



PCOS & Eating Disorders - Managing the Nutritional & Psychological Aspects

Research indicates that the prevalence of #eatingdisorders such as #anorexianervosa, #bulimianervosa and other unspecified eating disorders is higher in women diagnosed with Polycystic Ovary Syndrome (PCOS) compared to that in the general population. Current treatment approaches for #PCOS emphasize the importance of #weightmanagement, #exercise and #diet. However, if not administered holistically – taking into account the social and mental factors – these recommendations may push women & girls into a vicious cycle of starving, bingeing and purging and develop adverse relationships with food and their body weight.

February is #eatingdisordersawareness month and we are talking to registered dietician Angela Grassi of PCOS Nutrition – a PCOS survivor herself who is an internationally known #nutrition and health expert on PCOS – to get a deeper understanding about the management of the nutritional and psychological aspects of eating disorders in women with PCOS. PCOS advocates Lisa Rosenthal and Tatiana Alafouzo will help guide the discussion from the patient panel.

Full Transcript:

Shweta Mishra: Good evening, everyone. I'm Shweta Mishra and I welcome you all to this PCOS session on CureTalks in association with the PCOS Tracker app, more information about which is available on the website, pcostracker.app. It's Eating Disorders Awareness Week and today we are talking about Managing the Nutritional and Psychological Aspects of Eating Disorders in those dealing with PCOS, and I'm honoured and excited to welcome our eminent guest expert, registered dietitian, Angela Grassi, an internationally known PCOS nutrition expert, author of The PCOS workbook and the Founder of PCOS Nutrition Center where she provides evidence-based nutrition coaching to women with PCOS. Angela is a PCOS survivor herself and has received several awards for her work in the field. Welcome back to CureTalks, Angela. Thank you for finding time to educate us again.

Angela Grassi: Thank you. It's an honor to be with you again.

Shweta Mishra: It's our pleasure, Angela. On the patient panel, we have PCOS advocates Lisa Rosenthal from Illume Fertility who has been advocating for over 30 years now in the field of infertility, and Tatiana Alafouzo PCOS warrior and researcher who also fought and won over her eating disorders in her adolescence, and she is joining us from the UK. Lisa and Tatiana, welcome to the show and thank you so much for joining the panel today.

Lisa Rosenthal: Thanks for having me.

Shweta Mishra: My pleasure.

Tatiana Alafouzo: Thank you so much for having us.

Shweta Mishra: My pleasure, Tatiana. So, Angela for a little background and to begin with it'll be good if you can talk briefly about what are eating disorders? And what factors contribute to eating disorders in polycystic ovarian syndrome patients and all the more importantly, why is it important to talk about eating disorders in folks dealing with PCOS?

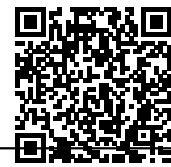


Angela Grassi: Yeah, well, I think we can start with why it's important that we're talking about PCOS and eating disorders because eating disorders are very prevalent in the PCOS population. One statistic I saw said that it's four times higher in PCOS sufferers, and there are lots of reasons for that. I think a lot of people that have PCOS are experiencing a lot of frustrations and challenges with the condition. A lot of symptoms are uncontrollable. So, if somebody has acne that's just popping up around their face and their back and hair growth in places, they don't want it and nothing seems to work, they gained weight and it's really frustrating to try and control these symptoms. So, one aspect of eating disorders that has a common theme and I'll go into the different eating disorders if that would be helpful. But one commonality is that it's a sense of control. Like trying to control what you eat and what you do to your body. So even though a lot of these symptoms of PCOS feel out of control, having an eating disorder, is a way to regain control, and then it's really common in PCOS to hear just lose weight to that weight loss is going to result in curing PCOS or really improving PCOS, helping people get pregnant, and there's a lot of pressure on people with PCOS to lose weight and it's not the cure for PCOS. We don't have a cure, but this weight loss focus really drives people to try different things, to lose weight. And there's a lot of conflicting information on social media, which isn't a surprise, but people hear different things, and they try different things. And something might work for somebody and then somebody tries it, and they feel like a failure if it's not working and they beat themselves up. And so, there's a lot of pressure on people with PCOS. And then an underlying condition with PCOS is insulin resistance or high insulin levels. And when somebody has high insulin levels, insulin is an appetite stimulant. So, it's a hormone that drives you to be hungrier. And for a lot of people, it can drive, binge eating behaviour. So, it's not uncommon at all to see people of PCOS engage in binge eating and one study I saw shows that 60% of women with PCOS engage in binge eating behaviour. So, it is really concerning. There are a lot of factors that contribute to eating disorders.

