra challenges because safe drug interventions to manage their health issues are limited, she adds.

The worry around all of these issues is a blow to the women's mental health, the survey showed.

When told to lose weight, 75% of those surveyed reported stress and 60% had other negative feelings.

"I felt very alone," Chambers recalls. "You start gaining weight seemingly out of nowhere and everyone thinks you just have to exercise more and eat better. I was already doing that. It's not about being lazy and not eating well."

"It's sort of a vicious cycle for these women, and they can be really stuck on figuring out how to help themselves," Vine notes.

How women can be their own advocates

She encourages women diagnosed with PCOS to advocate for themselves.

"They should learn as much about their disease as possible, know their symptoms and know they can ask to be referred to different specialists for assessment."

Resources offered through the [PCOS toolbox](#) can help with that, says Chambers, who started and leads an [online support group](#). Women should also advocate for themselves during doctors' appointments, she adds.

"Write down your questions, have a list of things you want addressed and don't leave until you've talked through them all, so that you're not leaving with more questions than answers."

Finding a supportive friend, family member or group is also helpful, Chambers says.

"It's important to your mental [health](#) to have that backbone to keep you up when you are pretty much collapsing."

People who know someone struggling with PCOS and its symptoms

should try to be kind, she adds.

"Reach out, be there for them and try to understand it."

"PCOS has a lot of visual symptoms like [weight gain](#), [hair loss](#), facial hair and acne that can make you feel less of a woman, so it makes it difficult when you have society judging you on top of that."

Provided by University of Alberta

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