

# Trust in Physicians and Medical Experience Beliefs Differ Between Women With and Without Polycystic Ovary Syndrome

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**Context:** Women with polycystic ovary syndrome (PCOS) report dissatisfaction with their early medical care. Little is understood about factors that can encourage stronger patient-provider relationships and promote treatment adherence.

**Objective:** To compare trust in physicians and beliefs about social support from health care providers between women with and without PCOS.

**Design:** Cross-sectional study with online questionnaire.

**Setting:** Medical clinic referral or broader community recruitment via advertising and websites.

**Participants:** Three hundred thirty-two US-based women with PCOS or with regular menses (n = 134 and n = 198, respectively).

**Main Outcome Measures:** Trust and social support toward health care providers [primary care physicians (PCPs), specialists, and/or nurse practitioners and physician assistants].

**Results:** PCOS was associated with greater distrust in the PCP's opinion ( $P < 0.01$ ) and greater confidence about the PCP's prioritization of general health concerns ( $P = 0.04$ ) than the comparison group. Patients with PCOS felt that the PCP spent less effort and were less qualified to treat PCOS health concerns than general health concerns (both  $P < 0.001$ ). No significant associations were observed between PCOS diagnosis and trust in specialists. When examining social support, women with PCOS felt they had more arguments with their health care providers than the comparison group ( $P = 0.02$ ).

**Conclusion:** Women with PCOS reported greater overall distrust in the PCP's opinions and more arguments with their health care providers than women without PCOS. These findings support a need to identify additional areas of improvement in the patient-provider relationship to ensure continuity of care for patients with PCOS who require life-long surveillance.

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**Freeform/Key Words:** healthcare, patient education, patient satisfaction, PCOS, primary care physician, social support

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Patient beliefs about medical care have long been used to evaluate health care quality and inform clinical practice guidelines [1, 2]. The emphasis on understanding patient beliefs about health care providers (such as trust and beliefs about social support) is relevant to its

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Abbreviations: BMI, body mass index; I-PCOSM, Instrument for Polycystic Ovary Syndrome, Medical Experiences; PCOS, polycystic ovary syndrome; PCP, primary care physician.

link with treatment adherence [3, 4], an important consideration when treating polycystic ovary syndrome (PCOS). PCOS is characterized by the presence of at least two cardinal features, which include androgen excess, irregular menstrual cycles, and/or polycystic ovarian morphology [5]. PCOS is recognized as a leading cause of anovulatory infertility yet its effects extend well beyond impaired reproductive function. Several metabolic abnormalities (such as obesity and increased prevalence of risk factors for cardiovascular disease and diabetes) are closely associated with PCOS, and lifelong medical care is required to manage PCOS symptoms and mitigate long-term health complications [6]. As such, patients with PCOS are encouraged to engage in healthy dietary and physical activity behaviors, which improve cardinal PCOS symptoms and metabolic status [7–9]. However, women with PCOS may face unique barriers that impede the adoption of these health-related behaviors due to their previous medical experiences [10, 11]. The degree to which trust and beliefs about social support from health care providers contribute to these barriers is uncertain.

There are few data evaluating the patient-provider relationship in PCOS [11, 12]. Among the studies conducted to date, a substantial proportion of patients with PCOS across several countries reported feeling frustrated with their early medical experiences [11], resulting in negative beliefs about medical care [12, 13]. Further, patients' beliefs about the quality of medical care appeared to vary between primary care physicians (PCPs) and specialists [12–14]. This observation may be particularly relevant in the United States, where a gatekeeping approach involving PCPs operates within the health care system for access to specialist referrals [15, 16]. Indeed, women with PCOS will likely require care from a variety of health care providers across the life course, due to the evolution of their endocrine and metabolic symptoms with aging and/or changes in treatment goals at different life stages [11, 17].

It is also unclear whether medical experiences related to PCOS influence patient beliefs during treatment of general medical concerns. Previous studies have revealed patients' beliefs that they received limited informational support provided about specific PCOS issues, but these studies did not investigate other health concerns that are addressed during patient-provider interactions [11, 13, 18]. Themes of social support have been only briefly discussed, leaving this concept largely unexplored in this patient population. To that end, our primary objective was to examine whether there were differences in trust and beliefs about social support between women with and without PCOS with types of physicians (*i.e.*, PCP, specialists) and/or other health care providers (*i.e.*, nurse practitioners, physician assistants). Our secondary objective was to examine whether trust in physicians varied between the types of health concerns (*i.e.*, general vs PCOS-related). This study provides context about the current beliefs about medical care in women with PCOS with the goal of identifying factors, which could be targeted to improve patients' overall medical experiences.