Shweta Mishra: Absolutely. Thank you so much for that explanation. Let's talk a little bit about adolescence. And when they are diagnosed with PCOS, right? Adolescence is the age when girls start to have concerns about their body weight, shape, and body image. And when they are diagnosed with PCOS they are suggested like you just mention, they are suggested to lose weight. And that's when they go all in, sometimes very aggressively with diet and exercise. So, I'm just curious. What criteria do you follow to know that an adolescent that just walked through your door in your clinic is dealing with an eating disorder or is it just a fair attempt at weight loss?

Angela Grassi: Yeah, it's a fine line and I don't know anybody who has an eating disorder that it didn't start off with a diet. So how do you know if it's just dieting weight loss efforts or somebody especially a teenager has an eating disorder. The first is we should be screening all patients with PCOS for eating disorders as well as mood disorders. And that's in the new evidence-based guidelines the most latest edition that was published that Health Care Providers, should be screening patients for these and I try and do it at the first visit. In my nutrition assessment, I will screen patients for eating disorders. So, I'll ask about their relationship with food. If they feel comfortable eating a variety of foods, what foods do they not feel comfortable eating? Are there foods that they are scared of, that they're fearful of, how do they feel eating with other people, what other methods do they use to control their weight? So, some people might be for example, taking laxatives or diuretics, or Diet Pills as an attempt to control their weight. So, screening, for any of these screening, for medical signs of malnutrition and if someone who is menstruating, if their menstrual cycles have stopped, that's a red flag for anorexia in particular. And if they do answer yes, to some of these questions, just probing more like, do you ever been to eat? And you ever feel like you lose control of food? Do you ever throw up, if you ever vomit to get rid of food and know the criteria for each, I mean the main eating disorders that we know of are anorexia nervosa, bulimia nervosa. We have binge eating disorder and then there are subgroups of these that might not meet the criteria exactly but might have some overlapping factors. So those are all to be concerned about as well.

Shweta Mishra: Alright. Thank you. Thank you so much for those answers, Angela. And with that, I think I'll move on to Tatiana now. Tatiana Alafouzo is a PCOS warrior, passionate about empowering women with PCOS to take control of their symptoms. She's a registered Associate Nutritionist with Association for Nutrition in UK. And currently, she's working on her Ph.D. focusing on mindfulness-based interventions for the management of PCOS symptoms. Tatiana, welcome to the show again, and before you begin with your



questions for Angela, could you please talk a bit about your journey with eating disorders and share with our audience, the most important mantra that you held while fighting to overcome your eating disorders?

Tatiana Alafouzo: Sure. Thank you so much for having me Shweta on such an amazing panel with such amazing people. I was diagnosed with PCOS at the age of 14. So, on the one hand, I recognize my privilege, I was extremely lucky that I was diagnosed very, very early in life, which many people are not, but on the other hand, it was sort of like a double-edged sword. I was told that the best way to control my PCOS symptoms was to cut calories and carbohydrates and to diet. So, this definitely affected my relationship with food. And as a result, I developed several different Eating Disorders throughout my life in my adolescence and in my early 20s. My relationship with food was extremely bad, I had bouts of starving binging, purging, exercise bulimia. Definitely had a problem with diet at one point, as Angela was saying and laxative abuse just sort of trying to find any way to control, “these symptoms of PCOS, which I thought were in control of me” and the one thing I can say as you said, what is the important mantra I’ve held, healing is not linear as probably the most important thing every day is a fight, but I am stronger than my Eating Disorders is what I try and tell myself. And another thing I think that’s definitely extremely important when you have PCOS or any kind of syndrome which may affect you in so many different ways, as PCOS does and Angela, definitely hit the nail on the head, which is that PCOS affects us, not just physically but also psychologically. It is just having a kind of self-love and self-acceptance of the fact that even though PCOS is part of you and woven into your story. It is not your whole story, and it is not all that you are, you are so much more than your PCOS and you are so much more than your PCOS symptoms. And you are worthy of love and acceptance of yourself. So, I think that that’s definitely a mantra that I’ve tried to hold close to me throughout this journey in my fight with my eating disorders. But again, I think also just self-forgiveness is also a big thing because I think we’re very, very different hard on ourselves when we have PCOS and when things are not going the way we like them to go and when we feel like we have lack of control or loss of control. So, I think something that I always just advise fellow patients and fellow PCOS warriors just that keep going, you are lot stronger than you think and you are stronger than this syndrome and it is only a very, very small part of you and you should love and accept yourself exactly as you are and just do the best to live in the best way possible, , in a healthy way psychologically, and physically.

