

Using a Clinical Lens to Understand and Treat PCOS & Eating Disorders

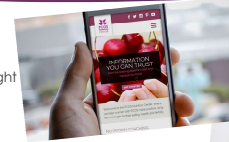
EDPRO



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Positionality: Angela Grassi, MS, RDN

- ▶ White, cis-het, mother of two
- ▶ Live in a large body. Person with PCOS who has experienced weight stigma
- ▶ Founder of the PCOS Nutrition Center
- ▶ I have worked in the PCOS and eating disorder field for over 20 years



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Disclosure

Retailer:

- Ovasitol by Theralogix
- Fish oil by Nordic Naturals
- PCOS Nutrition Center Supplements



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Outline

- ▶ Brief overview of PCOS
 - ▶ Pathophysiology
- ▶ Current research on mood and eating disorders
- ▶ Eating behaviors among PCOS women
- ▶ Treating PCOS and Eating Disorders with a weight-neutral approach
- ▶ Case study

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PCOS: Background

- ▶ Most common endocrinopathy in premenopausal women
 - ▶ PCOS: 6 – 13% of U.S. women
- ▶ Under-diagnosed, under-funded and under-treated
- ▶ Most common cause of ovulatory infertility
- ▶ Multi-factorial, polygenic disorder with variable phenotypes
- ▶ Condition of androgen excess



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Diagnostic Criteria

To diagnose you must have 2 of 3 *:

1. Oligo - or anovulation (8 or fewer menses in one year)
2. Clinical signs of hyperandrogenism: acne, excessive hair growth, hair loss and/or biochemical signs:
 - Total Testosterone > 50 ng/dL
 - Free testosterone > 6 pg/dL
 - DHEA-sulfate > 270 µg/dL
3. Polycystic ovaries

*In the absence of other etiologies

Final report from the 2012 NIH Evidence-based Methodology Workshop



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Ferriman- Gallwey Scale

Modified Ferriman-Gallwey (F-G) hirsutism scoring system. Each of the nine body areas is rated from 0 (absence of terminal hairs) to 4 (extensive terminal hair growth), and the numbers in each area are added for a total score. A modified F-G score ≥ 6 generally defines hirsutism.

Reiter et al. Diagnosis of hyperandrogenism. *Journal of Clinical Endocrinology & Metabolism* Vol. 30, No. 2, pp. 147-176, 2006

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Transvaginal sonography

- ▶ 12 or more peripheral follicles
- ▶ String of pearls
- ▶ < 10mm diameter
- ▶ Ovarian volume > 10 cm

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An Ancient Disorder?

- ▶ Medical records dating back to ancient times: absent/irregular menstrual cycles, infertility, hirsutism, and abdominal weight
- ▶ A biological advantage during the hunter and gather years:
 - ▶ food was limited and life expectancy shortened.
 - ▶ people with PCOS had a metabolic advantage:
 - ▶ increased muscle mass
 - ▶ slower metabolism and less need for food,
- ▶ Reproductive advantage: having no or fewer children which increased their survival rate.

Azziz A, Dumesic, A. Goodarzi M. Polycystic ovary syndrome: an ancient disorder? Fertility and Sterility. 2010

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PCOS: A Genetic Link?

- ▶ Familial clustering of PCOS common
 - ▶ 1st degree relatives of patients with PCOS may be at high risk for diabetes and glucose intolerance
 - ▶ Mothers and sisters of PCOS patients have higher androgen levels than control subjects
 - ▶ Yildiz et al. J Clin Endocrinol Metab 88:2031; 2003
 - ▶ Male individuals who are first-degree relatives of patients with PCOS have a higher degree of dyslipidemia and insulin resistance
 - ▶ Reis KS, et al: Rev Bras Ginecol Obstet 32(7): 334, 2010
- ▶ PCOS is a genetically determined ovarian disorder... symptoms are based on the interaction of genes and with the environment.