## 1. Materials and Methods

An expanded methods section is available in the Supplemental Materials [19].

### A. Participants

This project was registered as part of a larger observational study comparing health-related behaviors (*i.e.*, diet, physical activity) in women with and without PCOS (ClinicalTrials.gov no. NCT01859663). Flyers and online advertisements (*i.e.*, Twitter, Facebook, Reddit, ResearchMatch) were used to recruit locally around Tompkins County, New York, and broadly across the United States. Participants met inclusion criteria if they reported that they were between 18 and 38 years of age and had either a history of predictable menstrual cycles (*i.e.*, between 21 and 35 days) or an existing PCOS diagnosis. A participant was placed in the PCOS group if they responded affirmatively to the item, "Have you been diagnosed with PCOS by a medical professional?" Those who never received a PCOS diagnosis and reported predictable menstrual cycle lengths (*i.e.*, 20 and 35 days) were placed in the comparison

group. Participants were excluded if they had (1) incomplete surveys (less than half of the instrument) or reported (2) implausible or missing body mass index (BMI; defined as  $<16 \text{ kg/m}^2$  or  $>80 \text{ kg/m}^2$ ), (3) a major chronic disease, (4) a self-reported history of isolated oligomenorrhea (defined as unpredictable menstrual cycles and/or menstrual cycle length  $<20$  or  $>35$  days without a PCOS diagnosis), and/or (5) non-US resident status. The Institutional Review Board approved the study protocol, and all participants provided informed consent.

### *B. I-PCOSM Development*

The Instrument for Polycystic Ovary Syndrome: Medical Experiences (I-PCOSM) was distributed as a web-based instrument (Qualtrics, Provo, UT) over a 2-year interval (August 2014 to August 2016). Forty-eight items were modified from two published instruments to assess trust in physicians and beliefs about social support from health care professionals by women with PCOS [20, 21]. Items were modified with the goal of investigating beliefs related to medical experiences over a broad range of health care providers (PCP, specialists, nurse practitioners, and physician assistants) and perceptions of care over general and PCOS-related health concerns. Examples were provided for specialists, which included but were not restricted to gynecologists, endocrinologists, and dermatologists. The draft of the instrument underwent three rounds of peer review by individuals with expertise in instrument design to ensure clarity and organization of the items prior to administration to research participants.

### *C. Reliability and Validity of the I-PCOSM*

Details about the reliability and validation analyses of the I-PCOSM are described in the Supplemental Materials [19]. After evaluating validity and reliability, the final instrument contained 28 reliable and valid items that assessed the recent medical experiences of women with PCOS within the last 3 years. Items related to trust in physicians were consistently worded across types of physicians (PCP or specialist) and health concerns (general or PCOS-related). The PCOS group was presented with items on both types of health concerns, whereas the comparison group was only asked about general health issues. Responses to each item were formatted as five-point scales. Response options for trust in physicians ranged from “strongly disagree” to “strongly agree,” whereas the options on social support ranged from “never” to “always.” For all responses, we chose a midpoint of 3 to reflect neutrality. Thus, any score greater than 3.5 reflected greater agreement and/or greater frequency due to rounding principles.

### *D. Statistical Analysis for Primary Analyses*

Data were analyzed with SPSS 23.0 (IBM, Armonk, NY), and a  $P < 0.05$  was considered statistically significant. Demographic and anthropometric data were compared between PCOS and comparison groups using independent  $t$  tests and  $\chi^2$  analyses. To address the primary objective, multiple linear regression was used to examine associations between PCOS diagnosis (independent variable) with trust and social support outcomes. Mixed-effects regression models were used to investigate whether trust of physicians differed between types of health concerns. Given that each participant in the PCOS group had two observations (PCOS and other health concerns) for this secondary objective, participants were treated as a random effect in the mixed model. All regression models were adjusted for age (continuous), BMI (categorical), and income (categorical). As a result of the high correlation among trust and social support items, multiple comparison correction methods were not used in the analyses [20].

