Cross-sectional Study on the Knowledge and Prevalence of PCOS at a Multiethnic University

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ABSTRACT

Introduction: Polycystic ovary syndrome (PCOS) is a complex, poorly understood, and underdiagnosed endocrine disorder in women. Understanding PCOS prevalence and information sources allows for resource development for those with PCOS and their loved ones. The purpose of this study was to identify PCOS prevalence, knowledge, and information sources in a young multiethnic cohort in Texas.

Methods: An online survey polled students, faculty, and staff at Texas Woman’s University campuses in Denton, Dallas, and Houston. Seven hundred sixty-nine respondents including 722 females and 47 males completed the survey.

Results: Approximately, 28.5% of female respondents indicated a formal diagnosis of PCOS, and 40.5% of those without a formal diagnosis had 2 or more symptoms that align with PCOS. A majority of participants ranked their PCOS knowledge as “Know some” or less (66.3% women and 83% of men). Healthcare professionals were the most common information source in women with a PCOS diagnosis (83.7%). Hispanics were least likely to use healthcare resources (36%) and to seek information from family and friends (17.6%). Differences were also observed by education level.

Conclusions: Although women in this study recorded a PCOS prevalence above the national average (6%–12%) and were more likely to seek information from healthcare professionals, these numbers may have been skewed attributable to an increased likelihood of polycystic women to respond to the questionnaire. Ethnicity and education need to be accounted for in designing informative material for polycystic women and their family and friends.

Keywords: awareness, polycystic ovary syndrome, survey, young adults

INTRODUCTION

Polycystic ovary syndrome (PCOS) is a heterogeneous, chronic endocrine disorder commonly diagnosed in women of reproductive age. It often manifests with some or all of the following symptoms: menstrual dysfunction, infertility, hirsutism, acne, and obesity. Three sets of criteria have been created for the identification of PCOS: the National Institutes of Health criteria (1992), Rotterdam criteria (2003), and Androgen Excess Society criteria (2006). All 3 subsets include chronic oligo/anovulation, clinical and/or biochemical hyperandrogenism and polycystic ovarian morphology on transvaginal ultrasound, or various combinations of these conditions. All subsets recognize that other disorders causing anovulation and/or androgen excess should be ruled out before diagnosis of PCOS is confirmed.1–4 Several researchers and clinicians prefer to rely on menstrual cycles to ascertain ovulatory status. Oligo or anovulation is defined as menstrual cycles less than 21 or more than 35 days while polycystic ovarian morphology is considered diagnostically significant in the presence of ≥12 follicles with a diameter of 2–9 mm or an ovarian volume of >10 ml.1 These diagnostic criteria, however, cannot be applied to adolescents because physiological changes associated with puberty overlap with the pathological changes observed in PCOS.5,13 PCOS increases the risk for various dermatologic, oncologic, metabolic, reproductive, and psychological aberrations. The disorder itself and its associated comorbidities increase healthcare costs and contribute to reduced quality of life.6–9 Management of PCOS varies due to different goals based on symptom presentation and changes at various life stages. Although patients are at a high long-term risk of developing a multitude of disorders, PCOS may not be diagnosed until patients encounter troublesome cosmetic issues such as hirsutism, androgenic acne, alopecia, and/or problems associated with infertility. Issues contributing to delayed, or a lack of diagnosis include differences in primary patient complaints, divergent diagnostic guidelines, and accuracy and/or interpretation of test results.10 Recognition of physical manifestations is commonly the first step in the diagnosis of PCOS. It is imperative for women to draw their medical provider’s attention to their symptoms so that a detailed history may be gathered, and a thorough examination may be conducted for the diagnosis.8,11

Global prevalence of PCOS is estimated to be between 6% and 26%,12–15 Bozdag et al.16 conducted a systematic review and meta-analysis on published studies that reported the prevalence of PCOS according to at least 1 diagnostic criteria subset. Their
findings indicated that the global prevalence of PCOS ranges from 6% to 10% depending on the criteria used. Similar epidemiological studies concluded that the Rotterdam and Androgen Excess Society prevalence estimates were about twice those obtained with the National Institutes of Health criteria.4,17,18

