Our Pearls Matter: PCOS through the Lens of Women of Color and White Women

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OUR PEARLS MATTER: PCOS THROUGH THE LENS OF
WOMEN OF COLOR AND WHITE WOMEN

by

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ABSTRACT

The prevalence of PCOS is increasing and due to the associated health complications, it is important to understand how higher-risk populations (women of color) cope with said condition. Analyzing current symptom management and treatment could help develop more practical resources and treatment strategies to help improve healthcare expectations and quality of life.

Ten women aged 22-38 with PCOS participated in comprehensive individual interviews with goal-oriented, semi-structured questions. A 27-question survey was also completed. Sampling was continued until data saturation was reached. The data was analyzed using the grounded theory technique which codes emergent themes with keywords and phrases which ultimately are used as the basis of the development of a new theory.

The data analysis aided in finding the main themes of the research (1) Age of diagnosis (2) Symptoms (3) Body Fat Discrimination (4) Dismissiveness/Symptoms Triage (5) Poor Guidance (6) Life Impact (7) Mental Health (8) Support Symptoms (9) Religion/Spirituality (10) Cultural Comparisons and Differences.

In this study, the women with PCOS showed similarities with symptoms, symptom management, and experiences with healthcare providers regardless of race. However, there was an expression from several participants that racial discrimination could play a role in receiving inadequate care. Recognizing potential biases with race,
body size, and female reproductive health and staying current in PCOS symptom
management and available resources could help provide more inclusivity, guidance, and
support leading to a better quality of life and better healthcare experiences for women
with PCOS.
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CHAPTER 1

INTRODUCTION

As rates of obesity continue to rise in the United States, the incidence of health conditions is increasing (Apovian, 2016). One condition becoming more prevalent is polycystic ovary syndrome (PCOS). PCOS affects approximately one in every ten women. There is no specific etiology for PCOS due to it manifesting differently among women (Naz & Barthelmess, 2014). Women with PCOS are often overweight or obese but can manage their weight and symptoms with diet and physical activity. (Pataky et al., 2018). Losing 5 to 10% of their body weight can help improve current hormone imbalance, thus improving symptoms such as central obesity, hirsutism, and acanthosis nigricans, which improves health and overall quality of life (Naz & Barthelmess, 2014).

A condition that often occurs in tandem with PCOS is Metabolic Syndrome (MetS). MetS is often related to central obesity (Kaur, 2014) and is characterized by blood glucose intolerance and insulin resistance. Insulin resistance can exacerbate the symptoms of PCOS. Therefore, lifestyle changes such as diet and physical activity can lessen the symptoms of PCOS and MetS (Kaur, 2014).

Race and ethnicity are risk factors for many chronic conditions. This phenomenon is multifaceted and somewhat complex. The US Department of Health and Human Services has indicated gaps in clinical and research practice related to identifying and understanding health disparities associated with race and ethnicity (Quiñones et al.,
Women of color are more likely to develop Hypertension, Diabetes, and certain Cancers (Women of Color Health Data Book, pg. 121-134). These health conditions are often intertwined with environmental factors, making them difficult to treat. Some environmental factors include cultural expectations of weight and body size, physical activity, attitudes, beliefs, and traditions associated with food (Sanchez & Jones, 2017). Additionally, healthcare access and insurance coverage are two major factors contributing to racial and ethnic disparities (Chen et al., 2016).

**Background of the Problem**

Obesity is a significant health issue and is common among women with PCOS. One treatment strategy for PCOS includes weight management, as there is an elevated risk of developing MetS, Type 2 Diabetes Mellitus (T2DM), and Cardiovascular Disease (CVD). These health issues can cause infertility and mental disturbances, such as depression and anxiety, and can even increase their risk of developing endometrial cancer (Schock et al., 2016).

Unfortunately, weight loss for those with PCOS can be challenging. For women of color, weight loss may be difficult because of cultural beliefs and practices. Regardless of geographic region, there may be similar food cultures and preferences (Insel, Ross, & McMahon, 2016). However, regarding race and ethnicity, the numerous variations in cultural preferences may require individualized treatment.

The prevalence of PCOS among races varies, and the complications associated with the disease appear to be higher among women of color. Whites have a prevalence rate of 6.2%, whereas Hispanics’ prevalence ranges from 6% to 13% and Blacks’ from 3.4% to 8% (Wolf et al., 2018). Health complications such as metabolic syndrome occur
at a higher rate in Black, Latino, and Hispanic populations compared to their White counterparts (OR, 1.20; 95% CI, 1.02-1.40) (Moore, Chaudhary, & Akinyemiju, 2017).

It has been suggested that “the sexual and reproductive health of Black women has been compromised due to multiple experiences of racism, including discriminatory healthcare practices from slavery through the post-Civil Rights era. The legacy of medical experimentation and inadequate healthcare coupled with social determinants has exacerbated African American women’s complex relationship with healthcare systems. The social determinants of health associated with institutionalized and interpersonal racism, including poverty, unemployment, and residential segregation, may make Black women more vulnerable to disparate sexual and reproductive health outcomes” (Prather et al., 2018). Research shows that Hispanics are less likely to report having been screened for cancer, receiving Hgb A1C checks, or receiving healthcare on a routine basis compared to whites. (Amirehsani et al., 2017). Hispanic women experience social determinants of health that negatively impact access to healthcare services, such as being uninsured, having low incomes, low health literacy, and limited English proficiency (Amirehsani et al., 2017). These can lead to poor clinical outcomes and delays seeking medical care and emergency services (AHRQ.gov, 2015). These outcomes validate the importance of looking at women of color through a different lens to develop an effective plan to improve their experience and clinical outcomes related to PCOS. This study will describe the experience, symptoms, and treatment of women of color with PCOS.
Purpose

This study aims to describe the unique experience of women of color diagnosed with PCOS, assess their strategies to manage their condition, and document the difficulties they have endured while seeking medical treatment.

Objectives

There are four main objectives considered in this study.

- Describe the symptoms of women of color with PCOS before seeking medical treatment.
  - symptoms at diagnosis
  - current symptoms

- To describe healthcare experiences of women of color with PCOS concerning:
  - treatment options offered
  - the prognosis for becoming pregnant
  - payment of services
  - the demeanor of healthcare practitioners towards patients during the initial visit and after that

- To describe and assess the strategies that have been used to manage their condition with:
  - medication regimen
  - diet
  - exercise
  - counseling
  - support groups
• Describe the barriers women of color with PCOS have had in seeking medical treatment.

• Cultural Relations:

  1. Food and diet barriers
  2. Family support
  3. Healthcare access
  4. Healthcare availability

Justification

Due to the increasing prevalence of a PCOS diagnosis and associated health complications, it is vital to understand how women of color cope with the condition so that practical resources and treatment strategies can be employed to improve their quality of life. This study will describe the similarities, differences, and barriers women of color with PCOS have experienced while seeking healthcare treatment.
CHAPTER 2

REVIEW OF LITERATURE

PCOS: Defined

Polycystic Ovary Syndrome (PCOS) results from a hormone imbalance that affects 5 to 10% of all women in their childbearing years (Wright, 2017; Goyal & Dawood, 2017). The prevalence ranges from 2.2% to 26% globally, and its manifestation is highly variable, especially across races and ethnicity. The prevalence of PCOS among Hispanic women has been reported to be between 6% to 13% (Wolf et al., 2018) and 3.4% to 8% for Black women. (Wolf et al., 2018).

The hormone alterations can affect a woman’s appearance and overall health. The direct cause of PCOS is not fully understood, but research is still emerging (Naz & Barthelmess, 2014). Physicians use the Rotterdam Criteria to diagnose PCOS in adults. The first includes the excess production of insulin (Naz & Barthelmess, 2014). Many women with PCOS either have pre-existing insulin resistance or develop insulin resistance. Insulin, produced by the pancreas, helps the body’s cells to utilize glucose efficiently. When cells resist insulin, blood glucose levels rise because insulin cannot decrease glucose levels. As blood glucose levels rise, especially for prolonged periods, the body may produce more insulin to reduce glucose levels to normal (niddk.nih.gov, 2018). Excessive insulin in the blood may increase the production of androgens, such as testosterone. Excessive testosterone in women can make ovulation more complex,
leading to infertility and other complications that affect a woman’s overall health and wellness (Hart & Doherty, 2015).

Another factor that has been suggested to contribute to PCOS is the presence of low-grade inflammation (Shorakae, Joham, & Teede, 2015; Zafari Zangeneh, 2017). This inflammation can stimulate the formation of one or multiple ovarian cysts. The presence of cysts can increase the production of androgens, specifically testosterone, which can contribute to infertility and lead to heart and blood vessel problems over time (Hart & Doherty, 2015). Some research suggests that a hereditary component may contribute to the development of PCOS (Naz & Barthelmess, 2014); (Hart & Doherty, 2015). Although researchers have not identified the specific inheritance pattern, it has been estimated that 20 to 40% of women diagnosed with PCOS tend to have a mother or sister with the same diagnosis. This relationship suggests there could be a possible genetic link to PCOS. However, modifiable risk factors such as poor diet and lack of physical activity among family members may also play a role (Hart & Doherty, 2015).