## **2. Results**

Of the 755 women that completed the I-PCOSM in the nationwide sample, 332 (44%) met eligibility criteria for the PCOS ( $n = 134$ ) and the comparison groups ( $n = 198$ ). The remaining

participants (n = 423) were excluded based on incomplete surveys (n = 312), report of oligomenorrhea without a PCOS diagnosis (n = 80), non-US resident status (n = 30), and/or implausible or missing BMI values (n = 1). The eligible study sample included 262 (79%) white participants and 188 (57%) participants with a college degree (Table 1). Most women were New York state residents (62%), with the remaining participants residing at different areas in the United States. Groups did not differ by age, race, education, or BMI. By contrast, the PCOS group reported higher yearly household incomes relative to the comparison group ( $P < 0.001$ ).

Women with PCOS believed their physicians (both PCPs and specialists) were well qualified to treat general health concerns and were able to place patients' medical needs above other considerations (Table 2). Overall, the PCOS group had positive beliefs regarding the physicians' efforts to treat their general health concerns. Although women with PCOS somewhat disagreed with the statement, "I sometimes distrust the recent specialized doctor's opinions and would like a second one" [2.5 (SD 1.2)], they had more neutral attitudes toward the PCP [3.1 (SD 1.2)]. Relative to the comparison group in the fully adjusted models (Table 3), women with PCOS experienced greater distrust in the opinions offered by the PCP ( $P < 0.01$ ) but reported greater confidence in the PCP's prioritization of their general medical needs ( $P = 0.04$ ). Although PCOS was also positively associated with patient's trust in the PCP's qualifications to treat general medical problems in the unadjusted model ( $P = 0.03$ ), this association became nonsignificant after adjusting for covariates ( $P = 0.05$ ). No significant associations were observed between PCOS status and trust in specialists.

**Table 1. Characteristics of I-PCOSM Participants**

Characteristics	PCOS <sup>a</sup> (n = 134)	Comparison (n = 198)	P
Age (y)	28.2 ± 4.7	27.5 ± 5.5	0.22
Race (%)			0.39
Asian	4 (3.0)	15 (7.6)	
Black	8 (6.0)	15 (7.6)	
White	112 (83.6)	150 (75.8)	
Latina	2 (1.5)	3 (1.5)	
Other	8 (6.0)	15 (7.6)	
Highest education (%)			0.19
≤High school degree	34 (25.4)	61 (30.8)	
Associate's degree	16 (11.9)	33 (16.7)	
College graduate	54 (40.3)	75 (37.9)	
Advanced degree	30 (22.4)	29 (14.6)	
Household yearly income (%)			<0.001
≤\$19,999	19 (14.2)	57 (28.8)	
\$20,000–\$39,999	29 (21.6)	60 (30.3)	
\$40,000–\$59,999	16 (11.9)	30 (15.2)	
\$60,000–\$79,999	18 (13.4)	17 (8.6)	
\$80,000–\$99,999	35 (26.1)	16 (8.1)	
≥\$100,000	17 (12.7)	18 (9.1)	
BMI categories (%)			0.34
Underweight (<18.5 kg/m <sup>2</sup> )	2 (1.5)	2 (1.0)	
Normal (18.5–<25 kg/m <sup>2</sup> )	46 (34.3)	74 (37.4)	
Overweight (25–29.9 kg/m <sup>2</sup> )	23 (17.2)	46 (23.2)	
Obese (≥30 kg/m <sup>2</sup> )	63 (47.0)	76 (38.4)	
Medical visits in past 3 years: general health concerns			
Seen by primary care physician	112 (83.6)	164 (82.8)	0.88
Seen by specialist	70 (52.2)	129 (65.2)	0.02
Medical visits in past 3 years: PCOS health concerns			
Seen by primary care physician	62 (46.3)	NA	NA
Seen by specialist	81 (60.4)	NA	NA

Data are expressed as mean ± SD or n (%). Significance level,  $P < 0.05$  between PCOS and comparison groups. Abbreviation: NA, not applicable.

<sup>a</sup>Prompt used to determine PCOS status: "Have you been diagnosed with PCOS by a medical professional?"

