

Lack of adequate counseling about pregnancy complications in patients with polycystic ovary syndrome: a cross-sectional survey study

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Objective: To assess the counseling experiences of patients with polycystic ovary syndrome (PCOS) related to obstetric complications and preconception management of comorbidities.

Design: Cross-sectional survey study.

Setting: Not applicable.

Patient(s): Patients with PCOS with a history of or attempt at pregnancy.

Intervention(s): Not applicable.

Main Outcome Measure(s): Demographic characteristics, medical history, and counseling experiences.

Result(s): Of the 302 respondents, 72.9% had a previous pregnancy, with 66.8% reporting complications during pregnancy. Of the entire cohort, 52.7% received preconception counseling on PCOS-related obstetric complications, and 41.5% were satisfied with their counseling experience. Five percent were counseled on related postpartum complications, and 43.4% received counseling about prepregnancy weight management, with the minority satisfied with their counseling. Among the respondents with existing comorbidities including hypertension, diabetes, and anxiety or depression, the minority received counseling on their preconception management. Although there were no racial disparities in the overall counseling of pregnancy complications, more black patients were counseled about preeclampsia, cesarean section, and preterm birth than white patients. Of the patients who had a single provider managing their PCOS care, 78.6% who saw a reproductive endocrinologist, 53.2% who saw a general gynecologist, and 35.0% who saw a primary care physician reported receiving counseling on related pregnancy complications.

Conclusion(s): Despite the high prevalence of obstetric complications associated with PCOS, our study revealed inadequate patient counseling about both the antepartum and postpartum periods and preconception management of existing comorbidities. Our findings highlight the urgent need to increase provider education and patient awareness to optimize maternal and neonatal outcomes. (F S Rep® 2024;5:312–9. ©2024 by American Society for Reproductive Medicine.)

Key Words: PCOS, pregnancy complications, preconception counseling, patient education, patient satisfaction

Polycystic ovary syndrome (PCOS) is the most common endocrine disorder among reproductive-age women with a prevalence of 8%–13% (1). Current evidence suggests increased reproductive, cardiometabolic, and psychological comorbidities associated with PCOS (2, 3). Long-term cardiometabolic morbidities

are related to the hyperandrogenic phenotype defined by the Rotterdam criteria (4–6). As a result, international guidelines recommend assessment of cardiometabolic risk factors and screening for depression and anxiety at the time of diagnosis (4, 7, 8). In addition, there is substantive evidence that PCOS is associated with obstetric

complications including hypertensive disorders of pregnancy, gestational diabetes mellitus, preterm birth, cesarean section, and pregnancy loss (9–14).

Despite these publications, previous studies found a significant lack of awareness among physicians about the association between PCOS and pregnancy complications. A large international survey of physicians (n = 1,495) found that only 50% of general gynecologists (GYNs), reproductive endocrinology and infertility (REI) specialists, and medical endocrinologists associated pregnancy complications with PCOS (15). Similarly, when surveying obstetrician/GYN resident

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physicians across the United States, only 31% were aware of the association between obstetric complications and PCOS (16). To date, there are no studies that provide insight into the patient's perspective on counseling specifically related to obstetric complications. It is, therefore, not surprising that patients with PCOS in North America and Europe revealed that they were not given any information about long-term medical complications (52.5%) or were dissatisfied with or indifferent to the information given (39.6%) (17). The international PCOS guidelines recommend that chronic conditions, such as diabetes, high blood pressure, anxiety, and depression, should be optimally managed in the preconception period and individuals should be counseled regarding the increased risk of adverse pregnancy outcomes.

In this study, we, therefore, aimed to investigate the counseling experiences of patients with PCOS regarding obstetric complications as well as the preconception management of any preexisting comorbidities. We also aimed to identify factors that impacted the counseling experience.

MATERIALS AND METHODS

Study Design and Participants

We conducted a survey study of participants with PCOS who had been pregnant or attempted pregnancy. The questionnaire was disseminated from September 2022 to March 2023 by PCOS Challenge, a patient support group, via email and social media to all PCOS Challenge general members and publicized to website visitors. We chose to distribute the survey through PCOS Challenge to target a large, diverse sample of individuals with PCOS throughout the nation. We have successfully conducted previous surveys through this organization (17). The inclusion criteria included residence in the United States; age of 18–64 years; PCOS diagnosis, either made by a physician or self-reported; and history of or attempt at pregnancy. The diagnosis of PCOS was confirmed by the affirmation of ≥ 2 screening questions related to the Rotterdam criteria (Supplemental Table 1, available online) (18). We limited the age group because pregnancy complications were likely not described in the literature when patients beyond this age group were attempting pregnancy. Study participation was voluntary and anonymous. Completion of the survey was taken as consent to participate in the study. The study was exempt from review by the University of Pennsylvania Institutional Review Board.