**PCOS: Diagnosis in Adults**

The female reproductive system shows cyclic changes that teleologically may be regarded as preparation for pregnancy and fertilization. This cycle is the menstrual cycle, and its most conspicuous feature is the periodic vaginal bleeding that occurs with the shedding of uterine mucous (menstruation) (Thiyagarajan & Basit, 2019). Women without PCOS typically have regular menstrual cycles between 24 to 38 days, with an average of 28 days. The main symptoms and defining criteria used to diagnose someone with PCOS are either amenorrhea or oligomenorrhea ovulatory cycles which means they either do not ovulate at all or infrequently ovulate (Mohammad & Seghinsara, 2017). The
imbalance in the gonadotropin hormones, Luteinizing Hormone (LH) and Follicle Stimulating Hormone (FS) disrupt regular menstrual cycles among women with PCOS. The primary purpose of having a menstrual cycle is for the ovaries to release an egg so that sperm can fertilize the egg to create a fetus. The endometrium thickens to prepare for embryo implantation and nourishment. Without fertilization, the endometrium is shed with the unfertilized egg and excessive blood. Women with PCOS do not shed their lining as needed, which can cause complications such as a buildup of the uterine lining, which could increase the risk of endometrial cell dysfunction (Schock et al., 2016).

The critical criterion for diagnosing adults with PCOS is hyperandrogenism (Mohammad & Seghinsara, 2017). Hyperandrogenism usually occurs when high levels of insulin in the blood result from insulin resistance. Excessive insulin levels in the blood stimulate the ovaries to create excessive levels of androgens, such as testosterone. High androgen levels can result in excessive facial hair, also known as hirsutism, and contribute to anovulatory and oligo ovulatory cycles (Mohammad & Seghinsara, 2017).

The last criterion used to diagnose PCOS in adults is polycystic ovarian morphology resulting in enlarged ovaries or ovaries that appear to be surrounded by a pearl bracelet with multiple follicles maturing but not ovulating. Over time, these mature follicles can form cysts or inflammation, causing them to become enlarged. Only two of the three criteria are needed to confirm this diagnosis in adult women (Mohammad & Seghinsara, 2017).

**PCOS: Diagnosis of Adolescents**

Typically signs and symptoms of PCOS appear at puberty (Tsikouras, 2015). The average age of menstruation in the United States is 12 years, and most females have at
least one menstruation cycle before age 15. If a child has experienced a cycle before the age of 9 or has not experienced a cycle by the age of 15, a physician should address this to confirm or rule out PCOS (Committee on Adolescent Health Care, 2015).

Unfortunately, there are no set criteria to diagnose adolescents with PCOS officially. Due to continual hormone changes and the body’s attempt to regulate menstrual cycles, it is difficult to establish what is abnormal. Therefore, diagnosing adolescents based on criteria used to diagnose adults could result in unnecessary interventions (Mohammad & Seghinsara, 2017).

**Health Issues Associated with PCOS**

Given that PCOS is often associated with insulin resistance, there is an increased risk of developing prediabetes and/or Type 2 Diabetes over time (Gingery & Williams, 2017). Because insulin resistance typically results in weight gain, there may be increased pressure on the blood vessels, which influences the development of Gestational Diabetes, pregnancy-induced high blood pressure, and MetS (Chandrasekaran & Sagili, 2018). These could lead to chronic conditions such as T2DM and CVD. Due to the numerous complications of PCOS and their severity, prevention, and treatment, it is crucial to improve the quality of life and prevent further health complications of women with PCOS (Havelock, 2018).

**Metabolic Syndrome**

Metabolic Syndrome (MetS) is an array of physiological and biochemical abnormalities. Being overweight or obese can increase the chances of developing MetS because the organ systems are stressed (Mendrick et al., 2017). Obesity can be a
symptom of developing PCOS in some individuals due to a genetic predisposition, and having PCOS can worsen obesity (clevelandclinic.org, 2016).

**Type 2 Diabetes**

PCOS and insulin resistance have a close relationship. Impaired glucose tolerance and insulin resistance may predispose an adult or adolescent to develop diabetes. Excess weight could lead to insulin resistance if one does not intervene with lifestyle changes such as diet or physical activity. Once insulin resistance has developed, serum glucose levels will rise. Over prolonged periods, this could lead to the development of Type 2 Diabetes (Saklayen, 2018).

**Cardiovascular Disease**

PCOS patients have a higher risk of developing cardiovascular diseases such as hypertension and hypertriglyceridemia (Scicchitano et al., 2012). These conditions are related to metabolic dysfunctions related. As a result, an abnormal hormonal pattern is characterized by hyperandrogenism, insulin resistance, dyslipidemia, and a constant inflammatory state (Scicchitano et al., 2012). Hypertension, hypertriglyceridemia, and low HDL can predispose an adult or adolescent to develop CVD. All these can cause plaque buildup in the arteries, which can narrow and harden, causing them to become atherosclerotic. When arteries become atherosclerotic, this increases the chance of developing blockages which can cause heart attacks and/or stroke (heart.org, 2016). Since MetS also increase the risk of developing diabetes and CVD, two of the most common chronic conditions in the United States, it is clear that prevention and treatment should be a top priority in female adolescent and adult populations with PCOS (Kaur, 2014).
Non-alcoholic Fatty Liver Disease

PCOS can influence the development of a fatty liver. Fat accumulation in the liver can cause inflammation resulting in Nonalcoholic Fatty Liver Disease (NAFLD) (Vassilatou, 2014). The significant risk factors for NAFLD are obesity, DM, dyslipidemia, and MetS, common comorbidities in patients with PCOS. In a Nationwide cohort that evaluated 50,785,354 female hospital stays, 77,415 had PCOS. Of the patients who had PCOS, there was a higher prevalence of obesity (29.4% vs. 8.6%) than compared to women without PCOS (p<0.001 for all) (Asfari et al., 2020). The analysis of a national data set demonstrates that women with PCOS are four times more likely to have NAFLD than patients without PCOS after adjusting for confounding factors such as obesity and DM (Asfari et al., 2020). NAFLD can progress over time and increase the risk of developing more serious liver conditions. Therefore, managing comorbidities associated with PCOS can help prevent the development of more severe conditions, especially the decline in liver health.

Cancer of the Reproductive System

Due to the lack of or limited ovulation in women with PCOS, there is a likelihood of an accumulation of the uterine lining. The inability of the body to rid the uterus of the uterine lining can cause cells to mutate and become cancerous (Schock et al., 2016). Chronic hormone stimulation can lead to cancers in women, such as endometrial, ovarian, and breast cancer. Due to conflicting research, Ding et al. decided to examine the association between PCOS and the cancers mentioned above. In this large cohort study, an overall 17-fold higher risk of endometrial cancer was found in more than 8,155 Taiwanese women with PCOS than in women without PCOS. However, no association
was observed between PCOS and either breast or ovarian cancer (Ding et al., 2018). Ding et al. (2018) noted that in a previous study of a Danish population, there was a non-significant increase in the risk for ovarian cancer with PCOS compared with the general Danish female population (standardized incidence ratio = 1.8; 95% CI = 0.8 - 3.2). A major reason for the increased risk of endometrial cancer is the prolonged exposure of the endometrium to unopposed estrogen caused by anovulation. This exposure can cause endometrial hyperplasia leading to endometrial cancer. Other risk factors for endometrial cancer are obesity, unopposed long-term estrogen use, nulliparity, infertility, and HTN, which also contribute to the development and exacerbation of PCOS. (Ding et al., 2018).

**Fertility**

Infertility and subfertility (generally described as any reduced fertility with prolonged unwanted non-conception) are significant complications of PCOS (Melo, Ferriani, & Navarro, 2015). PCOS causes eighty percent of anovulatory infertility cases. The development of anovulatory infertility may be related to imbalances in testosterone, FSH, LH, progesterone, estrogen, and/or other hormones causing problems with ovulation (Melo et al., 2015).

**Pregnancy and Offspring Outcomes**

Human chorionic gonadotropin hormone (hcG), Human placental lactogen (hpL), estrogen, and progesterone may play a part in the conception and maintaining the pregnancy (Schock et al., 2016). Babies born prematurely are typically small for gestational age and are neurologically underdeveloped. PCOS can lead to premature births, which may have lifelong effects that may reduce the child’s quality of life (Schock et al., 2016).
Mental Health

According to the National Institute of Wellness, the Six Dimensions of Wellness (1976) include: emotional/mental, occupational, physical, social, intellectual, and spiritual. In the grand scheme of things, all aspects of health are interconnected and therefore impact one another. For example, mental health can have an impact on one’s physical health, and in turn, physical health can influence one’s mental health. The importance of mental health and the awareness of how it can impact a person’s quality of life has become an area of research interest. A person with no health conditions may have mental health issues. However, health conditions such as PCOS may impair an individual’s mental health and negatively impact their overall quality of life (QOL).