Shweta Mishra: Right, thank you. Thank you for sharing your story, Tatiana. Very motivating. And thanks for all those tips. I know you have some very relevant questions that will add important information to this discussion, please go ahead.

Tatiana Alafouzo: Yeah, absolutely. So, Angela, I guess, my first question was just, what are your thoughts on these DSM-5 criteria for various eating disorders. And do you think that these criteria should be expanded beyond what it is?

Angela Grassi: So, well, definitely it should be expanded. But the fact that they have included some eating disorders like orthorexia is now mentioned in the DSM-5 and we have other aspects to eating disorders that weren’t mentioned in DSM-4. But absolutely, there’s everybody is different and there are so many different factors that contribute to eating disorders and everybody presents in a different way. And I think more inclusion of different forms of eating disorders, how they might present would be great to include.

Tatiana Alafouzo: And do you feel that a multidisciplinary approach is probably the best way to go about handling someone who has an eating disorder. For example, them seeing not just a dietitian, but also a psychiatrist or psychologist, having people work together as a team in order for this person to heal as fast as possible?

Angela Grassi: Absolutely. My background actually is treating people with eating disorders and the very first patient I ever saw with PCOS was somebody that struggled with bulimia, I was working at an eating disorder treatment facility, and she couldn’t stop binging and purging and she was diagnosed with PCOS, and her doctor told her to do back in style diet. So, no carbs or like 15 grams of carbs a day. Something crazy like that and she couldn’t stay away from the carbs, and she was just so upset. I just remember her just crying in my office the first time I met her. So, as a registered dietitian nutritionist, I do provide medical nutrition



therapy to people with eating disorders and the best treatment is a multidisciplinary treatment approach. So that might involve the nutrition therapist as well as a therapist. And I don't like to work with patients unless they're also in therapy because so much comes up when you're in recovery. There are so many emotions around the food that they need to have a therapist to help them to process this because the food is usually a metaphor for a lot that's going on as you mentioned with the control. So, it's very important that they're working with a therapist and then they have this supportive environment. They have the dietitian on one hand and then they have the therapist and having the support on both sides, having this treatment approach is really effective.

Tatiana Alafouzo: Absolutely, I guess relating to my first question. How do you feel is the best way to deal with eating disorder patients who are being dismissed because they're not underweight? I know that this happens a lot, especially in the PCOS population and it definitely something I've also dealt with. How do you make these patients feel validated and how do you get them the help that they need which they might not be getting?

Angela Grassi: Yeah, it's so hard and I'm hoping that having the recommendation to screen patients for eating disorders, in the PCOS population is one way to start catching this better. Eating disorders affect everybody, every size, every color, every gender. And we really need more awareness about it and that it does affect people of all different sizes.

Tatiana Alafouzo: Absolutely. And then in your clinic, how do you approach? I want to see eating properly for PCOS with your clients knowing that they are at a higher risk for eating disorders. What sort of approach would you take with someone like that?

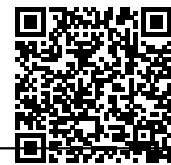
Angela Grassi: Yeah. I mean with my background in treating people with eating disorders. I am not going to have my clients wait, count measure food. I'm not going to put a restriction on it. So, I personally take a non-diet approach to treat my patients with PCOS. I'm always having in the background that they are at a higher risk for eating disorders. They might have an eating disorder. They certainly have dieted, and dieting is one risk factor for predicting the onset of an eating disorder. So, I help patients instead to help heal the relationship with food with this non-diet approach. So, instead, we focus on sustainable lifestyle changes. So, we work on mindfulness, and I would love to hear your work on the mindfulness interventions that you're doing the research on. We have to collaborate, but mindfulness is so important and so is taking care of your body with regular physical activity and mindful eating and sometimes there are certain supplements that can help, for example, bring down the insulin or help bring down cholesterol and so even sleep, prioritizing sleep could be really effective for helping to lower insulin and regulate hormones better. So, I like to take a whole comprehensive approach and take it from a non-diet standpoint that focuses more on developing those sustainable lifestyle changes.