**Table 2. Trust and Social Support Scores in the PCOS Group (n = 134)**

	General Concerns	PCOS Concerns	Scoring Range
Trust in physicians			
Primary care physicians			
I feel the recent primary doctor does not do everything he/she should about my medical care.	2.7 ± 1.2	3.4 ± 1.4	1 = Strongly disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly agree
I sometimes distrust the recent primary doctor's opinions and would like a second one.	3.1 ± 1.2	3.2 ± 1.2	
I trust the recent primary doctor to put my medical needs above all other considerations when treating my medical problems.	3.9 ± 1.0	3.8 ± 1.1	
The recent primary doctor is well qualified to treat medical problems that I experience.	4.1 ± 0.9	3.4 ± 1.4	
Specialists <sup>a</sup>			
I feel the recent specialized doctor does not do everything he/she should about my medical care.	2.3 ± 1.0	2.5 ± 1.2	1 = Strongly disagree 2 = Disagree 3 = Neutral 4 = Agree 5 = Strongly agree
I sometimes distrust the recent specialized doctor's opinions and would like a second one.	2.5 ± 1.2	2.5 ± 1.2	
I trust the recent specialized doctor to put my medical needs above all other considerations when treating my medical problems.	3.7 ± 0.9	3.8 ± 1.0	
The recent specialized doctor is well qualified to treat medical problems that I experience.	4.1 ± 0.9	4.0 ± 0.9	
Social support from health care providers <sup>b</sup>			
	Mean scores		
How often ...			
Do they give you advice or information about health (whether you want it or not)?	4.2 ± 0.8		1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Do they give you advice or information about nutrition (whether you want it or not)?	3.4 ± 1.2		
Do they give you advice or information about PCOS (whether you want it or not)?	3.3 ± 1.1		
Do they give you reassurance, encouragement, and emotional support (affection) concerning your health?	2.8 ± 1.2		
Do they listen to and try to understand your worries about your health?	3.4 ± 1.1		
Can you relax and be yourself around them?	3.1 ± 1.2		
Can you open up to them if you need to talk about your worries about your health?	3.3 ± 1.2		
How ...			
Satisfied are you with the emotional support provided?	3.0 ± 1.2		1 = Never 2 = Rarely 3 = Sometimes 4 = Usually 5 = Always
Often do they argue with you relating to your health?	1.7 ± 1.0		
Often do they criticize you relating to your health?	1.8 ± 1.0		
Often do they let you down when you are counting on them?	2.0 ± 1.1		
Often do they withdraw from discussions or try to change the topic away from your health?	1.5 ± 0.9		

Data are expressed as mean ± SD.

<sup>a</sup>Examples include gynecologists, endocrinologists, and dermatologists.

<sup>b</sup>Includes physicians, nurse practitioners, and physician assistants.

Women with PCOS provided favorable scores when asked about their trust in specialists regarding PCOS-related concerns (Table 2). Similar to responses about general health concerns, women with PCOS agreed that the PCPs were able to prioritize PCOS medical needs [3.8 (SD 1.1)] but had more neutral feelings about their PCP's qualifications to treat PCOS [3.4 (SD 1.4)]. The PCOS group's responses to items relating to the PCPs efforts to treat and advise on PCOS concerns suggested they experienced more neutral feelings regarding their interactions with their PCP on these issues [3.4 (SD 1.4) and 3.2 (SD 1.2)]. Results from the mixed model confirmed that the PCOS group felt their PCP placed less effort in treating

**Table 3. Differences in Trust and Social Support Scores Between PCOS and Comparison Group**

Trust in Physicians				
	Unadjusted $\beta$ (SE)	$P_{\text{unadjusted}}$	Fully adjusted $\beta$ (SE)	$P_{\text{adjusted}}$
PCPs (PCOS vs comparison group) <sup>a</sup>				
I sometimes distrust the recent primary doctor's opinions and would like a second one.	0.3 (0.1)	0.02	0.4 (0.2)	<0.01
I trust the recent primary doctor to put my medical needs above all other considerations when treating my medical problems.	0.4 (0.1)	0.01	0.3 (0.1)	0.04
The recent primary doctor is well qualified to treat medical problems that I experience.	0.2 (0.1)	0.03	0.2 (0.1)	0.05
PCPs (general vs PCOS concerns) <sup>b</sup>	Partial adjusted $\beta$ (SE)	$P_{\text{partial}}$	Fully adjusted $\beta$ (SE)	$P_{\text{adjusted}}$
I feel the recent primary doctor does not do everything he/she should about my medical care.	0.8 (0.2)	<0.001	0.8 (0.2)	<0.001
The recent primary doctor is well qualified to treat medical problems that I experience.	-0.8 (0.2)	<0.001	-0.8 (0.2)	<0.001
Social support from health care providers <sup>a,c</sup>	Unadjusted $\beta$ (SE)	$P_{\text{unadjusted}}$	Fully adjusted $\beta$ (SE)	$P_{\text{adjusted}}$
How often do they argue with you relating to your health?	0.3 (0.1)	0.02	0.3 (0.1)	0.02

Significance level,  $P < 0.05$ .