Franks et al. Int J Androl 29:278; 2006

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PCOS: Reproductive Associations

- ▶ Oligomenorrhea, amenorrhea
- ▶ Infertility
- ▶ Pregnancy loss, preterm and stillbirths
- ▶ Polycystic ovaries
- ▶ Endometrial carcinoma

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PCOS vs. Weight-Matched Controls

- ▶ Elevated prevalence of metabolic syndrome
- ▶ Higher prevalence of hyperinsulinemia
- ▶ 2.5-fold increased prevalence of Impaired Glucose Tolerance (IGT)
- ▶ 4-fold increased prevalence of type 2 diabetes

Moran LJ, Misso ML, Wild RA, Norman RJ. Impaired glucose tolerance, type 2 diabetes and metabolic syndrome in polycystic ovary syndrome: a systematic review and meta-analysis. Hum Repro Update 2010;16(4):347-363.

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PCOS: An Independent Risk Factor For Type 2 Diabetes

- ▶ Higher insulin levels, independent of BMI
- ▶ Rapid conversion from IGT to T2D
- ▶ Androgen Excess & PCOS Society:
 - ▶ Normal glucose = Screen with 2 h OGTT every 2 years
 - ▶ Other risk factors/IGT=Screen annually

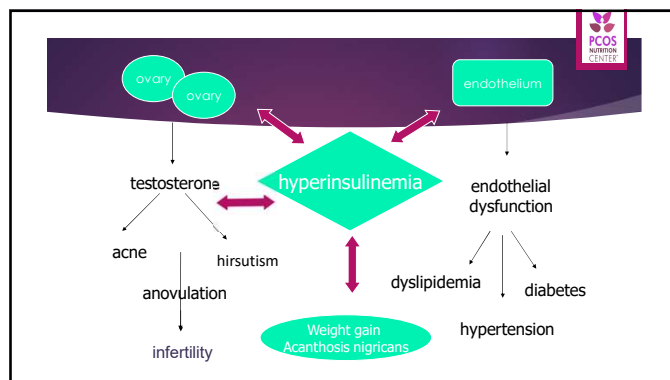
Moran L, Missa M, Wild R, Norman R. Impaired glucose tolerance type 2 diabetes and metabolic syndrome in polycystic ovary syndrome: a systematic review and meta-analysis. *Hum Reprod Update*. 2010;16(4):347-363.
 Gambarello A, Patton L, Killett P, Pagotto U, Tizi C, Marsala L, Pasquini R. Polycystic ovary syndrome is a risk factor for type 2 diabetes: results from a long-term prospective study. *Diabetes*. 2012.
 Salley KE, Wickham EP, Cheang KI, Bush PA, Karjane NW, Nestler JE. Glucose intolerance in polycystic ovary syndrome—a position statement of the Androgen Excess Society. *J Clin Endocrinol Metab*. 2007;92(12):4546-56.

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PCOS Associated with Other Diseases

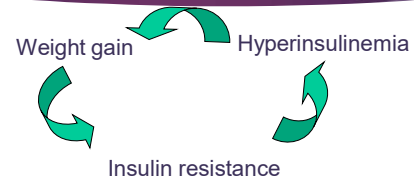
- ▶ Hypothyroidism & autoimmunity
- ▶ Obstructive sleep apnea
- ▶ Non-alcoholic fatty liver disease
- ▶ Coronary artery disease
- ▶ Gestational diabetes
- ▶ Mood and eating disorders

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Pathophysiology of PCOS: A Vicious Cycle



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Frequently Observed Lab Abnormalities

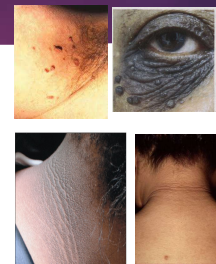
Lab Test	Result
Total Testosterone	Elevated
LH:FSH	Elevated
DHEA-Sulfate	Elevated
Fasting Glucose	Elevated
Fasting Insulin	Elevated
TSH and thyroid peroxidase antibodies	Elevated
C-reactive protein	Elevated
Triglycerides	Elevated
HDL	Decreased

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Acanthosis Nigricans

- ▶ PCOS, Insulin resistance, diabetes
- ▶ Associated with skin tags



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Other Observed Symptoms

- ▶ Acne
- ▶ Hirsutism
- ▶ Alopecia or hair thinning
- ▶ Hidradenitis Suppurativa (HS)