Survey Instrument

The online questionnaire was created specifically for the present study objectives (Supplemental Table 1). The survey was validated and refined with input from a multidisciplinary expert advisory group including members of the PCOS Challenge Scientific Advisory Board as well as members of the Patient Advisory Board. The Patient Advisory Board consists of 30 patient advocates of various ages with diverse racial, ethnic, geographic, and professional backgrounds and expertise. The questionnaire inquired about participant demographics, medical history, counseling about pregnancy-related complications, counseling about the pre-

conception management of related comorbidities, and satisfaction with the counseling (Supplemental Table 1). Participant satisfaction was rated on a Likert scale (very dissatisfied to very satisfied). No question was compulsory. The responses were collected using Luna, which is a community-owned digital platform for sharing genetic and health data. Registration into Luna, which assigned a deidentified number, only allowed respondents to complete the survey once. The deidentified responses were exported and analyzed by the investigators.

Data Analyses

Categorical data were presented as frequencies and proportions. The Pearson χ^2 test or Fisher exact test was used to identify any disparities in the information that the participants received. Specifically, comparisons regarding the counseling received about PCOS-related pregnancy complications were made by participant age, race, body mass index (BMI) group, type of provider managing PCOS, and the use of fertility medications. STATA 12 (StataCorp, College Station, TX) was used for all analyses. A *P* value of $< .05$ was considered statistically significant. The Bonferroni adjustment was used as needed for subgroup tests with multiple comparisons.

RESULTS

Respondent Characteristics

Of the 305 responses received, 3 were excluded on the basis of age, and 1 subject was unsure of their PCOS diagnosis. Table 1 shows the demographic characteristics of the 302 respondents. Most participants were between the ages of 26 and 35 years (56.0%), white (79.0%), and obese (74.8%). Most respondents had commercial or private insurance (69.0%) and a college degree or more (59.9%).

Pcos and Other Medical Histories

Most participants were diagnosed with PCOS by a physician (97%), with most knowing about their PCOS diagnosis for at least 6 years, and most were managed by a general GYN (63.6%) (Table 2). Of patients with common comorbidities associated with PCOS, 36.4% had hypertension, 45.0% had prediabetes or diabetes mellitus, and 83.1% had anxiety or depression. Most respondents reported using fertility medications, and 72.8% had been pregnant, whereas the remainder had attempted pregnancy. Moreover, of those who had been pregnant, 66.8% reported having a complication during their pregnancy.

Counseling about Pregnancy and Postpartum Complications

Of the entire group, 52.7% reported that they were counseled about pregnancy complications related to PCOS before attempting pregnancy, whereas 47.4% reported receiving no counseling. Participants were most frequently counseled on the risks of gestational diabetes (67.3%) and pregnancy loss (67.3%), followed by preeclampsia (40.9%), gestational hypertension (34.0%), cesarean section (24.5%), and preterm

TABLE 1

Demographic characteristics of 302 respondents.	
Demographic characteristic	No. of respondents (%)
Age (y)	
18–25	24 (9.0)
26–35	149 (56.0)
36–45	82 (30.8)
46–64	11 (4.1)
Race	
Black	39 (14.7)
White	210 (79.0)
Other	17 (6.4)
Body mass index (kg/m ²)	
Underweight	1 (0.4)
Normal weight	21 (7.9)
Overweight	45 (16.9)
Obese	199 (74.8)
Geographic region	
Northeast	54 (18.7)
Midwest	76 (26.3)
South	117 (40.5)
West	42 (14.5)
Highest educational degree	
High school or less	29 (10.9)
Some college or university	78 (29.2)
College degree or more	160 (59.9)
Insurance	
Commercial	184 (69.2)
Government	50 (18.8)
Multiple	27 (10.2)
Other	5 (1.9)
Marital status	
Married/domestic partnership	211 (79.3)
Divorced	12 (4.5)
Single	40 (15.0)
Other	3 (1.1)
Employment status	
Employed	221 (83.1)
Not working	29 (10.9)
Other	16 (6.0)

Note: Individual numbers in columns may not add up to the total because some subjects did not answer all questions. Underweight, <18.5 kg/m²; normal weight, 18.5–24.9 kg/m²; overweight, 25.0–29.9 kg/m²; obese, ≥30.0 kg/m².