<sup>a</sup>Adjusted models [PCOS (n = 134) vs comparison group (n = 198)]; independent variable: PCOS (reference category: comparison group); dependent variable: I-PCOSM item; covariates: age, BMI, and income.

<sup>b</sup>Adjusted mixed model [general vs PCOS concerns (PCOS n = 128)]; independent variable: PCOS (reference category: general health issues); dependent variable: I-PCOSM item; covariates: participant (partial and fully adjusted), age, BMI, and income (fully adjusted).

<sup>c</sup>Includes physicians, nurse practitioners, and physician assistants.

PCOS issues compared with general health concerns (Table 3,  $P < 0.001$ ). Moreover, women with PCOS were less likely to believe that their PCP was well qualified to treat PCOS concerns relative to general health concerns ( $P < 0.001$ ). The adjustment for potential covariates did not appreciably alter the estimates of these associations.

The PCOS group reported that they usually received general health advice (informational support) from health care providers but only sometimes receive specific information about nutrition and PCOS (Table 2). Women with PCOS reported that they rarely had negative encounters with their health care providers, yet only sometimes felt satisfied with the emotional support provided during their medical care. The limited satisfaction may be attributed to the patients' inability to usually relax and discuss their health concerns with their health care providers ( $3.1 \pm 1.2$  and  $3.3 \pm 1.2$ , respectively), as well as the patients' beliefs that health care providers only sometimes comprehended their health concerns ( $3.4 \pm 1.1$ ). When examining differences in beliefs about social support by mixed models, the PCOS group reported that their health care providers were more inclined to argue with them about health-related issues relative to the comparison group (Table 3,  $P = 0.02$ ).

### 3. Discussion

To our knowledge, this was the first study to directly investigate the trust and beliefs about social support with health care providers in a sample of women with PCOS. Our data support the conclusion that women with PCOS believe that their PCPs are well qualified to treat general health concerns but are less qualified to address issues related to PCOS. Accordingly, PCOS was associated with greater distrust of the PCP's opinions to treat PCOS concerns, but this association was not observed with specialists. Women with PCOS were only somewhat satisfied with the provision of emotional support experienced during medical visits with providers in general and felt they had more arguments with their health care providers about their health issues compared with the comparison group. Collectively, the evidence implicates the contribution of PCOS diagnoses on specific domains in the patient-provider relationship.



Differences in trust between study groups emerged only when medical experiences with PCPs were evaluated, suggesting that patients' trust may differ between PCP and specialists. We hypothesize that PCPs face greater feelings of distrust because they are at the front line of health care delivery [15] and frequently provide referrals when encountering medical conditions outside their usual scope of practice [22]. However, the absence of significant associations between PCOS and trust related to specialists should not be interpreted to mean that all types of specialized care are associated with stronger trust in these domains. The I-PCOSM did not distinguish patient experiences by physician subspecialty, leaving this as an important area of future research. The need for more research in this area was emphasized by recent findings of varying levels of knowledge between reproductive endocrinologists and gynecologists [23] and the substantial lag period between PCOS symptom onset and diagnosis by multiple health care providers [11].

This study showed that women with PCOS only sometimes received information about PCOS, *per se*, and beneficial dietary and physical activity behaviors, which is consistent with previous findings that patients with PCOS are provided with limited information from their health care providers [11–13, 18]. Further, we also noted that women with PCOS were only sometimes satisfied with the emotional support provided by their health care providers, which was closely linked to poor beliefs about receiving encouragement about their health. Among the few qualitative studies that have examined the concept of emotional support, interviews revealed that women with PCOS perceived a lack of empathy and experienced greater frequency of arguments with their physicians [12, 14]. Tomlinson *et al.* [12] identified conflicts stemming from disagreements about whether PCOS symptoms would alleviate with age and on the necessity of specialist referrals. Our demonstration that PCOS was associated with greater arguments about health-related issues relative to the comparison group supports these earlier findings. Collectively, results across studies reveal the health care provider should address different aspects of social support (informational and emotional) to improve the PCOS patient-provider relationship.