Harnaam Kaur

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PCOS and Mood Disorders

- ▶ 6 Study meta-analysis, 22 to 32 years old
- ▶ Rates of anxiety and depressive symptoms were higher in patients with PCOS compared to healthy controls
 - ▶ Blay SL. Neuropsychiatr Dis Treat. 2016;8:12:2895-2903
- ▶ 35% of women with PCOS versus 10.7% controls had depressive symptoms after adjusting for BMI, family history of depression and infertility
- ▶ 14% women with PCOS compared to 1% controls had anxiety symptoms
 - ▶ Hollnake E, Abreu A, Maifeld M, Van. Fertil Steril. 2007;87(6):1369-76.
- ▶ 8% of PCOS Women (n=110) and (n=66) had suicidality
 - ▶ Hussain A, Chandel RK, Ganie MA. Indian J Psychol Med. 2015 Jan-Mar;37(1):66-70.
 - ▶ Scaruffi E, Gambineri A, Cattivano S. Front Endocrinol (Lausanne). 2014 Nov 12;5:185.

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**Piltonen T. • Karjula S. • Auvinen J. •
Morin-Papunen L. • Miettunen J. •
Tapanainen J.S.**

Population based cohort analysis reveals persistently high depression and anxiety rates at the age of 46 in women with PCOS and/or hirsutism—a 15-year follow-up study.

Fertil Steril. 2014; **102**: e27

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Racial differences in anxiety, depression, and quality of life in women with PCOS

- ▶ Controlling for age, BMI, and SES
- ▶ White women with PCOS had a significantly higher prevalence of anxiety than Black women with PCOS (75.9% vs. 61.3%) and significantly higher anxiety scores (mean \pm SD, 10.3 ± 4.1 vs. 8.7 ± 4.6)
- ▶ The prevalence of depression (24.4% vs. 29%) and depression scores (4.8 ± 3.6 vs. 5.1 ± 4.0) was not significantly different
- ▶ Lower quality of life related to emotional well-being & infertility significantly lower in Black women with PCOS (mean \pm SD, 12.6 ± 7.8 vs. 17.5 ± 6.8)

Gupta S. F S Rep. 2021 Jun; 2(2): 230-237

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Distorted Eating in PCOS

- ▶ Case controlled study, women with PCOS (n=40) were compared with a healthy control group (n=40)
- ▶ Eating Disorders Assessment Questionnaire (EDE-Q) and the Three Factor Eating Questionnaire (TFEQ-R2)
- ▶ PCOS women displayed higher values of the tool scores indicating abnormal restraint eating, body shape concern and weight concern ($p < .05$)
- ▶ Average total and subscale scores of the EDE-Q & TFEQ-R21 were higher in larger bodied women with PCOS compared to controls
 - ▶ 'emotional eating', 'cognitive restraint' and 'uncontrolled eating'

Increased risk of eating disorders in women with polycystic ovary syndrome: a case-control study GYNECOLOGICAL ENDOCRINOLOGY 2020, VOL. 34, NO. 9, 764-767

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Increased Prevalence of Eating Disorders Among PCOS Population

- ▶ 8,467 participants (PCOS n = 875 vs. non-PCOS n = 7,592)
- ▶ Higher prevalence of EDs in women w PCOS
 - 11% vs. 7.6%
- ▶ Higher prevalence of low self-esteem in women w PCOS
 - 31.7% vs 24.2%
- ▶ Higher prevalence of psychological distress in women w PCOS
 - 21.0% vs. 13.5%

Chou T. Fertility and Sterility. 112(2):2019, Pages 353-361
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Higher Prevalence of Eating Disorders in PCOS Women

- ▶ Increased risk for overall abnormal EDE-Q scores compared with controls (12.16% vs. 2.83%)
- ▶ BN was 6.1%, of BED was 17.6%, and of NES was 12.9% in women with PCOS, with no differences compared with controls
Lee I, Cooney LG, Saini S. Fertil Steril. 2017;107(3):796-802
- ▶ The Prevalence of BN was 5.3%, AN 1.1% among PCOS women
Bernadett M. Psychiatr Hung. 2016;31(2):136-45.
- ▶ Binge eating behavior has been found to affect 60% of women with PCOS (small & large bodies) with 39% presenting with clinically significant behavior
Jeanes YM, Reeves S, Gibson EL. Appetite. 2017;109:24-32.

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Fertil Steril. 2018 May;108(5):888-895. doi: 10.1016/j.fertnstert.2018.01.038.