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birth (24.5%). Of those who received counseling on these risks, 41.6% were satisfied or very satisfied with the information provided (Fig. 1A). Only 5.0% of the respondents were counseled on potential postpartum complications related to PCOS, such as postpartum preeclampsia, thrombotic complications, peripartum cardiomyopathy, and postpartum depression. Similarly, only 6.3% were counseled on lactation issues.

Counseling about Preconception Management of Medical Comorbidities

Although lifestyle modifications are the first-line treatment for all patients with PCOS, only 43.4% reported being counseled on weight management including nutrition recommendations (86.3%), exercise recommendations (67.9%), and use of medications (47.3%). Only 38.1% were satisfied or very satisfied with the counseling (Fig. 1B). Of the subjects with hypertension (36.5%), only 25.5% reported receiving guidance on management of hypertension before pregnancy including medication

TABLE 2

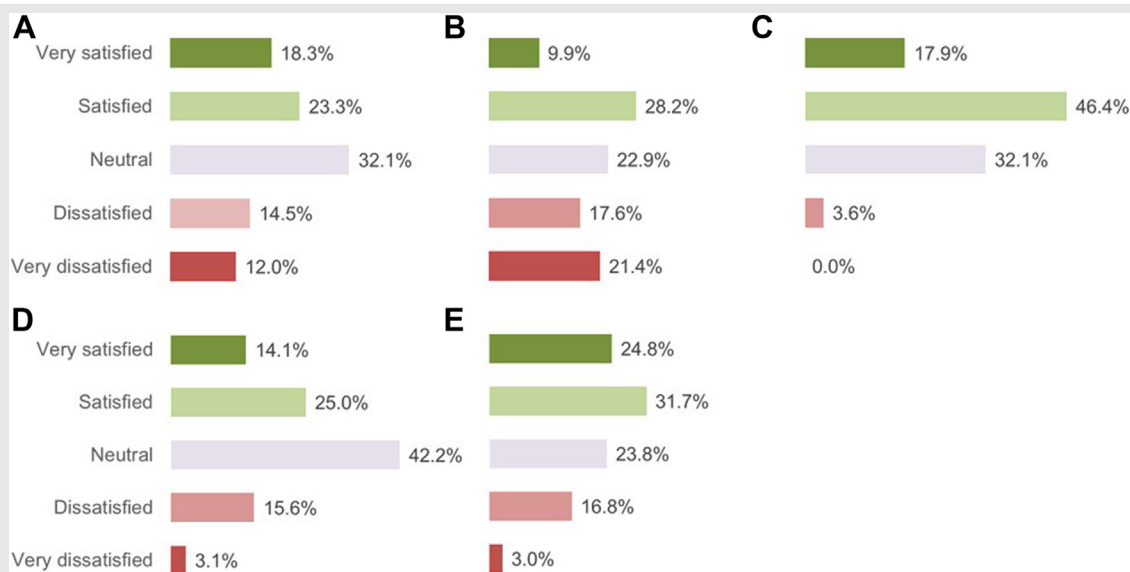
Polycystic ovary syndrome and other medical histories.	
Variable	No. of respondents (%)
Years of PCOS diagnosis	
<1	11 (4.3)
1–5	74 (28.7)
6–10	64 (24.8)
11–15	57 (22.1)
16–20	38 (14.7)
≥21	14 (5.4)
Provider that manages PCOS ^a	
General gynecologist	192 (63.6)
REI specialist	73 (24.2)
Primary care physician	76 (25.2)
No one	59 (19.5)
History of hypertension	110 (36.4)
History of prediabetes or diabetes mellitus	136 (45.0)
History of anxiety or depression	251 (83.1)
Fertility medications used ^a	
Letrozole	112 (37.1)
Clomiphene citrate	120 (39.7)
Gonadotropin injections	48 (15.9)
Metformin	170 (56.3)
Inositol	105 (34.8)
Other	31 (10.3)
Supplements	33 (10.9)
None	61 (20.2)
History of previous pregnancy	220 (72.9)
Gravidity	
1	91 (41.4)
2	56 (25.5)
3	38 (17.3)
≥4	35 (15.9)
Parity	
0	51 (23.2)
1	85 (38.6)
2	63 (28.6)
3	14 (6.4)
4	7 (3.2)
History of complications during previous pregnancy	147 (66.8)

Note: Individual numbers in columns may not add up to the total because as some subjects did not answer all questions.
PCOS = polycystic ovary syndrome; REI = reproductive endocrinology and infertility.
^a Participants were allowed to choose more than 1 option.