A study was conducted with 70 females between 18 to 45 to determine the effects of PCOS symptoms on psychiatric morbidity and whether psychiatric morbidity impacted QOL (Chaudari, Mazumdar, & Mehta, 2018). Results indicated there were associations, including anxiety and alopecia having an association with anxiety, acne with depression, and hirsutism with a lower psychological QOL. The study sample had a prevalence of 38.6% for anxiety and 25.7% for depression. (Chaudari, Mazumdar, & Mehta, 2018). These results indicate that 64% of the sample’s PCOS symptoms had a psychological impact that could ultimately lessen their QOL and validates that PCOS is not only physically taxing but also has psychological effects and symptoms; the need for research to understand better the impact of PCOS has on women from a psychological perspective.

A cross-sectional study was conducted with 250 women from different demographics (ethnic, socioeconomic, religious, etc.) to explore the prevalence of depression and anxiety symptoms using the Hamilton Depression Rating Scale (HAM-D)
and Hamilton Anxiety Rating Scale (HAM-A). The Hamilton Depression Rating Scale (HAM-D) is one of the longest-standing and most widely used clinician-administered depression assessment scales. The 17-item version was used; each item was scored between 0 and 4 points. Seventeen items measure the severity of depressive symptoms, and an additional four items measure factors related to depression, such as paranoia or obsessional compulsive symptoms. Scoring on the 17-item scale is: normal (0-7), mild depression (8-16), moderate depression (17-23), and severe depression >24 with the maximum score being 52 (Sharp, 2015). The Hamilton Anxiety Rating Scale (HAM-A) measures the severity of perceived anxiety symptoms. It consists of 14 symptom-defined elements which include psychological and somatic symptoms. Each item is scored from 0 to 4 points. Mild severity is indicated by a score of <17, mild to moderate is 18-24, and 25-30 moderate to severe (Thompson, 2015).

Of the 250 participants, 77% had a mild anxiety score, and 6% had a severe anxiety score. Of the anxiety symptoms, tension was experienced the most often, whereas somatic or muscular pain was experienced the least. Among the demographic variables, marital status, monthly income, and occupational status were significantly associated with anxiety symptoms (Almeshari et al., 2021). Single women (48%), those with lower income (67%), and unemployed women (45%) had a higher prevalence of anxiety symptoms than their married, employed, and higher-earning counterparts. (Almeshari et al., 2021).

An association between PCOS and depression has been demonstrated in many studies; however, in Almershari’s study (2021), 39% of the subjects did not report depression, whereas about 4% suffered from very severe depression. Depressed mood
and psychological anxiety were the two most noted depressive symptoms. In contrast, suicidal ideation was the lowest. This study noted that those participants from Sweden had a seven times higher rate of suicidal ideation than their Muslim counterparts. It is speculated that this may be due to the Muslims’ religious principles that discourage suicide. Also, symptoms such as infertility were associated with depressive symptoms. Those with ethnic and cultural backgrounds where fertility and family are essential suffered from more depressive symptoms than those with different cultural expectations. Therefore, exploring cultural and ethnic backgrounds related to PCOS patients’ mental health should be examined.

Infertility in PCOS is one of the issues that can cause great emotional and psychological turmoil. The inability to maintain or lose weight is a prominent issue among women with PCOS. It can cause the development of eating disorders (Pirotta et al., 2019) and depression (Chaudhari, Mazumdar, & Mehta, 2018). Variations and imbalances in hormones, such as low levels of estrogen and progesterone related to PCOS, can lead to depression and anxiety, which may alter mental and psychological health (Wright, 2017; Goyal & Dawood, 2017).

**Treatment of PCOS**

**Medication**

As far as medical interventions are concerned, numerous approaches can be implemented. PCOS can cause amenorrhea and/or oligomenorrhea due to hormonal imbalance. Therefore, regulation of menstrual cycles using a combination of birth control pills and/or progesterone therapy usually is an initial medication regimen implemented to
promote menstrual cycles and regulation of hormones (Williams, Mortada, & Porter, 2016).

One of the most common medications used to regulate ovulation is Metformin. 
Metformin is a drug that helps control blood sugar levels by decreasing the amount of glucose absorbed from food and the amount of glucose made by the liver. Metformin can indirectly help with ovulation by improving insulin resistance. Once insulin levels are lowered, the hormonal balance may be restored, supporting ovulation. Metformin can also help slow the progression of T2DM and encourage weight loss which could also help lessen complications of PCOS and lower the risk of developing MetS (Kataoka et al., 2017). However, Metformin has adverse effects, such as gastrointestinal upset, lactic acidosis, and increased homocysteine levels associated with atherosclerosis (Williams, Mortada, & Porter, 2016).

Due to excessive testosterone in the blood, some women can develop hirsutism (Barbieri, 2018). There are medication interventions to treat this condition. One medication that may be used is birth control pills, which can lower testosterone production. Another medication that can be recommended is Spironolactone which blocks the effect of testosterone on the skin, thereby reducing hair growth on the body and face (Williams, Mortada, & Porter, 2016). However, Spironolactone is not encouraged for individuals trying to conceive because it can cause ambiguous external genitalia in the male fetus due to its anti-androgenic properties (Enforcement Reports-fda.gov, 2017) as well as other adverse effects such as hyperkalemia, nausea, breast tenderness (Williams, Mortada, & Porter, 2016).
Lifestyle Modifications and PCOS

Treatment of PCOS is usually individualized. The interventions can range from lifestyle changes to implementing medication regimens (Wright, 2017; Goyal & Dawood, 2017). Physicians recommend 30 minutes or more of moderately intense exercise daily (Pataky et al., 2018). One of the simplest yet effective activities is brisk walking, biking, and taking the stairs (Pataky et al., 2018). An increase in physical activity can promote weight loss and improve health complications associated with PCOS (Wright, 2017; Goyal & Dawood, 2017). Research shows that losing 5 to 10% of current weight for those with PCOS can help regulate hormone imbalances and lower blood pressure, blood glucose, and cholesterol levels, lowering the risk of developing secondary conditions such as CVD and diabetes (Kataoka et al., 2017).

The Mediterranean diet, the Dietary Approaches to Stop Hypertension (DASH) diet, and other diets that limit sodium, unhealthy fats such as saturated and trans fats, and added sugars have been proven to promote weight loss and reduce the risk of developing MetS and other conditions (Castro-Barquero et al., 2017). Research reiterates that weight loss of 5 to 10% of current weight could help improve insulin resistance and blood pressure, which in turn can lower the risk of diabetes and CVD as well as MetS which are known complications of PCOS (Pataky et al., 2018). In addition, weight loss diets such as the ketogenic diet and certain foods such as fatty fish rich in Omega 3 fatty acids, whole grains, fruits, and vegetables are recommended to lower inflammation which can worsen PCOS symptoms (Ciccarelli, 2018).
Weight Management for PCOS

One of the most effective treatment strategies for treating PCOS (Kataoka et al., 2017) and MetS for those who are overweight and obese is weight loss (Pataky et al., 2018). Even a moderate weight loss of 5% can positively affect both conditions. Medications that aid in weight loss may be prescribed, but the first step is usually implementing a lifestyle change that involves increasing physical activity and altering one’s diet (Castro-Barquero et al., 2017). There can be multiple dietary approaches that can be used because no one diet is more effective than another because weight loss is an individualized component of the treatment of the condition (Castro-Barquero et al., 2017). Therefore, assisting women with PCOS to find a diet regimen that works with their lifestyle while reducing their symptoms is essential for effectively managing the disease. (Kaur, 2014).

Medication can play a role in PCOS treatment. However, it can only do so much. Diet management is essential when treating PCOS because it may improve fertility, reduce the risk of T2DM and gestational diabetes, and lower the risk of complications from CVD (Wright, 2017; Goyal & Dawood, 2017). Implementing lifestyle changes such as diet paired with exercise can enhance weight loss (Wright, 2017; Goyal & Dawood, 2017) which can improve other symptoms of PCOS (Pataky et al., 2018).

Very Low-Calorie Diet

For PCOS, some people implement a very low-calorie diet due to recommendations made by online sources or by some health care professionals. A very low-calorie diet only allows 800 kilocalories or less per day (Paoli, Rubini, Volek & Grimaldi, 2013). Persons with PCOS who have followed this diet for 12 weeks showed
significant weight loss ($P < 0.0001$) (Paoli, Rubini, Volek & Grimaldi, 2013). Although this diet may be recommended for weight loss, it is intended only for rapid weight loss because it is not sustainable. Prolonged use of this diet can lower metabolism, making it even harder to lose weight (Paoli, Rubini, Volek & Grimaldi, 2013) becomes counterproductive because women with PCOS already have difficulties losing weight; therefore, implementing a diet that could cause the body to retain weight could exacerbate the condition and its symptoms instead of providing treatment.

