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A Commentary on the New Evidence-Based Lifestyle Recommendations for Polycystic Ovary Syndrome and Potential Barriers to their Implementation in the United States

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Introduction.

Polycystic ovary syndrome (PCOS) is a complex endocrine condition that represents a lifelong health concern for one in ten women worldwide.¹ PCOS is commonly diagnosed by the presence of ovulatory dysfunction, androgen excess, and/or ovaries with polycystic morphology on ultrasound examination.² Half of patients experience overweight or obesity.³ Most are at increased risk for serious comorbidities, including infertility, pregnancy complications (e.g. gestational diabetes mellitus), impaired glucose tolerance, insulin resistance, Type 2 diabetes mellitus, cardiovascular disease, gynecological cancers, anxiety, depression, eating disorders, and poor health-related quality of life.^{4,5} Over the past decade, clinicians and researchers have increasingly recommended lifestyle modifications to achieve and maintain healthy weights and improve metabolic outcomes in women with PCOS.⁶ Now, with the recent publication of the first international evidence-based guideline for PCOS, diet and exercise have been solidified as fundamental components of the condition's management.^{7,8} It is clear that the expertise of a registered dietitian is essential to provide

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adequate nutrition care for this patient population. However, accumulating survey evidence suggests that dietitians receive limited referrals for PCOS and generally feel uninformed about its specific sequelae and treatments.^{9–11} This commentary aims to address these two gaps by summarizing the new international recommendations for lifestyle management of PCOS,^{7,8} and exploring some challenges that the current referral and knowledge landscapes might pose to their implementation in the United States. It concludes with a call to action for dietitians and provides additional recommendations and resources for those that care for women with PCOS.

New Recommendations for Lifestyle Management of PCOS.

PCOS is characterized by significant clinical heterogeneity, wherein its severity can be influenced by age, adiposity, ethnicity, and genetics, and its features difficult to assess using modern clinical standards and laboratory techniques.^{4,12–14} Historically, this has led to controversy over the most appropriate criteria to diagnose PCOS¹⁴ and substantial variation across providers and countries in how the condition is both diagnosed and treated.^{10,15} Such ambiguity has also been reflected in nutrition care for PCOS, as no consensus statement has ever existed to inform dietitians on its dietary management.⁹ Notably, an International Evidence-Based Guideline for the Assessment and Management of PCOS was released in July 2018 and represents a considerable endeavor to overcome these challenges. It promises to improve the “healthcare, health outcomes, and quality of life of women with PCOS,” in part by addressing the importance of adopting healthy lifestyle behaviors.^{7,8} The guideline and its methods for development are freely available online through *Human Reproduction*⁸ and Monash University (<https://www.monash.edu/medicine/sphpm/mchri/pcos/guideline>).

The guideline was spearheaded by the Australian Centre for Research Excellence in PCOS, in partnership with the European Society of Human Reproduction and Embryology and American Society for Reproductive Medicine.¹⁶ Clinical questions and priorities were identified in accordance with the GRADE Framework¹⁷ and through evidence synthesis and extensive collaboration with >40 professional societies and consumer advocacy groups across the globe.¹⁶ Recommendations were informed by systematic or narrative reviews; integrated with feedback from multidisciplinary scientists and providers (including dietitians), as well as women with PCOS; and evaluated in light of intersecting differences in healthcare systems and resources.¹⁶ The final guideline provides evidence-based recommendations (EBR), plus clinical consensus recommendations (CCR) and practice points (CCP) in cases where the data were insufficient to generate an EBR. With the guideline officially launched,^{7,8,16} collaborators and partner organizations are now working to disseminate the recommendations and promote their broad use in clinical and community practice.^{7,8} It is especially critical that the translation program reach dietitians, because “Lifestyle Management” encompasses one of the five guideline chapters and 24 of the 166 recommendations.^{7,8}

A selection of the key recommendations for lifestyle management of PCOS^{7,8} are presented according to the Nutrition Care Process¹⁸ in Table 1. Briefly, the Nutrition Care Process is an initiative of the Academy of Nutrition and Dietetics and provides a standardized framework for individualized and high-quality nutrition care. It contains four steps (i.e.