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use (96.4%), blood pressure monitoring (92.9%), and nutrition recommendations (50.0%). Most participants who received counseling were satisfied (Fig. 1C). Of those with prediabetes or diabetes (45.0%), 47.1% were counseled on preconception management including nutrition recommendations (85.9%), exercise recommendations (70.3%), and medications (68.8%). Of these respondents, 39.1% were satisfied or very satisfied with their counseling experience (Fig. 1D). Of those with anxiety or depression (83.1%), 40.2% stated that they discussed their mental health before pregnancy. Medications (78.2%), therapy recommendations (66.3%), and stress management (45.5%) were the most commonly discussed topics. Of those who received this preconception counseling, 56.5% were satisfied or very satisfied with their experience (Fig. 1E).

FIGURE 1



Proportions of the reported respondent satisfaction of the counseling that patients received on the following topics: (A) pregnancy complications (n = 159 received counseling, 52.7%); (B) preconception management of weight (n = 131 received counseling, 43.4%); (C) preconception management of hypertension (n = 28, 25.5%); (D) preconception management of prediabetes or diabetes (n = 64, 47.1%); and (E) preconception management of anxiety or depression (n = 101, 40.2%).

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Comparison of Counseling by Age

There were no differences in counseling rates about overall pregnancy complications by patient age ($P = .9$; Table 3), with no differences noted in the counseling of specific topics including cesarean section, gestational diabetes, gestational hypertension, preeclampsia, pregnancy loss, and preterm birth (Supplemental Table 2).

Comparison of Counseling by Race

There were no differences in counseling rates about overall pregnancy complications by patient race ($P = .2$; Table 3). Black participants were more likely to be counseled on the risks of cesarean section than white participants ($P = .03$) and of preeclampsia than white participants and those of other races ($P = .009$; Supplemental Table 3). Additionally, black participants and those of other races were more likely to be counseled on the risk of preterm birth than white participants ($P = .005$).

Comparison of Counseling by BMI

There were no differences in counseling rates about overall pregnancy complications among the BMI groups (Table 3). However, overweight (BMI, 25.0–29.9 kg/m²) and obese (BMI, ≥ 30.0 kg/m²) participants were more likely to be counseled about the risk of pregnancy loss than normal-weight (BMI, 18.5–24.9 kg/m²) participants ($P = .01$; Supplemental Table 4).

Comparison of Counseling by Provider Type

Of the respondents who had a single provider managing their PCOS (n = 128), 73.4% had their PCOS managed by a general GYN, 15.6% by a primary care physician (PCP), and 10.9% by an REI specialist. Overall, the prepregnancy counseling rates did not differ among provider types ($P = .08$; Table 3), although counseling was received by more patients who were managed by REI specialists than by those who were managed by PCPs (78.6% vs. 35.0%, $P = .012$). There were similar counseling rates for each topic (Supplemental Table 5).

Comparison of Counseling by the Use of Fertility Medications

Of the entire cohort, 80.5% (n = 243) reported using a fertility medication to attempt pregnancy. This group was of particular interest because they received care before conception and, therefore, had a clear opportunity to receive counseling. A higher proportion of those who used a fertility medication were counseled about pregnancy complications related to PCOS than those who did not use a fertility medication (59.3% vs. 25.4%, $P < .001$; Table 3). When evaluating individual topics discussed, there were no differences in counseling rates between the 2 groups (Supplemental Table 6).

DISCUSSION

Principal Findings

This study identified substantial gaps in counseling of patients with PCOS regarding pregnancy-related complications.

TABLE 3

Subanalyses comparing the overall counseling rates on polycystic ovary syndrome-related pregnancy complications by age, race, body mass index groups, type of provider, and fertility medication use.