**Ketogenic Diet**

Many women with PCOS have been prescribed a ketogenic diet (Ciccarelli, 2018). The primary focus of the ketogenic diet is to achieve ketosis. Ketosis is a metabolic state with a high concentration of ketones in the blood. Ketones are formed when the body does not have enough glucose to fuel the cells, which causes insulin to decrease and fatty acids to be released from fat stores. These fatty acids are then oxidized by the liver and converted to ketones to be used as an alternative energy source. The ketogenic diet allows about 30 grams of net carbohydrates (after the fiber is subtracted from total carbohydrates) or 50 grams of total carbohydrates per day while using fats as the primary energy source. When this plan is followed, the body produces ketones which become the primary source of energy instead of the preferred source, carbohydrates (Wright, 2017; Goyal & Dawood, 2017). A ketogenic diet causes weight loss and a reduction of insulin (Wright, 2017; Goyal & Dawood, 2017). In a study of five women with PCOS, a ketogenic diet was implemented for 24 weeks; during this period, women lost an average of 12% of body weight, significantly improved hormone regulation, and reduced insulin levels (Paoli et al., 2013). Unfortunately, long-term sustainability was not
assessed in this study to be able to recommend the diet long term. However, due to the restrictive nature of the ketogenic diet, it can be inferred that vitamin and mineral deficiencies can occur. Also, this diet could increase TC and TG due to the increased fat intake.

In another study, fourteen overweight women with a PCOS diagnosis were placed on a modified Ketogenic diet for 12 weeks to assess the effects on body weight, plasma cholesterol, triglycerides, hyperinsulinemia, and hormonal levels. This diet is known as the KEMEPHY diet and combines the Ketogenic and Mediterranean Diets. The Ketogenic diet lowers carbohydrate intake, which can lead to lower glucose levels and may lower inflammation. The Mediterranean diet, which includes lean meats, nuts and seeds, leafy vegetables, monounsaturated, polyunsaturated fats, and herbal extracts with antioxidant properties, may also lower inflammation and help with oxidative stress (Paoli et al., 2020). Therefore, both of these diets have the potential to lessen PCOS symptoms. The results indicated that after 12 weeks, there was a significant reduction in body weight, BMI, fat body mass (FBM), and visceral adipose tissue (VAT). There was also a slight decrease in lean body mass (LBM). A significant decrease in glucose, insulinemia, triglycerides (TGs), total cholesterol, and Low-Density Lipoprotein (LDL) was observed as well as a rise in High-Density Lipoprotein (HDL) and a significant improvement in Homeostatic Model Assessment for Insulin Resistance (HOMA-IR). The LH/FSH ratio, total LH, and free testosterone were significantly reduced, whereas progesterone, estradiol, and Sex Hormone Binding Globulin (SHBG) were increased (Paoli et al., 2020). The results concluded that the Ketogenic diet might be a valuable treatment for PCOS due to its impact on laboratory values that tend to be elevated in
women with PCOS; however, there is no data at this time that has assessed the long-term effects of implementing the Ketogenic diet for women with PCOS.

The ketogenic diet can also benefit those with MetS (Pataky et al., 2018). Ketosis not only creates the environment for weight loss recommended to treat MetS and PCOS but also lowers blood glucose levels, which can lower the levels of excess insulin in the blood. Thus, weight loss can help treat the elevated blood glucose levels that may be caused by insulin resistance associated with MetS and PCOS. Weight reduction can help lower the risk factors involved with PCOS. Unfortunately, the ketogenic diet is not a long-term solution because ketosis should not be implemented over long periods (Merra et al., 2017).

The ketogenic diet has some disadvantages despite the numerous advantages that are associated with the diet. Due to the ketogenic diet limits carbohydrates restricts a variety of nutrient-dense, fibrous carbohydrates, as well as fruits and vegetables, lean proteins, and healthy fats, which have been demonstrated as an effective strategy in promoting a healthy weight and overall health and well-being (Krishnan, Mehndiratta & Agrawal, 2019). When the body is in ketosis, it burns fat instead of glucose which could lead to the keto flu. The keto flu includes symptoms such as headache, weakness, irritability, and GI symptoms such as constipation, nausea, and vomiting (Krishnan, Mehndiratta & Agrawal, 2019). In specific individuals, the ketogenic diet could also lead to adverse effects on the gastrointestinal (GI) system if followed for extended periods (Krishnan, Mehndiratta & Agrawal, 2019). GI distress may be attributed to the high-fat content of the diet. Also, the ketogenic diet may lead to a higher protein intake which
could cause uric acid accumulation and lead to a condition known as gout (Krishnan, Mehndiratta & Agrawal, 2019).

**Healthcare Costs**

PCOS has a close relationship with infertility due to hyperandrogenism and oligo-ovulation. The prevalence of infertility and women with PCOS varies between 70 to 80% (Melo, Ferriani & Navarro, 2015). PCOS also represents 80% of anovulatory infertility cases. Medications and procedures such as in vitro fertilization and laparoscopic ovarian drilling are treatment options for those wanting to become pregnant (Melo, Ferriani & Navarro, 2015). Rates of the fertility of those of color it affects may vary among racial backgrounds. Research does not report a percentage, but it suggests that black women have a lower likelihood of getting pregnant and do not have as much success with In-Vitro Fertilization (IVF) compared to their white counterparts (bwhi.org, 2017).

In 2019, the global PCOS treatment market was worth $3.83 billion, with North America accounting for most of this revenue (prnewswire.com, 2020). The lack of drugs approved by regulatory bodies such as the FDA in many countries hampers the growth of the PCOS treatment market. Some treatments included in their markets are medications such as oral contraceptives, ornithine decarboxylase inhibitors, insulin-sensitizing agents, antidepressants, diuretics, and aromatase inhibitors. Procedures such as ovarian wedge resection and laparoscopic ovarian drilling are also a part of this market (prnewswire.com, 2020). The increasing healthcare costs related to PCOS increase the need for better screening and implementing other treatment options, which help reduce
healthcare costs and lead to long-term solutions for the treatment of PCOS, as well as preventing health complications associated with the disease.

**PCOS and Racial/Ethnic Differences**

PCOS affects 1 out of 10 women in the United States. Although this has been noted, it is vital to assess the difference that race and/or ethnicity play in PCOS prevalence. In a study that prospectively estimated the prevalence of PCOS using diagnostic criteria, there was a PCOS incidence rate of 6.5% among Whites. However, the study was not randomized, so it is unlikely to represent all populations. However, differences in the geographical locations of White women do not appear to affect the prevalence of PCOS (Wolf et al., 2018).

The current literature suggests that the prevalence of PCOS may vary between races and ethnicities. In Hispanic women, there have been various studies conducted about prevalence. In one study, there was a 6.0 to 6.6% prevalence using the Rotterdam criteria. This tool requires two conditions: oligo/anovulation, hyperandrogenism, or polycystic ovaries on ultrasound. (Wolf et al., 2018). This tool was used to obtain a homogeneous group of Mexican women in Mexico City. However, the sample was small, and the results were skewed. According to another study, the prevalence of Mexican American women living in Los Angeles was approaching 13%, likely due to co-founding factors such as the family history of coronary artery disease and other health issues (Wolf et al., 2018).

There is contradictory evidence regarding the prevalence of PCOS and Black women compared to White women. In a study that included a sample size of 369 women in the Southeastern part of the United States, a comparison was made between White and
Black women between the ages of 18 and 45 living in Alabama. Black women had a 3.4% PCOS prevalence, whereas Whites had a 4.7% prevalence. Other studies examining this data using the same database found no significant difference between the PCOS prevalence of 8% for Black women and 4.8% for White women in Alabama. The 2017 Chan et al. study conducted a national comparison of White and Black women in the United States. The results showed a much higher prevalence of metabolic syndrome in Black women with PCOS. However, when adjustments were made for age, the BMI (obese) prevalence was similar. Therefore, even with the most current research, there is no potentially significant difference between Black and White women in the United States with PCOS (Wolf et al., 2018).

Although some research has produced contradictory results, it is still essential to look at racial and ethnic backgrounds when dealing with those with PCOS due to increased risk for other metabolic conditions and health disparities. PCOS has significant public health importance since some women can develop MetS, T2DM, and/or CVD when left untreated. Blacks and Hispanics have a higher morbidity and mortality rate in the general population due to CVD and T2DM. Since MetS is a known risk factor for the progression of CVD and T2DM, understanding the prevalence of MetS by race and ethnicity in women with PCOS is vital in targeting relevant populations for early prevention and treatment (Engmann et al., 2017).

Hispanics have a significantly higher prevalence of hyperandrogenism, hyperglycemia, and low sex hormone-binding globulin than non-Hispanic Whites. Black women have a milder PCOS phenotype than Hispanics in some respects (such as having lower rates of metabolic syndrome and triglyceride levels) and non-Hispanic Whites
Black women also have an increased rate of hirsutism and a higher risk of CVD or MetS., and a lower likelihood of getting pregnant. For example, studies have shown that Black women do not have as much success with in vitro fertilization as white women, and they are also more likely to be obese, which is also a risk factor for infertility (bwhi.org, 2017).