Androgen Excess- Polycystic Ovary Syndrome Society: position statement on depression, anxiety, quality of life, and eating disorders in polycystic ovary syndrome

Angela Dinkler¹, Elizabeth Steiner², Rebecca J. Ryland³, Rong Li⁴, Sasha Chetty⁵,
Dana Shah⁶, Neil Epperson⁷, Andrew Tanaka⁸

Conclusion(s)

In women with PCOS, screening for depressive and anxiety symptoms should be offered at the time of diagnosis and screening for disordered eating should be considered. Further research is required across PCOS phenotypes, in longitudinal cohorts and on impact of therapy on depressive and anxiety symptoms, HRQOL, and disordered eating.

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Factors that Contribute to Eating Disorders in PCOS

- ▶ Conflicting nutrition and lifestyle advice
- ▶ Social media, diet culture
- ▶ Past dieting history, weight cycling
- ▶ Mental health, shame, weight stigma, body-image distress
- ▶ Weight loss recommendations from family members/doctors
- ▶ Infertility challenges
- ▶ Activation of the HPA axis in response to psychological stress/continuous secretion of cortisol
- ▶ Difficulty with attempts at control (symptoms, weight, mood)
- ▶ Impaired levels of ghrelin & leptin
- ▶ Increased hunger, carbohydrate cravings
- ▶ Hyperandrogenism
- ▶ Hyperinsulinemia
- ▶ Having the condition
- ▶ Hypoglycemia

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Low Blood Sugar and Mood

- ▶ Hypoglycemia-related mood and behavioral problems in PCOS
- ▶ Women with PCOS reported significantly more mood and behavioral symptoms associated with reactive hypoglycemia than other women
 - ▶ Statistically significant after controlling for age, BMI and eating behavior
- ▶ "It might be speculated that the type of food eaten may have an impact on the symptoms typical of hypoglycemia"
- ▶ 58% of the PCOS group reported binge and/or comfort eating compared to 32% of control women
 - ▶ Barry JA1, Bouloux P, Hardiman PJ. The impact of eating behavior on psychological symptoms typical of reactive hypoglycemia. A pilot study comparing women with polycystic ovary syndrome to controls. Appetite. 2011 Aug;57(1):73-6.

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Main Advice Given to PCOS Women

"Just lose weight!"



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Eating Behaviors Among PCOS Women

In a unpublished survey of 1,167 women with PCOS:

- ▶ 66.6% (n=777) do not follow any formal nutrition guidelines
 - ▶ such as the DG for A, myPlate, AHA, ADA
- ▶ 57.3% (n=667) of the women are following some type of restrictive diet
- ▶ 16.3% (n=189) of the women are following a diet plan recommended by their physician
- ▶ 35.8% use the Internet for nutrition advice
- ▶ Other sources: social media, TV, radio, friends, family

Manaham L, Grassi A, Harris J, Moran L, Jeanes Y, Teedie H

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Diet Followed	%	N N=1,167
Diet Type		
Low-carb, high protein	36.3	432
low glycemic index	21.0	244
gluten-free	18.2	212
dairy free	17.4	203
soy free	11.3	132
paleolithic/paleo	7.7	90
ketogenic	2.7	31

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Reason for Dieting	%	N N=1,167
weight loss	39.0	454
treatment of PCOS features	38.0	442
general health	23.6	275
food allergies	14.2	165

Monahan L, Grassi A, Harris J, Moran L, Jeanes Y, Teede H

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3-Factor Eating Habit Questionnaire Respondents who answered 'definitely or mostly true'			
Characteristic	< 35 years % (n=882)	≥ 35 years % (n=338)	P-value
Cannot stop eating	46.7	47.3	0.037
Eats too much when sad	60.0	56.5	0.034
Eats when someone else is eating	69.1	68.6	0.048
Stomach feels like a bottomless pit	48.0	44.1	0.005
Difficult to stop eating before plate is empty	41.3	34.6	0.013
Consoles self with lonely by eating	47.2	42.3	0.019
Feels hungry when seeing delicious food	37.8	41.1	0.027

Monahan L, Grassi A, Moran L
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What the PCOS Literature Shows & Doesn't Show	
▶	There is NO research that shows weight loss helps people with PCOS long-term
▶	PCOS studies in general not long term
▶	Assumption that body weight is entirely controllable by lifestyle choices and that self-directed efforts can reverse PCOS
▶	Assumptions that PCOS people are gluttonous, lacking in willpower and self-discipline, incompetent, unmotivated to improve their health, non-compliant with medical treatment, and are personally to blame for their higher body weight.
▶	Studies where little to no weight loss still show improvement of symptoms/labs with lifestyle changes
▶	What about smaller bodied people with PCOS?