Variability in PCOS prevalence estimates can be attributed to several factors. First, depending on the location of data collection, there may be a heterogeneity in racial, ethnic, and age distribution in the sample population. These variables may influence the clinical presentation of hyperandrogenism and ultrasonographic appearance of ovarian follicles over time. For example, Hispanic women with PCOS often have a higher prevalence of hirsutism, hyperandrogenism, and hyperglycemia compared to non-Hispanic White women and tend to have higher rates of metabolic syndrome and hypertriglyceridemia than non-Hispanic Black women.19,20 Second, running biochemical and ultrasound tests for the diagnosis and exclusion of related disorders can be logistically challenging due to reasons associated with cost, time, and personnel. Third, convenience sampling for research may not reflect the actual prevalence in the population.13,21

Not all women who have PCOS receive a formal diagnosis or if they do, it may take years and several different doctors before diagnosis is made. This may be attributable to both a lack of awareness and educational material available at the correct level for individuals and healthcare providers. A recent study showed that over one-third of women with PCOS had to wait over 2 years and visit with at least 3 different health professionals before their diagnosis was established.22 Furthermore, when these women were finally diagnosed, they received little, if any, information regarding long-term complications for PCOS, treatment options, or emotional support and counseling. Instead, women reported seeking information about PCOS from online resources, where the information quality is variable.22 Overall, there is an obvious need to study different aspects of women’s awareness and understanding of PCOS as well as their sources of information. Understanding these parameters will inform the development of educational tools not only for women with PCOS but also for their family members and healthcare providers.

Texas Woman’s University (TWU) is the nation’s largest university primarily for women and has campuses in Denton, Dallas, and Houston, Tex. TWU is a highly diverse university system with 30% of its undergraduate population identified as Hispanic, 17% as African American, and 38% as Caucasian.23 Although the university system is predominantly female, roughly 12% of the student population is male.23

This study had 2 main objectives. The first was to evaluate the prevalence of PCOS, its symptomatic presentation, and management among a young, multiethnic population at TWU. The second was to assess the knowledge and source of information about PCOS among young women and men at TWU and to evaluate ethnic differences that may exist in knowledge and source of PCOS. Overall, the findings from this study will help provide information to support the development of education-level and ethnicity-specific learning tools for women and men about PCOS.

METHODS

Ethics Approval
This study was approved by TWU Institutional Review Board. Participation was voluntary and anonymous. Completion of the survey was interpreted as consent to participate in the study.

Survey Development
All questions in the survey were based on PCOS-related surveys published and distributed online both, within and outside the United States.24–27 Questions were designed keeping in mind racial, cultural, ethnic, and lifestyle variations. The online survey was created on PsychData (PsychData LLC, State College, Pa.).

The questionnaire had 3 components each of which was designed to be completed by women with diagnosis of PCOS, women without PCOS, or men. No personal identifying information was collected.

General demographic was collected from all respondents. Women answered the following questions via a select all that apply approach (Fig 1):

(a) Medical information included questions regarding diagnoses of PCOS, and its associated comorbidities such as diabetes, hypertension, dyslipidemia, infertility, thyroid problems, eating disorders, hypoglycemia, cardiovascular diseases, and gastrointestinal issues.

(b) PCOS symptoms included frequency of menses, signs of hyperandrogenism (defined in the survey as excessive facial or body hair, hair loss on crown of the head, acne in adult life, and excess weight gain), acanthosis nigricans (defined as darkened skin in certain areas of the body, i.e., back of neck, arm pits, under the breasts, groin, etc.), and obstetric history (e.g., infertility).

(c) Pharmacological and lifestyle changes that included exercise and dietary modifications for management of PCOS.

Men answered a separate yet similar survey that contained questions regarding the presence of PCOS within their family and friends (Fig. 2). Both men and women were asked about levels of perceived knowledge regarding PCOS and their sources of information. Level of knowledge regarding PCOS was assessed on a 5-point scale, where 1 is I do not know anything about PCOS and 5 is I know everything about PCOS.

Recruitment
In this cross-sectional study, the faculty, staff, and students at TWU Denton, Dallas, and Houston campuses were solicited for participation in the survey. Overall, 823 individuals (48 men and 775 women) above the age of 18 years responded to the online request and participated in the online survey. Self-reported demographic (including ethnicity and campus location), dermatological, medical, and reproductive data were collected from each participant. In total, 769 respondents completed the survey. Ethnicity was grouped into 5 main categories for statistical evaluation: Caucasian, African American, Asian, Hispanic/Latino, and others (which included Native American, Native Hawaiian, Middle Eastern, and Mixed/Multiple races).