Although women of color have different health disparities and comorbidities that may play a role in their PCOS diagnosis and symptomology, they are still underrepresented in magazines and social media (Sanchez & Jones, 2016). A research study showed that magazines portray PCOS symptoms as a hindrance to women’s social roles as wives and mothers and place the responsibility on women to improve their health so that their symptoms may improve. (Sanchez & Jones, 2016) To a lesser extent, women have not received recognition for using their experience with PCOS to advocate for women’s health. For those of African American and Latino descent, their experiences are essentially non-existent even though these populations have a higher morbidity and mortality rate associated with PCOS. Their experiences were not depicted in magazine articles (Sanchez & Jones, 2016) which validates a need for the representation of women of color with PCOS in the media to promote change and improve clinical outcomes in PCOS and comorbidities. No official data depicts the percentage of women of African American and Latino descent diagnosed with PCOS. However, it is the most common endocrine disorder that affects women of reproductive age. More depictions of Women of Color with PCOS in the media may help bring awareness to these populations to recognize symptoms so that they may seek help promptly.
According to the Women of Health Data Book, it is essential to inform healthcare professionals, researchers, biomedicine, and health policy about the unique health features of women of color (Women of Color Health Data Book, 2015). This includes but is not limited to these women’s biology, genetics, culture, behavior, and access to care. It is crucial to understand and recognize different patterns of health disparities among this population. Socioeconomic and employment can significantly affect access to health insurance and health care. Hispanics and Blacks are more likely than non-Hispanic whites to be among the workers who earn low pay because of this job position (Women of Color Health Data Book, 2015). Therefore, Hispanics are more than three times likely as non-Hispanic whites and nearly twice as likely as Blacks to be full-time workers yet lack health insurance (Women of Color Health Data Book, 2015). The lack of health insurance inherently limits this population’s access to adequate health care, which could be detrimental due to their heightened risk of developing chronic health conditions.

**Religion and Spirituality**

To better understand the experience of women of color with PCOS, it is also essential to explore their religious and spiritual beliefs. Religion and spiritual practices are usually an integral part of the culture. For many, their faith provides them the strength to endure challenging times. For example, “in a nation and society ripe with legal and social racial segregation, Black churches and homes have offered powerful social and religious spaces where Blacks could have control over their daily lives” (Clark, 2017).

According to Merriam-Webster, religion is “a personal set or institutionalized system of religious attitudes, beliefs, and practices and/or “a cause, principle, or system of beliefs held to with ardor and faith.” These beliefs vary among religions, cultures, and
communities. Based on the US 2020 Census, Christianity is the most prominent religion of Black Americans, Hispanic Americans, and Native Americans. A majority of each of these racial/ethnic groups identify as Christians: Black Americans (72%), Hispanic Americans (76%), and Native Americans (60%). From Christianity the two major subgroups from this data are Protestant and Catholicism. Protestant makeup is as follows: Black American (63%), Hispanic American (24%), and Native American (47%), and Catholicism makeup are as follows: Black American (7%), Hispanic American (50%), and Native Americans (11%). As for Asian Americans, 34% are religiously unaffiliated, and 34% are Christian (20% Protestant and 10% Catholic). Other religions/spiritual beliefs that were mentioned were Hinduism, Buddhism, Judaism, and Islamic/Muslim religion.

The article “A Woman’s Work: Roles of Women in World Religions” discusses women’s traditional roles in several of the world’s religions. According to this article, women’s primary responsibilities, aside from Judaism, encourage women to have children, build a family, and tend to that family. These roles could be an issue when members of these religions have PCOS because infertility is one of the main symptoms (Infographic, 2016). Considering that infertility is a common result of PCOS and that many religions focus on child-rearing, it is important to understand the dynamics of different religious stances on assisted reproductive therapies. Among various religions, there are varying views on assisted fertility treatments. For example, Catholicism has guidelines that all forms of assisted reproduction, including intrauterine insemination (IUI), in vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI), embryo transfer (ET), and surrogate motherhood, are not accepted. Protestantism has varying
beliefs on IVF because there are no ethical guidelines to follow (Sallam & Sallam, 2016). Therefore, treatment options may be welcomed or frowned upon based on preconceived notions. It is essential to know these stances to understand potential barriers to treatment plans and the psychological effects that religion and infertility can have on patients.

With religion and spiritual beliefs playing an important part in the household of many ethnic cultures, the traditional expectations of fertility can cause stress on women with PCOS. Studies show that ethnic and racial minorities, including Black and Hispanic women, experience infertility significantly more frequently than their White counterparts and are less likely to receive infertility treatment. (Siegel et al., 2021). This could be related to the health disparities that commonly plague these communities, such as lack of fertility awareness, cost of fertility treatment, and distrust in healthcare professionals. However, it should be noted that religion can play a significant role in how infertility is perceived by different cultures and what treatments are sought.

Many religions encourage fruitful and multiplying, but the scriptures do not consider current problems such as infertility. These religions usually focus on dealing with medical conditions through faith. Although faith is important, there comes a time when medical intervention may become necessary. Medical treatment such as infertility could be frowned upon, causing people not to seek help. In addition, shame associated with not being able to conceive may hinder treatment and significantly impact their physical and mental health. Further, this could alter a woman’s outlook on her femininity and overall position of importance in her family dynamic.
Cultural Aspects of Diet

There are over 8.7 million African American families in the United States, with the largest populations being in New York, California, Texas, Florida, Georgia, Illinois, North Carolina, Louisiana, Michigan, and Maryland. The African American diet is heavily influenced by traditions that enslaved Africans started in the 1600s (foodbycountry.com, 2020). Enslaved people brought several different types of food, such as okra, sesame seeds, peanuts, black-eyed peas, and rice, as well as various cooking styles. Enslaved people were given only a small portion each week, so they learned how to make dishes using pork, cornmeal, and vegetables to extend their dishes. African heritage is reflected in a unique ethnic cooking style called “soul food.” Some foods that African Americans eat during meals are collard greens, hush puppies, sweet potato pie, red beans and rice, potato salad, barbecue, baked macaroni and cheese, fried apples, tomato cucumber and onion salad, fried bologna, grits, and more (foodbycountry.com, 2020). Many of these meals may be inexpensive but can have a negative impact on health because most of the foods are cooked using saturated fats, sodium, and sugar, which has been linked to higher rates of obesity, CVD, T2DM, and MetS.

The Hispanic/Latino population is the largest growing population in America. Traditionally, they eat dishes such as chili, fajitas, salsa, tortillas, chimichangas, quesadillas, burritos, nachos, enchiladas, tamales, sweet bread, and more. These foods are typically cooked using fresh ingredients such as guacamole, onions, chiles, spices, and lime juice rather than sodium (lifeintheusa.com, 2020). However, many of these foods have a high carbohydrate content which is associated with increased rates of obesity,
T2DM, MetS, and exacerbation of PCOS symptoms. Also, many of these foods are prepared using saturated fats, which could lead to a higher risk of CVD.

**Qualitative Research and Phenomenology**

Research involves the detailed study of a subject to truly understand it and their experiences of these subjects so that new insight can be gained about a particular phenomenon. To maximize the effectiveness of feedback, clinical reasoning, workplace-based learning, or any other myriad of phenomena, researchers need to be able to carefully explore and learn from the experiences of others (Neubauer, Wiktop & Varpio, 2019). This type of qualitative research is not extensively followed because, to truly understand phenomenology, it requires the development of an appreciation for the philosophies related to the human experience. The researcher is to become familiar with the philosophies and interpretations of the human experience, which can be daunting. The goal of phenomenology is to describe the meaning of the experience, which includes what the experience is and how this experience is (Neubauer, Wiktop & Varpio, 2019). Phenomenology is commonly described as the study of phenomena as a manifestation in our experience, the way we perceive and understand phenomena, and the meaning of phenomena in our subjective experience (Neubauer, Wiktop & Varpio, 2019).

**Reliability and Validity**

When identifying the context of the experiences of the members of a particular group, it is important to find consistency. However, individuals within a cultural group may have different experiences and perceptions. This does not make them wrong or invalidate the research, but it offers insight into the complexity of the research study (Hammarberg, Kirkman & de Lacey, 2016). In qualitative research, the researcher needs
to defend the integrity of their work by different means, which include trustworthiness, credibility, applicability, and consistency as their evaluative criteria (Hammarberg, Kirkman & de Lacey, 2016).

**Research Purpose**

This study aims to describe the unique experience of women of color diagnosed with PCOS, assess the strategies they have used to manage their condition, and document the difficulties they have endured while seeking medical treatment.

**Hypotheses**

Three hypotheses are tested in this study.