Strengths of this study include the systematic approach used to develop and ensure the validity and reliability of the I-PCOSM in a large study sample. Further, the main effect of PCOS on trust and social support toward health care providers was investigated after adjusting for several potential covariates (*i.e.*, age, BMI, income) to better reflect an approximation of the actual effect sizes between exposure and outcome variables.

We acknowledge that this study relied on participants' self-report of having a PCOS diagnosis by a medical professional, and hence, it is possible that women who reported being told that they have PCOS may not actually have the condition. However, there is evidence to support that self-reported PCOS correlates well with the clinical manifestations of the condition [24], and this approach has been used in many survey-based studies [11, 25]. Further, women who self-report having a formal diagnosis of PCOS will likely "self-identify" with that condition, thus influencing health-related behaviors [26]. Our decision to exclude women with oligomenorrhea with no known PCOS diagnosis from the comparison group was intended to enable a comparison of women with the highest likelihood of having PCOS (per self-report) vs women with the lowest likelihood of having (or self-identifying) with PCOS. By applying these approaches, we attempted to reduce the heterogeneity within each study group.

We acknowledge that this study was limited by the possibility of self-selection bias particularly by those with Internet access and interest in study participation. We also did not exclude for the presence of other physical or psychiatric disorders that might be important determinants of trust in health care providers. Further, previous research has shown that patients who were most satisfied with their medical care were often the first to respond to surveys, but that evaluations became less affirmative through repeated prompting of initial nonresponders [27]. This study did not use repeated prompts to ensure participants completed the survey, so it is possible that our survey primarily captured responses from individuals with more positive outlooks about their medical care. Compared with a study with an unselected population [28], a greater percentage of women with PCOS in our study identified as white. This suggests that we may not have captured a representative sample of

US women with PCOS and reduces the generalizability of the results to other racial and ethnic groups. There is some evidence that black women are less trusting of physicians than white women and more concerned about potential for harm in hospital settings [29]. For these reasons, future research would benefit from evaluating health-related beliefs across a more diverse spectrum of patients with PCOS.

This study provides new evidence regarding the trust and beliefs about medical care in the PCOS patient population and identified potential areas of improvement to enhance patient-provider relationships. Though delays in the diagnosis can be partly attributed to controversies with the PCOS diagnostic criteria [30], negative medical experiences can ultimately lead to feelings of greater dissatisfaction with health care providers [11]. When interacting with a patient seeking answers about PCOS, we suggest that physicians consider tailoring their advice to acknowledge the unique challenges and concerns of women living with PCOS and listen to the patients without judgment. Providing strong informational and emotional support may help reduce feelings of distrust between patients and physicians. We also recommend the importance of strengthening the specialty referral process and identifying patient cues for when a referral may be the optimal approach when diagnosing and/or treating women at risk for PCOS [11, 22]. Future studies should investigate and establish recommendations to improve the medical experiences of women with PCOS. Efforts to directly compare experiences by subspecialty and how the PCOS diagnosis experience influences impressions of general medical care are needed. By investigating these questions, the far-reaching implications of PCOS medical experiences could be further understood with the goal of ensuring quality and continuity of care for patients who require life-long surveillance to curb health risks related to PCOS.

## Acknowledgments

We thank our participants for their participation in this study, the Cornell University Statistical Consulting Unit, particularly Stephen Parry, for his guidance with the statistical analyses, Dana Larsen and Hayden Chung for their help with the development of the I-PCOSM, Brittany Jarrett for her input on the manuscript, Avigdor Nosrati for his administrative support, the PCOS Nutrition Center and participating nearby Ithaca clinics for their help with recruiting for this study, and the Cornell University Human Ecology Alumni Association and College of Agriculture and Life Sciences Alumni Association for funding this study.

**Financial Support:** This work was supported in part by Cornell University grants from the College of Human Ecology Alumni Association and the College of Agriculture and Life Sciences Alumni Association (to A.W.L.).

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**Disclosure Summary:** The authors have nothing to disclose.

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