Data Analysis
The data obtained were analyzed using IBM SPSS v. 25 (IBM Corporation, Armonk, N.Y.). Statistical significance was set at $P \leq 0.05$. Relationships between categorical variables were analyzed by $\chi^2$ analysis. Descriptive analysis (frequency statistics) was also conducted to understand/explore perceptions about PCOS in general.
Fig. 1. Example of selected female survey questions.

9) Are you presently experiencing any of the following? (Check all that apply)
   - Irregular menstrual periods
   - Excessive facial or body hair
   - Hair loss on crown of the head
   - Acne in adult life
   - Darkened skin in certain areas of the body, i.e. back of neck, arm pits, under the breasts, groin, etc.
   - Excess weight gain
   - Infertility
   - None of the listed symptoms

10) Have been diagnosed or treated by a physician or healthcare professional for any of the following conditions? (Check all that apply):
    - Heart Problem
    - High Blood Pressure
    - Diabetes
    - Hypoglycemia (low blood sugar)
    - Hyperlipidemia (high blood cholesterol or triglycerides)
    - Thyroid problems
    - Eating disorder (anorexia or bulimia)
    - Stroke
    - Bleeding or clotting disorder
    - Stomach problems
    - Infertility
    - Polycystic Ovary Syndrome (PCOS)
    - None
    - Other (please specify)

*11) Do you have a formal diagnosis of Polycystic Ovary Syndrome (PCOS) by a healthcare professional?
   - No
   - Yes

Fig. 2. Example of selected male survey questions.

*5) Has any of your female relative (mother, sister, aunt, grandmother or cousin) or significant other been diagnosed or treated by a physician or healthcare professional for Polycystic Ovary Syndrome (PCOS)?
   - Yes
   - No
   - I do not know

6) If 'yes' then please specify the relationship(s). (Check all that apply)
   - Not applicable (if 'No' checked in previous question)
   - Grandmother
   - Mother
   - Sister(s)
   - Aunt (Mother or father's sister)
   - Cousin
   - Girlfriend/ wife
   - Other (please specify)

*7) Do you, your sibling or child have an established diagnosis of Autism Spectrum Disorder (ASD)?
   - Yes
   - No
   - I do not know
RESULTS

Participation and Demographics

Of the 823 individual respondents, 769 completed the survey (7% incomplete), capturing about 4%–5% of the student population on each TWU campus. The mean age of the survey participants was 32.9 ± 11.4 years. A majority of the respondents were Caucasian (60.8%), followed by Hispanics (15.2%) and then African Americans (10.5%, Table 1). Approximately, 6% of individuals completing the survey were male. Of the 722 responding women, 28.5% had a formal diagnosis of PCOS from a medical practitioner (Table 1). Interestingly, of the women who had not been formally diagnosed with PCOS, 40.5% responded that they manifest with 2 or more physical characteristics associated with PCOS according to the Rotterdam criteria. Of the women who were not sure whether they had received a formal PCOS diagnosis (6.2% of respondents), 8.6% had symptoms associated with the diagnostic criteria (clinical hyperandrogenism and irregular menses). Furthermore, African American, Asian, and Hispanic participants were more likely to respond that they were not sure if they had been formally diagnosed (12.2%, 11.6%, and 8.3%, respectively).

When PCOS was diagnosed, it was primarily done so by an Obstetrician/Gynecologist (68.4%, Fig. 3) with an average age of diagnosis of 22 years (age range 11–45 years). Of these, 70.3% and 66.0% of the women reported that they had been diagnosed via pelvic ultrasounds and biochemical tests, respectively. Common clinical symptoms experienced by women with PCOS included irregular periods and features suggestive of hyperandrogenism and hyperinsulinemia (hirsutism, rapid weight gain, postpubertal acne, and acanthosis nigricans).

Self-assessed Awareness about PCOS

Approximately, 66.3% of women and 83.0% of men ranked their knowledge of PCOS as a 3 (“Know some”) or less, with 42.6% of men and 21.7% of women indicating that they know nothing. Only 4% of the women and 2.1% of the men said that they knew everything about PCOS (Fig. 4). Overall, women with a diagnosis of PCOS reported that they had better knowledge than those who did not have PCOS. There were no ethnic differences in perceived knowledge of PCOS.