Hypothesis 1: Women of color will have similar healthcare experiences in relation to PCOS.

Hypothesis 2: Women of color will have similar strategies to manage their condition in relation to PCOS.

Hypothesis 3: Women of color with PCOS will have similar barriers when seeking medical treatment.
CHAPTER 3

METHODS

This chapter describes the research design and methodology for the study. A description of a qualitative research design will be explained as well as phenomenology. The procedure for data collection and analysis will be defined, and an explanation of the guiding questions to support this study will be provided.

Research Design

Qualitative Research and Phenomenology

This study will use a qualitative research design. Qualitative research is usually used to answer questions about an experience and assign and describe a perspective of an event of a selected group of people (Hammarberg, Kirkman & de Lacey, 2016). Although quantitative data is numerical and objective, qualitative data is recognized for adding a new dimension to studies that cannot be obtained through the measurement of variables alone (Pathak, Jena, & Kalra, 2013). Conducting interviews allows the participants to share their experience of an event which can reveal potential issues that may not have been voiced before. The purpose of choosing this research design was to gain insight into the experiences of those who do not have access to communication.
Reliability and Validity

Reliability and validity are two key considerations in all research (Cypress, 2017). Due to the nature of the qualitative research design, reliability is often challenging to achieve, and replication is not always possible. Explaining phenomena will vary according to cultural significance. Cultural groups may be part of a country, a community, or virtual groups (Hammarberg, Kirkman & de Lacey, 2016).

Investigator Triangulation

Triangulation is a method that adds depth to the data being collected. It does this by collecting data from multiple sources, a unique way to mitigate bias and enhance research data saturation (Fusch, Fusch & Ness, 2018). For this specific study, the experience of Black women with PCOS and comparing those experiences to other women of color and their White counterparts was examined. Therefore, using multiple methods to study this particular phenomenon is beneficial. The combination of qualitative and quantitative methods can be used to answer a specific research question. This may result in 1) May converge and if results to the same conclusion; 2) Results related to different objects or phenomena being complementary and 3) Results being contradictory. The overall purpose of using triangulation in this study was to add to the overall richness and validity of the research and see if any common themes were apparent among the subjects with their race/ethnicity being a commonality.

Objective

There are four main objectives considered in this study.

1. Describe the symptoms of women of color with PCOS before seeking medical treatment.
2. To describe healthcare experiences of women of color with PCOS concerning:
   - treatment options offered
   - the prognosis for becoming pregnant
   - payment of services
   - the demeanor of healthcare practitioners towards patients during the initial visit and after that

3. To describe and assess the strategies that have been used to manage their condition with:
   - medication regimen
   - diet
   - exercise
   - counseling
   - support groups

4. Describe the barriers women of color with PCOS have had in seeking medical treatment.
   - Cultural Relations:
     1. Food and diet barriers
     2. Family support
     3. Healthcare access
     4. Healthcare availability
**Study Population, Sampling Design, and Method**

Due to the extensive interviews provided by this qualitative research design, it was suggested to have a limited number of participants (between 6 and 10). Therefore, the selection was purposeful because the primary purpose of conducting a phenomenology study is to describe the lived experiences of the participants (Neubauer, Wiktop & Varpio, 2019). All participants were interviewed via video call. The interviews were recorded and then transcribed to create Microsoft Word files for the interviews.

Eligibility requirements for participation in the study included:

- Having a PCOS diagnosis
- Be between the ages of 18 and 50 years
- Experience at least one of the following PCOS symptoms: amenorrhea, oligomenorrhea, excessive body hair, facial hair, acne, or other PCOS-related symptoms

The researcher recruited these participants via social media PCOS support groups.

**Procedure**

An application for permission to conduct this qualitative study was submitted to Louisiana Tech University Human Use Committee. There were no physical or social risks associated with this study. There may have been minimal psychological risks associated with participation related to emotional feelings that the participants may have regarding symptoms and challenges associated with infertility and other experiences that may be difficult to discuss. Before participating in the study, each participant was asked to sign a consent form, which outlined the exact nature and methodology of the study. In addition, each participant was given the right to leave the study without any penalty.
To minimize this risk, the researcher reminded the participants that they had the right to withdraw from the study at any time without any consequences. The participants received a $25.00 gift card for participating in the study. Data collection began after written approval was received from Louisiana Tech University’s Human Use Committee. Confidentiality of the participants were maintained by using fictional names only the researcher could identify. Before each interview, the participants received a consent form and the researcher advised the participants of their right to withdraw from the study at any point during the interview process.

**Setting**

All interviews were scheduled by the researcher and conducted using video call or a location agreed upon by the researcher and participant. Interviews were conducted only with the subject and the researcher so that privacy and confidentiality were ensured. Interviews occurred separately and each participant was interviewed once. Data was collected via video recording of one-on-one interviews with the participants. The following guiding questions were utilized to orchestrate the interview.

**Instrumentation and Data Collection**

After agreeing to participate in the study, a link was sent to each participant to complete a survey which included 27 questions that inquired about: anthropometrics, mental health, religion/spirituality, insurance status, and demographics such as socioeconomic and educational level and race/ethnic background. Upon notification that the survey was completed, the researcher scheduled a private zoom meeting with each participant to conduct an interview.
An interview with 27 questions and follow-up questions for total of planned questions were asked to the participants, these questions allowed them to describe their PCOS journey from diagnosis to the time of the interview and gathered their perspective on their healthcare, education, treatment, and experience based on their racial and/or ethnic background. All participants in this study remained anonymous by being represented by initials and their files were only accessed by the investigators and were destroyed after the experiment.

**Role of the Researcher**

The researcher is a Black woman who has been diagnosed with PCOS for approximately eight years. Her treatment included receiving oral medications such as birth control to regulate menstruation. This experience allowed the researcher to have an understanding of the potential hardships and emotions of the participants. The researcher documented the behaviors of these participants throughout the interview. These observations along with the answers provided from the guiding questions were documented as field notes using paper and pen. These field notes were later transcribed using Microsoft Word software.

**Data Analysis Plan**

This qualitative research study used Grounded Theory analysis for the statistical analysis plan. Grounded Theory-based analysis generally analyzes data by finding repeating themes by thoroughly reviewing the data; coding the emergent themes with keywords and phrases; grouping the codes into concepts through relationship identification. Then the categories created through this process and the links found between them are used as the basis for the development of a new theory.
CHAPTER 4

RESULTS

Purpose

The purpose of this study was to describe the unique experience of women of color (notably, Black women) that have been diagnosed with PCOS, assess symptom management for their condition, and examine their experiences while seeking medical treatment. Additionally, the data was compared and contrasted to highlight the differences each participant has had in coping with their PCOS condition.

The recruitment flyer was uploaded to social media platforms and PCOS support groups to recruit participants. Recruitment lasted three weeks and 10 participants were chosen.

Each zoom meeting was reserved for an hour and a half but most meetings were concluded within 15-40 minutes. Before each interview, it was reiterated that the interview would be recorded and transcribed within 24 hours for analysis purposes while keeping each participant’s identity anonymous. The participants were again reminded that they could withdraw from the study at any time without penalty. The interviews were conducted using pre-prepared guiding questions that inquired about age, PCOS diagnosis journey, experience with health care practitioners, medication regimen and compliance, and their perspective on similarities and differences of PCOS experiences based on
race. Data was analyzed using triangulation which was used to tease out any common themes across the participants as well as validate the content collected. Table 1 outlines the demographics of the study group.

**Table 1**

*Demographics of PCOS Participants (N=10)*

<table>
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<td>20</td>
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<td></td>
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<td>20</td>
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<td></td>
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<td></td>
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</table>
The researcher attempted to enroll participants that representing different races/ethnicities that included not only Black women but also women who were Hispanic, Latino, Spanish, Pacific Islander, and Asian. Unfortunately, the people who agreed to participate were only White and Black women. So, five (50%) of the participants reported being Black and five (50%) reported being White. The participants were from varying regions of the country (Arkansas, Georgia, Louisiana, Missouri, North Carolina, Ohio, and Texas) which may have influenced their experiences and resource access and availability. The age range of the participants was 22 to 38 years and the average age was 28.4 years. An important struggle for most women with PCOS is weight. Therefore, the reported weight and height without shoes were collected to determine each participant’s BMI. All of the participants had a BMI >30 with an average of 44.5. In addition, half of the participants reported being married whereas the rest reported never being married and/or being a part of an unmarried couple. All participants reported having health insurance.

Themes

Each interview was transcribed within 24 hours of completing the interview. The data collected was triangulated by the researcher, the faculty research chair, and two additional healthcare professionals who are Registered Dietitians. The themes identified by each reader were compared. Presented below were the most common themes noted amongst the participants.
Age of Diagnosis

When diagnosed with PCOS, patients seem to start showing symptoms either before or during puberty (Tsikouras, 2015) but may not be officially diagnosed until much later. This was the case for many of the participants as 7(70%) did not receive a formal diagnosis until they were over 18 years of age.