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Weight Stigma, Shame and PCOS	
▶	Health care providers
▶	Fertility treatments denied to fat people
▶	PCOS research
▶	Society
▶	Social Media
▶	People with PCOS/ Weight bias internalization

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The Seattle Times	
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Fitness Nicole Tsong Health News	
Life Wellness	
Why prescribing weight loss for polycystic ovary syndrome is futile and dangerous	
Sep 20, 2021 at 6:00 am	
By Carrie Dennett	
Special to The Seattle Times	

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A Paradigm Shift to PCOS Care

- ▶ Focusing on weight loss is harmful to people with PCOS
- ▶ Empathetic, supportive and non-shaming weight-neutral approach
 - ▶ Health at Every Size®
- ▶ Educate people/providers about sustainable lifestyle changes to support health
 - ▶ Nutrition assessment screen all patients for ED behaviors
- ▶ Skills: self-care, pleasurable food and exercise
- ▶ Heal relationship with food and body
 - ▶ Intuitive Eating
 - ▶ Accept all foods (avoid "good/bad" or "healthy/unhealthy")
 - ▶ Trust and rely on body cues

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Benefits of Weight Neutral Approach

- ▶ Improved well-being and mood
- ▶ Normalized eating
- ▶ Sustained healthy behaviors
- ▶ Improved metabolic labs
- ▶ Prevent yo-yo dieting
- ▶ Improved diet quality
- ▶ Reduced risk of eating and mood disorders

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How a Weight-Neutral Approach Works for People with PCOS & Eating Disorders

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Treatment Needs to be Individualized

- ▶ Focus first on treating eating disorder symptoms
- ▶ Education on PCOS, hormones, symptoms
- ▶ Education about why diets don't work for PCOS
- ▶ Education on how food affects insulin, benefits of antioxidants
- ▶ Gentle nutrition/Self care with food:
 - ▶ Permission to eat all foods
 - ▶ Benefits of incorporating protein and fat with carbohydrate foods
 - ▶ Not waiting too long to eat
 - ▶ Structure vs. no-structure
 - ▶ Intuitive eating/emotions and observations at meals
 - ▶ Self discovery of what food feels right

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Possible Nutrition Modifications for PCOS

- ▶ The optimal eating plan for PCOS is not yet determined
- ▶ Eating plans need to be individualized
- ▶ Eating plans that have shown favorable effects on fertility & metabolic parameters in PCOS:
 - ▶ Balanced eating plans
 - ▶ Modifying glycemic index (GI) and glycemic load (GL)
 - ▶ Modifying carbohydrate, fat or protein amounts
 - ▶ Including anti-inflammatory foods
 - ▶ Intuitive eating/gentle nutrition

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Help with Cravings

- ▶ Eating enough?
- ▶ Carbohydrate modifications
- ▶ Exercise
- ▶ Sleep
- ▶ Stress
- ▶ Inositols
- ▶ Do you just want to enjoy the food?

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Common Supplements for PCOS

Supplement	May help with	Dosage
Inositol (Myo: DCI 40:1)	Insulin, cravings, improving egg quality, regulating menses, androgen lowering	2 grams MYO, 50 mg DCI, twice daily with food
Vitamin D	Egg quality & ovulation; mood	2,000 IU to 4,000 IU daily fat containing foods
Zinc	Acne, excess hair growth, hair loss; androgen lowering	30mg to 60 mg
Magnesium	Anxiety, insulin & glucose	320mg to 500mg
N-Acetylcysteine	Egg quality, insulin, cholesterol, fatty liver	900mg to 1.8g
EPA and DHA rich fish oil	Ovulation, elevated TG, mood, regulating menses, inflammation	2,000 mg to 4,000mg

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Lifestyle Changes: Primary Approach