Sources of Information about PCOS

Those with a formal diagnosis of PCOS were more likely to use healthcare professionals (83.7%), as their source of information than those who were undiagnosed (31.1%) or unsure (52.3%) counterparts (Fig. 5). Furthermore, diagnosed individuals were more likely to utilize PCOS support groups (32.3%), whereas undiagnosed or unsure individuals were more reliant on family and friends (29.4% and 25%, respectively) for information. Additionally, diagnosed and unsure individuals were equally likely to use government websites/journal articles (25.7% and 20.5%, respectively) for information, at a level about twice that for undiagnosed (14.4%, Fig. 5). Although the most common sources of information about PCOS for males were healthcare professionals (29.8%), their reliance on this source was about half that for undiagnosed and unsure and about one-third that of diagnosed polycystic women. Male use of family and friends (23.4%) and government websites/journal articles (19.1%) closely emulated those seen for women unsure of their PCOS status (Fig. 5). Additionally, although not statistically significant, African Americans were the least likely to use social media to obtain information about PCOS from healthcare professionals (50.1%) or family and friends (31.1%) than other ethnicities. Hispanics were the least likely to get information from these sources (36.0% and 17.6%, respectively). Additionally, although not statistically significant, African Americans were the least likely to use social media to obtain information, and Asians were among the highest users for newspapers/magazines as sources of information (Fig. 6).

The education level also impacted what sources of information were chosen to learn about PCOS. Those who were high school graduates were the least likely to get information from their healthcare professional (26.9%) or government websites/journal articles (6.0%) compared to the other education levels. The use of social media to obtain information was popular among those with some college or technical training (27.9%) or an associate’s degree or...
equivalent (27.4%), but was the least popular among those who had a graduate degree (11.4%). Participants with a graduate degree were more likely to obtain information from government website/journal articles (21.3%) than other education levels (Fig. 7).

**DISCUSSION**

**Summary of Findings**

In this exploratory survey on the prevalence and knowledge of PCOS among men and women, we found that 28.5% of the women who responded had a formal diagnosis of PCOS. However, this prevalence may be an underestimate because almost half (40.5%) of the women who had not been formally diagnosed had symptoms consistent with the Rotterdam diagnostic criteria for PCOS. Conversely, our prevalence could be an overestimation due to selection bias. Participants are more likely to respond to a survey when they have the symptoms of the disease or know someone who does. Although most women received information about PCOS from a healthcare provider, differences in source preferences were influenced by ethnicity and educational level. The great disparity for information sources identified herein indicates that...
Fig. 6. Frequency in which respondents said yes to the different sources of PCOS information split by ethnicity. *$P < 0.05$ within sources.

Fig. 7. Frequency in which respondents said yes to the different sources of PCOS information split by the highest education degree obtained. *$P < 0.05$ within sources.
Overall, healthcare professionals were the primary source of information on PCOS may not be universally effective. There is a need for the development of readily available, through any avenue, information for use for women and men that can be disseminated to or accessed by individuals, healthcare providers, friends and family, journals, with the need to be linked to government health sites. Overall, a majority of both men and women cumulatively ranked their knowledge of PCOS at “Know some” or lower.

**Prevalence of PCOS**

According to the Centers for Disease Control and Prevention, PCOS prevalence in the United States is between 6% and 12%. This is one-fourth to one-half of the prevalence that was recorded in our survey (28.5%). Although TWU does have a highly diverse population, this does not explain the higher prevalence for PCOS that was recorded in our survey because most of the participants were Caucasian. This data could indicate that there is either a higher prevalence of PCOS in Texas compared to the balance of the United States, or that the Centers for Disease Control and Prevention numbers are drastic underestimates and may need to be updated. It may very well be a combination of both. In fact, it has been estimated that the percentage of women who remain undiagnosed after visiting their healthcare professional could be as high as 75%. Furthermore, although there is limited knowledge about geographical trends in the United States, one study reported that there was a 47.5% prevalence of PCOS in Southern United States (of which Texas is included). Cost of diagnosis and treatment may be additional deterrents for women with symptoms of PCOS. Nonavailability of adequate health insurance coverage and delayed transition from pediatricians to adult care providers may affect women’s ability to continuously access quality services.

**Sources of PCOS Information**

Overall, healthcare professionals were the primary source of information about PCOS, regardless of respondent’s diagnosis status. Interestingly, women who had received a formal diagnosis of PCOS were more likely than others to receive information from government websites and journals. This is encouraging because these sources tend to be more reliable in the accuracy of their information. With this high reliance on government sources, it is critical that these information sources be peer-reviewed and accurate and that the information meet the needs for different ethnicities and education levels. Overall, men were more likely to seek information about PCOS from a healthcare professional or their family and friends.