WW3: “I always knew something wasn’t right. Ever since that...you know...and I got my first period...I think I was like nine. I can’t even remember that far back. But, um, I never really had regular periods. But I didn’t really get the diagnosis of PCOS until I was in my 20s”

One participant even voiced that had she been diagnosed sooner that she would’ve been better prepared to manage her PCOS symptoms.

BW2: “It would have given me the time...you know what I mean? And the ability to gain the knowledge about the diagnosis...that I could have probably curved a lot later on. But just finding out, you know, later into my 20s...after I’ve already had years of irregular cycles and just on and off weight gain and loss and things of that nature...

Symptoms

Eight (80%) of the participants had irregular periods, some of which were so painful, it led to emergency room visits and hospitalizations. Some of the participants expressed that the pain was so intense that they were debilitated by not being able to walk or talk and even ran the risk of becoming septic.

WW4: “I would say like, typically it’s probably on a scale of one to ten and... It’s probably like a six or a seven, like consistently but there’s been times where I actually
went to the ER because I’m falling over in pain, and like, could barely walk and things like that just because I’m hurting so bad”.

WW1: “But when I was 19, I had a cyst that burst. And I ended up in the ER because of pain and had to have antibiotics intravenously to ward off sepsis. And that is actually when I was...a... when I was...got the first bit of that...being diagnosed with PCOS”

WW5: “And it wasn’t until I was 16 that I had one morning... I knew that I was about to start my period and I got super nauseous like I always did... And it was a Sunday. So, I would like...told my mom I don’t think I could go to church, I don’t feel well. I’m glad that I did that because not even like an hour later I had a stabbing pain in my stomach...and I couldn’t like even talk or walk or anything. I crawled to my mom. And it turns out she thought my appendix ruptured, but it was an ovarian cyst that burst. They said it was probably the size of like a baseball because of how much blood was in my abdomen. But then...the ER...So my mom took me to the ER and stuff. And she got me, thankfully, rushed in - Like because she’s a nurse and has been an ER nurse -- or has been an ER nurse at one point. So, they got me on pain meds immediately and immediately got me into a CT scan and saw that it was not my appendix, but an ovarian cyst.”

The symptoms reflected in Table 2 were expressed the most by the participants during the interview.
Table 2

Symptoms of PCOS Participants (N=10)

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Responses</th>
<th>Composite (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>White n (%)</td>
<td>Black n (%)</td>
</tr>
<tr>
<td>Irregular Periods</td>
<td>4 (80)</td>
<td>4 (80)</td>
</tr>
<tr>
<td>Heavy Periods</td>
<td>2 (40)</td>
<td>2 (40)</td>
</tr>
<tr>
<td>Pain</td>
<td>4 (80)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Hair Growth</td>
<td>1 (20)</td>
<td>3 (60)</td>
</tr>
<tr>
<td>Acne</td>
<td>1 (20)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Weight Gain</td>
<td>1 (20)</td>
<td>2 (40)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>1 (20)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Issues/Anxiety/Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormonal-related</td>
<td>0 (0)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Emotional Issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GI-related Symptoms</td>
<td>2 (40)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Headaches</td>
<td>1 (20)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Hormone-induced tumor</td>
<td>0 (0)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Discoloration of skin on chin</td>
<td>0 (0)</td>
<td>1 (20)</td>
</tr>
<tr>
<td>Lethargy</td>
<td>0 (0)</td>
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</table>

Although not all the participants discussed having the same symptoms, most did admit to having pain as well as heavy and irregular periods. Additionally, some reported experiencing challenges with unwanted hair growth and weight gain, GI issues, acne, and mental health disturbances.

Treatment Options

Participants mentioned that their doctor’s visits were not very helpful and that treatment options were limited and lacked personalization. Weight loss and medication were commonly recommended interventions for the participants. The discussion of medications offered by the participants appeared to center around being prescribed birth control as they were a common treatment offered to the PCOS participants. Of the participants, seven (70%) were prescribed birth control pills. However, only one (10%) found this effective in managing her symptoms.
BW1: “Yeah, I mean, it did its job. It did its job. So, I have my period and everything...and yeah, like I said, I didn’t really deal with...like...acne that much in high school. So that was never really something where I saw like a physical result, but I knew that I would get my period.”

Six participants (60%) felt this intervention was not helpful due to side effects and essentially had no impact; in some cases, the participants provided no reason.

WW3: “Okay. The first doctor that I went to see, I told her about my problems, but she just assumed—“let me just put you on birth control”. Which, the birth control made me far worse. It made me physically ill; I threw up all the time...and finally decided... You know what, I’d rather just deal with it like it is.”

Metformin, a medication prescribed for regulating blood glucose levels, combating insulin resistance, and assisting with weight loss was recommended as another treatment option for 4 (40%) of participants. Metformin was discontinued by the participant or healthcare professionals for all 4 (40%) participants due to side effects, 2 (20%), was not continued because of not providing improvement 1 (10%), or discontinued by the healthcare provider because it was not needed 1(10%).

WW3: “One of my doctors put me on Metformin. He claimed it...it might help. But my digestion system’s kind of funny. And then they tell you, it takes a while to get used to Metformin. And I used to have to plan when I left the house, and not because I have... My stomach would just be like “Nope, you gotta use the bathroom and it ain’t gonna be pretty”, right? *laughs* So he eventually took me off of that, because it was like 6 months... And he was like “obviously, your body’s not going to adjust at this point, if it’s still happening.”
Other medications that were prescribed to help treat PCOS symptoms were used to address anemia (iron), pain (800 mg Ibuprofen), Gastrointestinal symptoms (Miralax and Prilosec), hormonal imbalances/deficiencies (Progesterone and testosterone), Spironolactone (hirsutism), and anxiety and depression (Sertraline, Vyvanse, and Adderall).

Although supplements were not offered to all of the participants, one (10%) participant reported that she was recommended to take specific supplements to aid in weight loss. When asked what these supplements were, she was unable to recall the name of the weight loss supplements.

Finally, of all the interventions reported by the participants from healthcare providers, pregnancy appeared to be an option that may relieve some mental anguish over the struggles associated with PCOS.

WW1: “No. I...in passing doctors have been like, “oh well when people...when women are...were pregnant, a lot of times they have...they don’t have the symptoms of PCOS”. And I was like, “don’t want that”. *chuckles* and they’re like, ‘well, it’s also a little more difficult to have kids with PCOS ... Sometimes’ I’m just like, *confused look.*”

**Body Fat Discrimination**

Many overweight and/or obese patients feel a sense of fat discrimination or shame during doctor’s visits due to the stigma associated with obesity; thus, one side effect of PCOS is increased focus on body weight by healthcare practitioners and may cause the PCOS patients to feel a sense of alienation and humiliation (Phelan et al., 2015). Five (50%) participants felt that their size was a major focus of their healthcare practitioners
when discussing their PCOS symptoms. Many of the participants were told that their weight was the main culprit of this condition and most of their doctors recommended weight loss only as a way to manage the condition without listening to any other concerns and/or testing for any underlying conditions.

WW1: “it was always “because of your weight, it’s going to be harder, it’s going to...that’s what makes it irregular.” And it was never paid attention to the fact that my pain was always downplayed”...”That I didn’t matter. That nothing...it didn’t matter what I said or how I was feeling ‘cause it was always going to be my weight or it was going to be because I just have a low pain tolerance and “cramps are normal”. And that as long as I lost weight, everything would be fine. It would be the magic cure-all.”

The practitioner’s focus on weight and weight loss caused frustration for one of the participants because she felt that her body size led to dismissiveness in her PCOS-related care.

WW4: “Now, I feel like if you’re not of a small stature, that’s always...they write you off, write you off, write you off, right? And it’s like “Hey, can I get help too”, you know? “...”I was coming 19-year-old, 20 years old. And I’m just like, dang, all my life doctors are supposed to help you. And here I am. And all they’re telling me is “Oh, you’re fat, you need to lose weight.”

Some of the participants mentioned that even though their healthcare practitioners mentioned that their weight was a major contributor to their PCOS symptoms they offered discouraging words related to losing weight.

BW2: “My doctor at the time did tell me—um, she was...had very little bedside manner ...told me at that point, you know, you probably won’t be able to lose weight. So,
you probably want to think about the surgery, and also told me that I probably would have a hard time conceiving and that was all I left the doctor knowing about PCOS.”

In one instance, one of the participants was even told that trying to lose weight was a lost cause for her.

WW3: “Well, if you have PCOS, you’re not going to lose weight. So, you might as well not even try” and I was like, okay, man, now you really made me feel unmotivated, right? That’s worse than telling me you know, “you need to lose weight” because you told me not to even bother because you can’t do it. So, you know, I’ve always had some weird relationships with...with doctors.”

However, one patient mentioned that since her healthcare practitioner did not fat shame her and because she felt encouraged and supported, she felt that she could manage her weight.