Assessment, Diagnosis, Intervention, and Monitoring / Evaluation) and allows dietitians to modify their approach to care as a patient's condition evolves over time.¹⁸ This framework is relevant to the implementation of the new guideline, because PCOS imparts symptoms and comorbidities that require continuous monitoring and evaluation.^{4,7} Overall, the new recommendations for lifestyle management of PCOS reflect ones made in the general population^{19–21} and prioritize weight management across the lifespan. The emphasis on weight management reflects the higher prevalence of weight gain²² and excess³ in women with versus without PCOS, as well as evidence that obesity worsens the reproductive, metabolic, and psychological features of the condition.¹² It is important for providers to be aware of these unique risks, respectful during nutrition assessment, and empathetic while communicating the need to prevent weight gain or initiate weight loss.^{7,8} Subsequent nutrition interventions in women with PCOS should promote appropriate weight management²¹ through the adoption of healthy eating and physical activity patterns.^{7,8} Although popular opinion suggests some benefit of specific eucaloric macronutrient modifications (e.g. low glycemic index) for PCOS, there is limited evidence that any one dietary pattern is better than another for improving health outcomes in this population.²³ Rather, it is apt for *all* patients (regardless of body mass index) to follow current government recommendations,^{7,8} such as the Dietary¹⁹ and Physical Activity Guidelines for Americans²⁰ for women living in the United States and Canada. Healthy eating and physical activity patterns that aim for energy balance are suggested to prevent weight gain in patients with normal weight.^{7,8} Likewise, weight loss is advisable in those with overweight / obesity, and should be sought through a multicomponent lifestyle intervention that includes diet, exercise, and cognitive-behavioral approaches.^{7,8} The intervention could still reflect government recommendations for balanced dietary composition¹⁹ and aerobic and resistance exercise,²⁰ while promoting a modest energy deficit (e.g. 500–750 kcal/d).^{7,8} As in individuals without PCOS,²¹ it may help to incorporate techniques for behavior change and self-monitoring; to design Specific, Measurable, Achievable, Realistic, and Timely (SMART) goals; and to provide strong social support as often as possible.^{7,8} Provider interactions related to weight management need to be patient-centered; attentive to the potential for heightened cardiometabolic risk in certain ethnicities (i.e. South East Asian and African American);¹ and considerate of emotional well-being, individual preferences, and ethnic, cultural, and socioeconomic differences.^{7,8} Again, continued monitoring and evaluation of weight and lifestyle behaviors are essential to protect the short-and long-term health of women with PCOS (Table 1).^{7,8}

Potential Barriers to Implementation of the New Lifestyle Recommendations for PCOS.

The new international guideline highlights an important message to both patients and providers: *“Healthy lifestyle and optimal weight management appear equally effective in PCOS as in the general population.”*^{7,8} This message reflects evidence that the adoption of healthy eating and physical activity patterns can improve body composition and metabolic status in women with PCOS – independent of any changes in weight.^{24,25} It also echoes the findings of hundreds of controlled and uncontrolled trials that have confirmed that modest weight loss (i.e. 5%–10% of initial body weight) is a realistic expectation during short-term

lifestyle interventions (Table 1).^{6,24,26} However, most patients describe ‘weight management’ and ‘difficulty losing weight’ as their primary concerns related to having PCOS.^{27,28} In line with these reports, some investigators have found that PCOS is associated with poorer perceived control over lifestyle behaviors, weight gain, and health outcomes.^{28–30} Moreover, when compared to reference cohorts, patients seem less inclined to follow government recommendations for diet and exercise²⁸ and less motivated to engage in self-help methods.²⁹ Providers agree that weight management is an important issue,^{7,8,15} but it is clear that efforts to “increase support, engagement, retention, adherence, and maintenance of healthy lifestyle behaviors”^{7,8} are urgently needed for the guideline to be effective. That said, there may be at least two major barriers to increasing support for healthy lifestyle behaviors in PCOS.