Tatiana Alafouzo: That's wonderful. Your patients are so lucky to have you. I wish I had someone like you when I was going through everything. So, thank you so much, and thank you for answering my questions.

Angela Grassi: Absolutely.

Shweta Mishra: Thank you. Thank you, Tatiana. At this point, I will now invite Lisa to ask her questions. Motivated by her personal journey, Lisa is determined to help others undergoing fertility treatment. She is the founder and teacher of the Fertile Yoga Program and is also a certified grief recovery specialist. Lisa, thank you for joining today again. Welcome and please ask your questions.

Lisa Rosenthal: Thank you. I certainly will and I had the opposite experience with PCOS that Tatiana had. I didn't find out about PCOS till I was in my 50s and explained an awful lot of things, retroactively. I know Angela, right, unbelievable. So, these questions were literally taken from patients. The first one is, I can't tell the difference between my cravings. I often feel hungry even right after eating a complete meal, what is that about?



Angela Grassi: That is not uncommon to hear from patients with PCOS that they crave carbs and sweets all the time. I experienced that as well. I know that a big contributing factor to it is higher levels of insulin. So again, that appetite-stimulating hormone. We also see impaired levels of ghrelin and leptin which affect appetite. So, it's very common for people with PCOS to have these cravings. I think you have to take a look at it from a different standpoint, that maybe the cravings are just because you want the food, that's totally normal. People without PCOS have food cravings. Maybe you have these cravings because you didn't get enough sleep the night before, you haven't been getting enough sleep or you haven't exercised. So, these are all things to keep your insulin down. Other things that can contribute to cravings are if you are not eating balanced meals. So, usually, if you add protein and fat to your meals, it helps to stabilise your blood sugar level. So, it keeps it from going like a roller coaster all day, and instead, you have even more steady blood sugar fluctuations and that really can help with cravings. And then I also have found that inositol supplements, inositol is a B vitamin that helps to regulate insulin levels better. And a lot of people that take it, myself included, have seen cravings decrease because it does bring down insulin levels. So, a lot of things to consider with those cravings.

Lisa Rosenthal: Yes. Thank you, and I didn't hear any shame or guilt on any of them, and none of it was about blaming, which I really appreciate. Because when you speak to patients, it's just so often that it's about self-will and they have been shamed. So, thank you. And the second question is similar, which is I've tried every suggestion out there, but I can't stick to any food plan. I'm hungry all the time. So maybe you've really kind of covered that, anything else that you wanted to add to that? Like, maybe seeing somebody?

Angela Grassi: Yeah, I mean, they should definitely work with someone because the more you're trying to fight this and limit your intake, it's going to just lead to more distorted eating or a full-blown eating disorder. So, working with a Nutrition professional. I would talk with your doctor. Maybe your insulin levels aren't being managed very well. Maybe there are some underlying aspects like hypothyroid that can be contributing to it too. So sometimes medications can help, the right supplements can really help but balanced eating is really key. Sometimes patients with PCOS just aren't eating enough food because they're trying to lose weight.

Lisa Rosenthal: It's a shock sometimes to hear that.

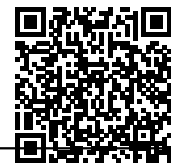
Angela Grassi: So, when you don't eat enough food, you're hungrier.

Lisa Rosenthal: And then you get hungrier and eat foods that you don't _____

Angela Grassi: Even binge eat. And then you're like, oh, I can't believe I did that. And then you restrict your intake and be like, oh, I'm not going to eat breakfast the next day and then you get so hungry again and the whole cycle just repeats itself. So going into balanced meals and working on things like I discussed earlier sleep and exercise may be supplements or medications that can help get your insulin better controlled.