The education level played an important role in which source of information respondents accessed. Those with a graduate degree were the most likely to obtain information from government websites and journals, whereas those with a high school degree alone were the least likely. This is consistent with the graduate education practice in which students are trained to seek information from these sources first before turning to other sources of information. Furthermore, the use of social media as a source was highest among those with an associate degree or some college or technical training. This is consistent with findings from the Pew Research Center, in which the current college population is more digitally active than any other previous generation.

Ethnicity also played a factor in identifying where an individual went to for information about PCOS. Of the 5 main ethnicities (Caucasian, African American, Hispanic, Asian, and others), Caucasians were the most likely seek out information from a healthcare professional or family and friends, exceeding the other ethnicities. Interestingly, Hispanics had the lowest ethnic likelihood to use these 2 sources for PCOS-related information. It is well established that Latinos and Hispanics face may barriers when it comes accessing healthcare in the United States. This includes, but is not limited to, language barriers, inability to afford health insurance, and a cultural mistrust coupled with a predisposition to seek alternative care before conventional treatment. Culturally, Hispanics and Latinos are often encouraged to seek direction and advice from their family members, specifically their female family members. This makes the finding in which only 17.6% of Hispanics (the lowest of all ethnicities) sought out family and friends regarding information about PCOS very intriguing. One explanation for this could be that perhaps Hispanics respondents may be embarrassed by their PCOS symptoms (specifically those associated with hyperandrogenism and acanthosis nigricans) and do not feel comfortable seeking information from family and friends as they normally would. Instead, as indicated by our results, they turn to social media, where they can seek information anonymously and be in control of what information they obtain (Fig. 4). This theory is further supported by that the fact that in 2018, Hispanics had the highest-dependence on smartphones for online access (35% compared to 14% Caucasian and 24% African American).

Social media is a powerful tool for disseminating information. With an increasing number of studies being conducted that focus on increasing African American health literacy using social media, it is surprising that in our survey, they were the least likely to use this platform to obtain PCOS information (Fig. 4). According to the Pew Research Center, approximately 72% of the US adults use some types of social media, with very little differences among ethnicities (Caucasian 73%, African American 69%, and Hispanic 70%). In a report by PricewaterhouseCooper (PwC), more than 40% of the US adults surveyed reported that information found via social media would affect the way they coped with a chronic condition, their approach to diet and exercise, and even their selection of a specific doctor. Because of this, more and more health educators are turning to social media as a way to distribute information to adults, specifically among different ethnic groups. For example, several studies have been conducted among African Americans in which social media was used to provide information about pregnancy and early motherhood (e.g., breastfeeding, infant development, etc.). Difference in African American social media use seen here that do not follow patterns seen with pregnancy/motherhood may be related to differential use for maternal health versus understanding a disease/disorder.

It is vital to increase awareness about PCOS, and its health risks among all ethnicities, age groups, and genders because the genetic defects can be inherited by both, men and women. Close relatives of women with PCOS may exhibit metabolic and reproductive phenotypes resembling those observed in women. Early detection of corresponding PCOS characteristics in men may help in identification of cardiometabolic risk factors and subfertility and suitable preventive/treatment options.

**Strengths and Limitations**

The prevalence of PCOS in our survey was based on self-reported medical diagnosis only, and we did not attempt to identify specific PCOS phenotypes. Selection bias could have also lead to an overestimation of our prevalence estimates. Furthermore, the scope of this survey was exploratory and did not include questions related to health literacy, nature of information participants sought from available/preferred resources, or how often they utilized these sources for information. Without these pieces of information, only limited conclusions can be drawn from our results. Despite these limitations, our survey was able to show ethnic and educational
CONCLUSIONS
In this exploratory survey at a young multiethnic university community in Texas, PCOS prevalence was reported at double the national average with most respondents (both female and male) responding knowing some or less about PCOS. Conversely, the high numbers reported herein may also be attributable to a higher response rate in those afflicted with PCOS. Of critical importance is not the difference in the response rate or the percentages but the requirement to address the need for information accessibility for those without PCOS and sources they use for information. A critical part of this information development is the need to ensure that all materials are developed at appropriate education levels while accounting for specific ethnic differences. Although medical practitioners play an important role in diagnosing PCOS and educating individuals about this disorder, the cost and time for diagnosis and treatment discourages several young women from seeking help. Additionally, it is important for healthcare providers to be culturally cognizant while disseminating this information. Overall, raising awareness about PCOS is critical not only among women but among men as well. Our results indicate ethnic and education differences exist that should be taken into account when designing educational materials for women with PCOS as well as their family and friends.

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