The first barrier relates to patient access to nutrition services. Several groups have observed that dietitians have limited involvement in current routine care for PCOS.^{9–11} Lin and colleagues recently developed and validated an Internet-based questionnaire to assess medical experiences among women with self-reported diagnoses of PCOS.¹¹ The questionnaire was accessed by 722 women of reproductive age (mean age $\pm$ SD, 28 ± 5 y) across the United States.¹¹ In general, respondents with PCOS ($n = 215$) identified as white ($n = 175$ of 215, 81%), had obesity (mean body mass index $\pm$ SD, 31.6 ± 9.9 kg/m²), and were college-educated ($n = 167$ of 215, 78%) (Lin et al., data unpublished).¹¹ When asked about their interactions with healthcare providers, most women reported visiting either a primary care physician or specialist (e.g. endocrinologist or obstetrician / gynecologist) for general and PCOS-related healthcare (Figure 1). Less than 10% reported ever seeing a dietitian (*General Care*: $n = 18$ of 215, 8%; *PCOS-Related Care*: $n = 12$ of 215; 6%) (Figure 1) (Lin et al., data unpublished).¹¹ Such findings complement those of other surveys administered to patients and providers in North America and Europe.^{9,10,15,31} Namely, in the United Kingdom, 15% of women with PCOS reported ever seeing a dietitian and just 3% reported attending more than two appointments after their diagnosis.⁹ More than half of endocrinologists and obstetrician / gynecologists reported suggesting lifestyle modifications to women with PCOS.^{15,31} Yet, only one-third cited routine collaborations with nutrition professionals.¹⁰ Recommendations for lifestyle modifications^{15,31} and referrals to dietitians⁹ largely occurred in general practice or endocrinology / diabetes clinics. Most dietitians estimated that they had less than one PCOS-related appointment per month and were more likely to see patients with overweight / obesity than normal weight.⁹

Physician screening and referral precede the Nutrition Care Process in most countries and a variety of factors can influence whether patients are sent to dietitians. For example, in the United States, some insurance companies may require a medical diagnosis (e.g. of obesity or diabetes mellitus) for referral. Others may not cover wellness or preventive services and/or may require explicit authorization from a licensed physician before nutrition services can be initiated. Referrals may also be challenging to offer in limited-resource or rural areas.³² The emphasis on the treatment of diagnosed obesity and diabetes mellitus, rather than the prevention of these diseases, is especially concerning in the context of PCOS. Half of patients have normal weight³ but are at increased risk for developing obesity later in life.^{3,22} Likewise, insulin resistance manifests independent of adiposity in PCOS and places women at a four-times higher risk for Type 2 diabetes mellitus versus controls.³³ The management

of diabetes mellitus alone costs \$1.77 billion annually and comprises 41% of the total healthcare costs associated with PCOS.³⁴ The use of lifestyle modifications has proven more cost-effective than the use of medications to prevent diabetes mellitus in other patient populations.³⁵ Women with PCOS are likely to benefit from early access to dietitians to manage progression of their condition.

The second barrier to increasing support for healthy lifestyle behaviors in PCOS relates to the inadequacy of current nutrition care for this population. Several groups have observed that providers may have limited knowledge of the importance of lifestyle management in PCOS. In qualitative and quantitative surveys, patients reported that their physicians and specialists rarely offered them nutrition information¹¹ and only 11% reported being satisfied with the support they received for making lifestyle changes.²⁷ Many patients relied on nutrition information from unregulated sources including the internet³⁰ and books⁹ – which have been shown to provide poor quality content related to PCOS.³⁶ Women with PCOS also reported frustration that their physicians exhibited little empathy or encouragement for overcoming barriers to successful weight management.³⁰ This was particularly apparent in reports by Tomlinson and colleagues, wherein patients described the traumatic experience of being denied fertility treatment based on their overweight. One woman said: *“I was more or less told that you’re chubby, you’re overweight, there’s nothing we can do, we’re not giving you any fertility treatment because you’re overweight, that would be a danger to a baby... and I was quite traumatized by that.”* In the few cases where dietitians were consulted, only 34% reported feeling informed about lifestyle management of PCOS⁹ and instead offered non-specific advice for modifying macronutrient composition (e.g. following low carbohydrate dietary patterns) (Lin et al., data unpublished).¹¹ Most dietitians believed that there were insufficient data to provide any recommendations at all.⁹

Taken together, there appears to be a disconnect in current clinical practice. Women with PCOS have limited access to dietitians – the very providers with the greatest potential to improve their health outcomes and quality of life. Simultaneously, dietitians seem somewhat underprepared to provide these services. To that end, dietitians are encouraged to increase their involvement in PCOS-related care (Table 2). There is a clear need to improve current mechanisms of referral, so that women with PCOS can interact with dietitians immediately following their diagnoses. Dietitians should “be persistent and proactive” and “communicate / collaborate with physician groups, medical directors, compliance offices, office staff, and other dietitians” to improve their referral systems.³² Greater public health advocacy is essential to expand insurance coverage to wellness and preventative services for women with PCOS. There is also a clear need for dietitians to learn more about PCOS. Although the evidence suggests that general lifestyle changes are effective in this patient population, the condition is not synonymous with ‘obesity.’ Instead, it imparts a spectrum of unique reproductive, metabolic, and psychological concerns. Dietitians can learn more about PCOS by reviewing the guideline^{7,8} and referring to several excellent reviews on its pathophysiology,¹³ diagnosis,¹⁴ health risks,^{4,5,37} and treatment^{6,38} (Table 2). To best manage patient and provider expectations, it should be appreciated that lifestyle modifications have been consistently shown to improve metabolic status, but the data remain inconclusive regarding any effect on endocrine or reproductive abnormalities.^{6,24,39}

Conclusion.

