

Polycystic ovarian syndrome: Losing weight can help but many sufferers are vulnerable to bad advice on social media

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Credit: AI-generated image (disclaimer)

Polycystic ovarian syndrome (PCOS), a hormonal condition which affects how the ovaries work, is thought to affect 20% of women worldwide. Yet despite how common the condition is, and the serious effect it has on women's health, researchers still aren't completely sure



what causes PCOS—let alone how best to manage and treat the condition.

Alongside taking hormonal therapy, most guidance states <u>weight loss</u> is one of the best ways to manage PCOS. Even just a 5% loss of body weight is shown to <u>improve symptoms</u>. Weight loss can also help reduce risk of developing more serious health problems related to excess weight, such as type 2 diabetes, high blood pressure and sleep apnea.

But hormonal imbalances linked to PCOS can make it difficult for women to lose weight. Historic underfunding for PCOS-centered research also means there's a serious lack of reliable, evidence-based guidance on the best ways to lose weight—and what PCOS symptoms may improve as a result.

This leads many women to turn to the internet, where diet advice is abundant. But this information is often <u>profit-driven</u> and potentially <u>grounded in misinformation</u>. Not only does this questionable diet advice provide false hope for people with PCOS, it may also be putting them at risk of harm—<u>including disordered eating</u>.

Social media and PCOS

There are almost half a million posts on Instagram under the hashtag #pcosdiet. On TikTok, videos with this hashtag have over 470 million views.

You need only scroll through this hashtag for 30 seconds to be faced with dozens of posts containing contradictory information from self-proclaimed "experts". Many offer lifestyle advice, diet or exercise programs promising improvements to symptoms—and even reversal of PCOS (which cannot be cured).



Only a <u>small fraction of these posts</u> (around 1.4%) are estimated to be made by registered dietitians. This leaves audiences vulnerable to misinformation.

While social media can act as a support system for people with PCOS, many women find the way weight loss is sometimes depicted on social media as easily achieved with the right diet or exercise regime to be discouraging.

Not to mention that many social media posts discussing weight management are created by <u>young</u>, <u>white</u>, <u>female-presenting users</u> who promote aspirational bodies and lifestyles. Many #pcosdiet content creators appear to fit this brief, which does not accurately represent many of the people who have PCOS.

Narratives shared online often describe long struggles with PCOS symptoms, (including weight issues) until the user found the "key" to fixing their symptoms—with before and after pictures showing substantial weight loss. Intended as motivational, the result is often detrimental.

Women with PCOS describe often long, complex and frustrating relationships with <u>weight management strategies</u>. Previous difficulties with weight loss make it hard to keep trying—risking frustration and fatigue, potentially worsening body image and <u>mental health issues</u>.

The diets championed by online influencers vary, ranging from ketogenic diets to anti-inflammatory or vegan diets. But while research studies have investigated low-carbohydrate, calorie-restricted, Mediterranean and vegan diets to see what affect they have for people with PCOS, there's no definitive evidence that any one diet is best.

Rather, the evidence suggests that the more weight lost, the greater the



improvements in the <u>hormonal profiles</u> and symptoms of PCOS—including the number of periods a person has.

There's also worry that the promotion of certain weight loss drugs by influencers on <u>social media</u>—specifically semaglutide, sold under the brand names Ozempic and Wegovy—may lead to an <u>uptick in unsupervised use</u> among women with PCOS. This is especially concerning, given the lack of evidence for the long-term risks and outcomes of these drugs.

This information—and misinformation—may make women with PCOS feel discouraged when trying these diets, only to find they don't achieve the same results as their favorite influencers.

Need for research

The lack of precise information on weight loss for people with PCOS is largely due historic <u>underfunding for women's health research</u>. Over the last decade, research funding allocated to PCOS has been <u>less than half</u> of that allocated to research for equally or less common health conditions—such as rheumatoid arthritis.

This lack of funding also means that few research studies have investigated the PCOS symptoms that people find most distressing—such as male-patterned hair growth and irregular periods. This means people with PCOS have even less information about how to best manage these symptoms.

There is currently research being conducted into whether the same <u>lifestyle changes</u> that help people with type 2 diabetes achieve remission can also help people with PCOS. But there's still a clear need for more investment and research into PCOS.



If weight loss is one of the best steps to take to manage your PCOS symptoms, the research needs to catch up, or we risk women turning to more dubious online sources. We need high-quality evidence to support people with PCOS about their dietary options, to help them make informed decisions about the best <u>diet</u> for them.

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