- ▶ Enjoyable exercise
- ▶ Good sleep hygiene
- ▶ Stress management
- ▶ Mindfulness
- ▶ Body image

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Enjoyable Movement for PCOS

- ▶ Both aerobic and anaerobic exercise associated with reproductive and metabolic improvements
- ▶ Mental health/body image
- ▶ Women with PCOS have more testosterone/muscle mass
- ▶ Explore relationship with exercise
 - ▶ Resistance, enjoyment, overexercise
- ▶ When ready, discuss enjoyable activities, realistic amounts

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Benefits of Yoga for PCOS

- ▶ One hour yoga practice daily for 12 weeks
 - ▶ Reduces anxiety
 - ▶ Lowered glucose, lipid, and insulin resistance
 - ▶ showed significant improvement in AMH, LH, and testosterone, even more so than exercise

Nidhi R J Altern Complement Med. 2013 Feb;19(2):153-60.

- ▶ Yoga + Mindfulness, 1 hour, 3 days a week
 - ▶ Lower testosterone
 - ▶ DHEA
 - ▶ Anxiety
 - ▶ Depression

Patel 2020



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Mindfulness Practice Benefits PCOS

Impact of a mindfulness stress management program on stress, anxiety, depression and quality of life in women with polycystic ovary syndrome: a randomized controlled trial

Charikleia Stefanaki ¹, Flora Bacopoulou, Sarantis Livadas, Anna Kandaraki, Athanasios Karachalios, George P Chrousos, Evanthia Diamanti-Kandaraki

"8 week MBSR program revealed statistically significant reductions in stress, depressive and anxiety symptoms, as well as in salivary cortisol concentrations, along with an increase in Life Satisfaction and Quality of Life scores in the intervention group only."

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Increased Sleep Disturbances in PCOS Women

- ▶ PCOS women experience more sleep disturbances
 - ▶ Frank G, Krysta K, Madej P, Gynecol Endocrinol. 2014 Dec;32(12):1014-1017.
- ▶ Increased risk for obstructive sleep apnea
 - ▶ Helvacı N, Karabulut E, Demir AU. Endocr Connect. 2017 Oct;4(7):437-445.
- ▶ Affects fertility
 - ▶ Women with sleep disorders had 3.7 higher-fold risk for infertility
 - ▶ J Quao Wang, Yung-Liang Liu, Chung-Kan Peng. Sleep. 2017;186.
- ▶ Reasons?
 - ▶ Elevated androgens, other hormones, mood disorders



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Indicators of Progress without Weight Focus

- ▶ Symptoms improve
- ▶ Regular periods
- ▶ Energy levels
- ▶ Mood
- ▶ Improved relationship with food/exercise
- ▶ Lab values improved
- ▶ Sleeping better
- ▶ Better stress management

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Long-term effects of a three-component lifestyle intervention on emotional well-being in women with Polycystic Ovary Syndrome (PCOS): A secondary analysis of a randomized controlled trial

Geranne Jiskoot ^{1, 2}, Alexandra Dietz de Loos ¹, Annemerle Beerhuizen ², Reinier Timman ², Jan Busschbach ², Joop Laven ¹

"Lifestyle treatment (diet, exercise, CBT), independent of weight loss, can reduce depression and body image." 12-months

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Nutrition And Lifestyle Factors Work Synergistically To Support Health



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Conclusion

- ▶ Eating and mood disorders and lower quality of life are more common in PCOS population
- ▶ The suggested links between PCOS and binge eating are not yet well understood
- ▶ Contributing factors may include metabolic (hyperandrogenism), hormonal (insulin resistance), and psychological (body dissatisfaction, depression, anxiety) factors
- ▶ HCP need to screen all patients with PCOS for ED and Mood disorders
- ▶ Weight loss recommendations cause harm
- ▶ Weight-inclusive care can improve physical and emotional health of people with PCOS

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Questions?

PCOS Nutrition Center Resources (PCOSnutrition.com)

- ▶ Online PCOS Nutrition Training Course for RDNs
- ▶ The PCOS Workbook: Your Guide to Complete Physical and Emotional Health
- ▶ The PCOS Nutrition Center Cookbook
- ▶ PCOS Supplements
- ▶ Webinars/Courses/Handouts
- ▶ Blog



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