Provider discussed PCOS-related pregnancy complications	Yes (%)	P value
By participant age		.88
18–25 y (n = 24)	54.2	
26–35 y (n = 149)	51.7	
36–45 y (n = 82)	51.2	
46–64 y (n = 11)	63.6	
By participant race		.22
Black (n = 18)	46.2	
White (n = 115)	54.8	
Other (n = 6)	35.3	
By BMI group		.59
≤ 18.5 kg/m ² (n = 1)	0	
18.5–24.9 kg/m ² (n = 13)	61.9	
25.0–29.9 kg/m ² (n = 23)	51.1	
≥ 30.0 kg/m ² (n = 103)	51.8	
By provider type		Reference
REI specialist only (n = 14)	78.6	
General GYN only (n = 94)	53.2	.07 ^a
PCP only (n = 20)	35.0	.012 ^a
Multiple providers (n = 111)	57.7	.13 ^a
By fertility medication use		< .001
Medications used (n = 243)	59.3	
No medications used (n = 59)	25.4	

Note: Proportions of participants who received counseling on PCOS-related pregnancy complications before attempting pregnancy by patient age, race, BMI group, provider type, and fertility medication use. The Pearson χ^2 test was used for comparisons.

BMI = body mass index; GYN = gynecologist; PCOS = polycystic ovary syndrome; PCP = primary care physician; REI = reproductive endocrinology and infertility.

^a Comparisons were made with the REI specialist-only group using a *P* value cutoff of .017 because of multiple comparisons. There were no differences overall when comparing REI specialist only, general GYN only, PCP only, and multiple providers (*P* = .08). However, PCP only had lower counseling rates (*P* = .012) than REI only (reference group) (*P* = .012).

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Approximately half of the respondents in our large survey study received PCOS-specific pre-pregnancy counseling, and the minority were satisfied with the information. Furthermore, >50% reported that they did not receive preconception counseling about the management of comorbidities, including obesity, hypertension, diabetes, anxiety, and depression. Respondents had varying levels of satisfaction with their counseling experiences regarding these topics. Participants who had used fertility medications were more likely to be counseled about pregnancy complications, whereas factors such as age, race, and BMI of the patient or provider type did not have a significant impact on overall counseling. Given the high prevalence of preconception comorbidities as well as obstetric complications in patients with PCOS, our findings indicate a need to improve patient counseling and management of modifiable risk factors to improve maternal and neonatal outcomes.

Pregnancy Complications

Four meta-analyses demonstrated increased risks of maternal complications including hypertensive disorders of pregnancy,

gestational diabetes, preterm delivery, and cesarean section as well as neonatal complications including small for gestational age in patients with PCOS (9, 10, 13, 19). The European Society of Human Reproduction and Embryology, American Society for Reproductive Medicine, American College of Obstetricians and Gynecologists, and 2018 and 2023 International Evidence-Based Guideline for the Assessment and Management of Polycystic Ovary Syndrome all highlight the increased pregnancy risks in individuals with PCOS and the need for preconception counseling and optimization of health (4, 7, 20, 21). Despite this information, 47.4% of our respondents reported receiving no counseling on this topic. The lack of counseling on pregnancy complications is mirrored more broadly by the lack of counseling on general long-term complications in patients with PCOS. In a survey study of patients with PCOS in North America and Europe (n = 1,385), our group similarly reported that approximately half of the respondents were either not given any information about general long-term complications related to PCOS or were dissatisfied or indifferent with the counseling provided (17).

Reassuringly, the increased risks of gestational diabetes and pregnancy loss were discussed with most respondents. Although individuals with PCOS also have higher odds of gestational hypertension (pooled odds ratio [OR], 2.58; 95% confidence interval [CI], 1.95–3.41), preeclampsia (pooled OR, 1.87; 95% CI, 1.55–2.25), cesarean section (pooled OR, 1.39; 95% CI, 1.23–1.57), and preterm birth (pooled OR, 2.2; 95% CI, 1.59–3.04) than those without PCOS, these important complications were less commonly discussed (9, 11, 19). Only 5% of our respondents received counseling on the postpartum risks associated with PCOS despite the previously described risks of several postpartum cardiovascular disease complications and postpartum depression (22, 23). Similarly, very few participants were counseled on the potential issues regarding lactation (24–26).

The reasons for this overall lack of counseling on obstetric complications are likely multifactorial. First, the lack of physician knowledge of such complications and time constraints of patient visits may contribute to inadequate counseling. Two previous survey studies found that $\leq 50\%$ of physicians were aware of the PCOS-related obstetric complications, although this topic was not the main focus of the studies (15, 16). Structured interviews of both providers (n = 18) and patients with PCOS (n = 25) have also identified limited provider knowledge and short patient visit times limiting counseling on comprehensive reproductive, cardio-metabolic, and psychological comorbidities (27, 28). Other factors that may contribute to inadequate counseling include limited access to PCOS-specific healthcare providers or lack of opportunities to receive counseling if patients have a spontaneous pregnancy. There are few multidisciplinary PCOS clinics globally despite the expressed needs by patients for more PCOS-specialized providers (27, 29, 30). Furthermore, qualitative studies suggest that patients with PCOS have distrust in providers and significant unmet needs (31–33).