Lisa Rosenthal: Wonderful. So, this next question is from a mom who has been battling eating disorders. And her question is, it's very hard to manage my own food when I'm responsible for cooking for the whole family. I can't concentrate on my food when I'm so pressured about taking care of if you've had a two-year-old trying to get a two-year-old to eat and then focusing on yourself. Any suggestions for a patient like that?

Angela Grassi: Yeah. It's so hard to put yourself first when you are a parent, but you're going to be a better parent if you're better nourished and your needs do come, are important. So, I would ask for help. If the child is old enough, they can maybe make their own meals. If you make something, it's rare that everybody's going to like something at the dinner table, but if you can make some meals, that everybody will eat that puts down on the work. Sometimes using prepared meal services, if you can afford it can really be helpful if people have different dietary restrictions or food allergies or something like that and don't be afraid to go for a simple meal like an even making eggs and egg sandwich and be balanced, put some veggies in there or frittata and some potato, it can be pretty easy. It doesn't have to be really elaborate.



Lisa Rosenthal: What do you think about the idea about a parent, a mom eating before the meal? Just having something to eat before the meal so that they can focus on their own food first. And then maybe the family second. What do you think is happening there?

Angela Grassi: Depending on where they are in their recovery, it could be helpful or not. I mean, for some people it's helpful to eat with their family. But if they are really struggling then, maybe they need to take care of their own needs first, and then feed everybody else.

Lisa Rosenthal: Okay. Thank you. And this next person asks, how do I as a patient right, understand whether it's PCOS or a psychological thing? How do I go about knowing and then this part was really I think, important Angela. How do I go about finding the right kind of professional to help me with food, eating disorders, and eating and PCOS obviously?

Angela Grassi: Yeah. That's really important. So, if you feel that you are struggling, definitely reach out for help. You can find somebody I know like the National Eating Disorder Association has a list of providers. These are people that have experience treating people with eating disorders, look up their bios, look up their experience, have they worked at an eating disorder treatment facility, how long have they been in practice, just even asking the doctor if they know anybody or what kind of doctor it is, but it's really important that you reach out for help. I mean, we didn't talk that much about mood disorders, but people with PCOS also have higher rates of anxiety and depression, and that correlates with eating disorders. So, working with a therapist can be really helpful.

Lisa Rosenthal: Excellent. Thank you. And my last question from a patient is what professional should I be looking for? And what would a food eating disorder workup look like especially in conjunction with PCOS, like will blood work be done, what kind of testing would be appropriate?

Angela Grassi: Yeah. Absolutely. The doctor should run medical labs to look for malnutrition and look for signs of, for example, if somebody is engaging in purging behaviour, their electrolytes might be out of whack and that's really dangerous. If electrolytes kind of contribute to heart beating and heart rhythm and you don't want to mess around with that. So, checking for that and hydration and it's very important to work with a physician and then you could start probably with a mental health professional in this space of eating disorder. And they should have a lot of connections with dieticians that also are in your area.

Lisa Rosenthal: Thank you so much. And thank you always Shweta for having me here today.

Shweta Mishra: Thank you. Thanks, Lisa. Thanks for collecting all those wonderful questions from the patients and Angela thanks for the answers. And I have one last question before we wrap up the show today, and that is if you could get one message out to the women dealing with PCOS and eating disorders, what would that be?

Angela Grassi: You can recover, you can reclaim your life from PCOS. It's doesn't need to control every aspect of your life. It shouldn't control every aspect of your life and it can be so much better. And don't be afraid to reach out for help.

Shweta Mishra: Thank you. Thank you, Angela. That was a great discussion. And I know eating disorders are a complex topic and we could not cover all the aspects of it, but I'm sure we were able to touch upon the most important ones. So, thank you for answering, all those questions and all the information shared, and I'm sure this will be helpful to the PCOS and Eating Disorders Community. Lisa and Tatiana, thank you so much for your questions and guiding the panel and folks in the audience thanks for listening. And if you have questions for Angela you can reach out to www.pcosnutrition.com. And I would like to request all of you to visit the website, pcostracker.app to check out the free PCOS Tracker app and see if it is helpful to you in tracking your symptoms. We are working to give you a better tracking experience and your feedback would be very helpful to make it more efficient. So, please send your feedback to shweta@trialx.com, and this talk will be available on curetalks.com as well as on our YouTube channel. Until we meet next time. Thank you,



everyone. Have a great day and stay safe.

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