The International Evidence-Based Guideline for the Assessment and Management of PCOS represents a tremendous advance in our potential to care for women with PCOS. Not only does it promise to improve diagnosis and evaluation, but it reinforces healthy lifestyle behaviors as a cornerstone of the condition's management across the lifespan. Dietitians have the necessary training to implement these new diet and exercise recommendations and to help these patients manage the physical and psychological challenges that often accompany behavior change.²¹ A greater understanding of the individual and systems-level barriers to multidisciplinary care will further strengthen efforts in the lifestyle management of PCOS.

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Figure 1.

Proportion of women with polycystic ovary syndrome (PCOS, n=215) that reported at least one interaction with a certain type of healthcare provider for general or PCOS-related issues. Classifications: *Specialist* encompass endocrinologists, obstetrician / gynecologists, dermatologists, fertility doctors, and other specialized physicians. *Other* refer to additional, unspecified providers. These data were collected as part of a recent Internet-based questionnaire administered by Lin *et al.*, 2018.¹¹ Please note that categories are not mutually exclusive; women may have reported visiting more than one type of provider.

Table 1.

Key Lifestyle Recommendations from the International Evidence Based Guideline for the Assessment and Management of Polycystic Ovary Syndrome (PCOS) Per the Academy of Nutrition and Dietetics' Nutrition Care Process ^a

Nutrition Assessment	
CCR ^b	"Health professionals and [patients] should be aware that women with PCOS have a higher prevalence of weight gain and obesity, presenting significant concerns for women and impacting [their] health and emotional well-being, with a clear need for prevention."
CPP ^c	Assessment should be respectful of weight-related stigma, negative body image, and low self-esteem.
Nutrition Intervention	
For women with PCOS and Body Mass Index < 25 kg/m ²	
CCR	General population recommendations for healthy eating should be followed across the life course.
CCR	"Healthy eating and regular physical activity should be recommended to achieve [or] maintain healthy weight and to optimize hormonal outcomes, general health, and quality of life across the life course."
For women with PCOS and Body Mass Index ≥ 25 kg/m ²	
EBR ^d	Lifestyle intervention should be recommended for reductions in weight and insulin resistance.
CCR	"A variety of balanced dietary approaches could be recommended to reduce dietary energy intake."
CPP	Achievable weight loss (i.e. 5–10% within 6 months) yields significant clinical improvements.
Nutrition Monitoring and Evaluation	
CCR	"All those with PCOS should be offered regular monitoring for weight changes and excess weight."
CPP	Monitoring weight, preventing weight gain, and "encouraging evidence-based and socio-culturally-appropriate healthy lifestyle [behaviors] is important in PCOS, particularly from adolescence."

^aRecommendations were reproduced either verbatim (in quotations) or with minor modifications for conciseness (not in quotations) from Teede *et al.* (2018).^{7,8} Please note that the guideline presented these recommendations across five sub-categories (i.e. effectiveness of lifestyle interventions, behavioral strategies, dietary intervention, exercise intervention, and obesity and weight assessment) – not in the format of the Nutrition Care Process,¹⁸ as is shown here.

^bCCR, clinical consensus recommendation.

^cCPP, clinical practice point.

^dEBR, evidence-based recommendation;

Table 2.

Suggested Ways that Registered Dietitians Can Increase their Involvement in Polycystic Ovary Syndrome (PCOS)-Related Care

Work to Increase Physician Referrals to Registered Dietitian for PCOS
• Collaborate with other relevant providers to improve the referral systems in your current practice.
• Engage in advocacy efforts to increase insurance coverage for wellness and preventative services.
Work to Increase Knowledge of PCOS
• Review the new international guideline for the assessment and management of PCOS.
• Appreciate that there may be both genetic and environmental determinants of PCOS.
• Become familiar with the current diagnostic criteria and primary treatments for PCOS.
• Understand the reproductive, metabolic, and psychological health risks associated with PCOS.
• Recognize the importance of weight management in patients across body mass index categories.