Preconception management

The preconception period provides a unique opportunity to counsel patients on the optimization of existing health

conditions and target modifiable risk factors, with the goal of improving maternal and fetal outcomes (34–37). This is especially important for patients with PCOS because it is known that many chronic conditions, such as obesity, type 2 diabetes, hypertension, depression, and anxiety, are more prevalent in this population (4, 38). Moreover, a small qualitative study demonstrated that patients with PCOS have concerns about pregnancy and desire evidence-based information and preconception care to better inform decisions about their reproductive goals (39).

Despite the recommendation of lifestyle interventions as the first-line treatment for all patients with PCOS, few participants in our study reported adequate counseling on weight management in the preconception period. These findings were alarming in the context of the high prevalence of obesity among our respondents (75%). Furthermore, low rates of adequate counseling on the preconception management of both hypertension and diabetes were reported in our survey. Taken together, our present findings highlight an exigent problem and the imperative need for counseling and guidance of this high-risk group during this pivotal period of preconception care. Future studies should identify health system-related barriers to providing comprehensive preconception counseling and management of comorbidities.

Strengths and Limitations

Our study is the first to provide in-depth insights on the patient perspective of preconception counseling on obstetric complications and management of comorbidities with regard to PCOS. Second, our nationwide cohort and large sample size allowed us to capture a racially, geographically, and socioeconomically diverse population, thus increasing the generalizability of our findings to US patients with PCOS. Our questionnaire was designed with input from a multidisciplinary expert advisory group including a diverse panel of patients with PCOS.

As with the nature of survey studies, there may be sampling bias because we distributed the survey to individuals with general membership to PCOS Challenge. Selection bias is possible because the sample may not be representative of the general population of individuals with PCOS. Certain factors, such as overall dissatisfaction with previous care, may have contributed to the participants seeking support from PCOS Challenge that may not represent the population at large. There may also be response bias for potential differences between survey respondents and nonrespondents. Moreover, we were unable to calculate a true response rate because we were unable to ascertain the denominator of eligible participants. A total of 19,916 PCOS members were on the research mailing list, with 8,906 opening the email with the survey invitation. However, these estimates included people who do not have PCOS or have not attempted pregnancy and, thus, were not reflective of the eligible participants. Another limitation of our study was the recall bias regarding the report of complications and the counseling provided. The diagnosis of PCOS and presence of comorbidities and pregnancy complications were based on self-reported data. However, with regard to self-reported PCOS status,

large-scale genome-wide studies have previously confirmed that women with self-reported PCOS had similar genetic profiles to those with confirmed diagnoses (40). Similarly, self-reported BMI has been previously validated against measured data and, thus, may be relevant in the context of a self-reported history of existing medical conditions (41). Our cohort of patients with PCOS also reported a high level of education, which may not accurately represent the broader PCOS population. Lastly, we did not account for the temporal aspect of the counseling experiences in relation to specific index pregnancies, which would provide additional insight to future interventions in improving patient counseling. Despite these limitations, this first investigation into this important topic lays the groundwork for future research in ameliorating the preconception and prenatal care of patients with PCOS and minimizing the complications that could have lifelong detrimental effects.

CONCLUSION

To our knowledge, this is the first study to describe the inadequate counseling experiences of patients with PCOS with regard to obstetric complications and the preconception management of comorbidities that also confer risk to pregnancy. Patients with PCOS have expressed their concerns about pregnancy and their desires to optimize their health before achieving pregnancy; however, these needs are currently unmet (39). Given these findings, there is an urgent need to increase provider education among PCPs, general GYNs, and REI specialists and ensure patient access to these providers so that this high-risk group can obtain the essential preconception counseling and interventions to improve maternal and neonatal health.

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CRedit Authorship Contribution Statement

Anne E. Kim: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Iris T. Lee:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Sasha Ottey:** Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Anuja Dokras:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of Interests

A.E.K. has nothing to disclose. I.T.L. has nothing to disclose. S.O. reports funding from the American Society for Reproductive Medicine Advocacy grant 2022–2023, honoraria from the American Electrology Association, travel support from the University of Colorado Anschutz PCOS Multidisciplinary Clinic and Androgen Excess and PCOS Society, and advisory board for Ovum Health, outside the submitted work. A.D. has nothing to disclose.

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