WW5: “Like he was never blaming me for anything and helped me feel empowered, which was nice as a 16-year-old girl...especially in the south, where, you know, like doctors will...a lot of the time fat shame you and make you feel...especially anything to do with reproductive health is your fault.”

Dismissiveness/ Symptom Triage

In terms of dismissiveness, six (60%) participants reported experiencing disparaging remarks by their healthcare providers when it came to their PCOS-related symptoms. One participant expressed that after experiencing inattentiveness from her gynecologist about her concerns, she now feels more inclined to take the advice from her current doctor that listens to her and takes her complaints and health concerns into consideration.
WW3: “To have a doctor that I feel like at least listens to me, I will take what the doctor says, and I’ll take their advice, but I feel like so many doctors just didn’t listen to what I was saying. Or, at least take it into account.”

However, when they voiced their concerns to their healthcare practitioner, most felt demeaned before being diagnosed with PCOS as well as after a formal diagnosis.

BW4: “Oh, I will say it was like... It was very dismissive. It was like one of those things where you know, “Hey, you have this and in order to make it better, or make it go away, it’s just...it’s like lose weight”, and it’s like, “Well?” *shrugs.*

BW5: “The gynecologist didn’t really... Didn’t really listen. It was like a...I don’t know. Like a male gynecologist. He didn’t really like listen, he was like, “Oh, no, you’re fine.” But that’s it.

In some cases, some of the participants had outward symptoms of PCOS but were not diagnosed for quite some time. This was the case for the majority of the participants, 7 (70%). One participant indicated that this led to years of dealing with the symptoms such needless pain and discomfort.

WW1: “Um, so I was finally diagnosed when I was 19. So, after eight, seven or eight years of dealing with this, and even before that, it was always “because of your weight, it’s going to be harder, it’s going to—that’s what makes it irregular”. And it was never paid any attention to the fact that my pain was always downplayed.”

One participant mentioned that they were diagnosed well into adulthood (between 23 to 25 years of age) and voiced that she felt if healthcare practitioners had intervened earlier that she may have been able to become more knowledgeable and better adjusted to living with PCOS, and therefore better able to prepare for her future.
BW2: “And so, I feel like earlier on had I had a doctor who at least would even look into it...once I began to gain the weight. You know, once you could see the discoloration in my face, the patience... had just...having somebody to say, “well, let’s just test for this” to see if I would have someone to say at 13 or 14, like “Hey, you have this condition we can get ahead of it while you’re still young.”

One participant reported that after her diagnosis, the practitioners pushed her into choosing birth control as her primary treatment option despite it going against her reported personal beliefs.

WW4: “Nope, but keep, they push me - almost like trying to convince me like, “Oh if you get on birth control”, “if you get on birth control”, “if you get on birth control”, and they don’t truly listen to my reasoning as to why I don’t want to do that. So instead of giving me like a secondary option, it’s like “Well, it’s either this or this.”

Poor Guidance

When asked how satisfied they were with the health care they received, 6 (60%) of the total participants reported being either very satisfied or somewhat satisfied and 4 (40%) total participants reported not being satisfied at all. When asked if the doctors and nurses were helpful, 3 (30%) participants reported that the doctors were helpful whereas 7 (70%) reported that they were not helpful.

One of the participants reported that she received no help or guidance but at least received comfort.

BW4: “Oh, I don’t feel like they were very helpful. I will say, they were very, like comforting, but not necessarily helpful. Like, not really giving me any alternatives or anything like that. But they were very comforting.”
Another participant voiced that after her diagnosis, she received no further information and guidance and therefore were not very helpful.

**BW5:** “I would say they maybe...they weren’t that helpful just because I was diagnosed but like, I didn’t really get any... too much help after that. Like it was just like, “Oh, you have this” and that was pretty much it. Like I really didn’t know... You know, what to do after that. Or you know I don’t have any like next steps, I guess.”

As mentioned, weight loss has been suggested to decrease PCOS symptoms. When many patients are overweight or obese, they are often encouraged by healthcare professionals to lose weight. Bariatric surgery was suggested to 1(10%) participant by a healthcare provider.

While weight loss was the second recommended strategy for managing the symptoms of PCOS, most participants did not get clear instructions on how to execute this intervention.

**WW1:** “I was not...no. Other than losing weight. And that...that was only...that losing weight was the only... It was only recommended to lose weight. Never given any “Hey this what I recommend. This is getting you in touch with a nutritionist” or anything like that. It was only “Hey you should lose weight...Lose weight. Just work out some.”

One participant even mentioned that due to the lack of guidance, she had to take matters into her own hands by managing her PCOS on her own.

**WW4:** “Other than lose weight? No. *chuckles* No, like everything I’ve learned. I’ve just had to manage on my own and kind of figure out things through, like, trial and error.”
One participant voiced that she was never given any detailed information about
PCOS or how to manage symptoms. This led her to seek information on her own by way
of her community.

**BW2:** “And no one ever went in-depth, no one ever had that sit down
class conversation where they were able to like just very concretely detailed to me what it
actually was and how it affects the body. You know, what I could look forward to... What
I might need to look into a little bit more, none of that came”...”But the truth is, most of
what I know about PCOS has not come from, you know, medical professionals. It has
come from my own research... From my own community of people who also have the
diagnosis and everybody just sharing like information.”

One participant detailed that she was fairly young at the time of diagnosis and was
told she had PCOS during an OBGYN appointment. However, she received little to no
information or guidance about the condition and this led her to seek information from
outside sources. She indicated that what she has learned about PCOS through social
media platforms.

**BW3:** “I had to have been 17, freshman year college. Going to the OBGYN for
the first time. Yeah, for the first time. And just getting told, “oh you have PCOS. Here’s
birth control”. That’s it. I didn’t get no pamphlet. I didn’t get a “this is why this is
happening”. You know, all these feelings you’ve been feeling are validated because of
this, yada yada--like nothing. Nada. I had to go Google myself and even that was broad
because it’s not like me personally”...”But there’s just a lot of cool people who, I guess,
are just fed up and have the platform to kind of help the rest of us figure out what’s going
on. Which has been definitely more... What’s the word I’m looking for... Reachable, more accessible... Then getting help from healthcare people.”

One of the participants indicated she was not given clear instructions on how to lose weight or manage her PCOS symptoms, but she chose to try a multi-level marketing intervention that was not a part of a work-site wellness program. She reported that this intervention caused her to drastically limit Calories and portion sizes which lead to disordered eating behaviors.

WW5: “I would like almost get light-headed because I wasn’t eating enough. And it would definitely ... went more into honestly, I think eating disorder territory than anything”

Most of the participants were not only not given instructions by the doctors for weight loss 7 (70%), but many were not referred to a Registered Dietitian who is best trained to assist individuals with weight loss. Presented in Table 3 are the questionnaire results that are reflective of the participants’ responses about Registered Dietitians.

Table 3

Referrals to a Registered Dietitian (N=10)

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<tr>
<th>Survey Question</th>
<th>Responses</th>
<th>Composite</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>White Women</td>
<td>Black Women</td>
</tr>
<tr>
<td>Referred to a Registered Dietitian</td>
<td>1 (20%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Presented with the option to visit a Registered Dietitian</td>
<td>2 (40%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Not referred or presented with the option to see a Registered Dietitian</td>
<td>2 (40%)</td>
<td>5 (100%)</td>
</tr>
</tbody>
</table>

As previously mentioned, only one participant was referred to a Registered Dietitian and that participant stated that the RD was not helpful. Her rationale was that
the diet recommendations were more centered around general healthy eating and were not tailored to her individual needs, lifestyle, and preferences.

WW3: “I was. I don’t…I didn’t find her very… I went a couple of times. And that was like…I pretty much…I get what you’re telling me. And it wasn’t really helping me. She was telling me don’t eat processed foods. I’m like, well, that’s great. But I can figure that out on my own. Yeah, it wasn’t…it wasn’t…You know, like I would… she had me fill out like a menu every week of what I ate. And I was like, okay, and then she would look at it, but not really read it. And I’m like, well, what’s the point of me filling this out? If you’re not going to tell me what I’m doing wrong during the week, or whatever. You know what she’s like” well that’s just for you”. And I’m like, I can make my own menus. On my own. I didn’t get it. I don’t know, I hate to hate on her. Because maybe there—maybe she’s really effective with certain things. But I mean, she was just kind of like “make sure nothing’s packaged.” And things have to be packaged. I can’t go to a farmer’s market and just get a whole bunch of stuff. At some point packaging is gonna come in, and I get if you want me to avoid certain things, I mean, what do you ask me to avoid it? I just feel like maybe it was just her and I didn’t gel… It wasn’t even like; I feel like it was general menu planning too. It wasn’t even like, “in your case with your history, you should avoid XYZ” because that would have been helpful. Yeah, it was just kind of like, “well, if you want to lose weight, eat less fat.”

The various dietary changes/therapies used by the participants to improve their PCOS symptoms are presented in Table 4. The two most common interventions that the participants reported which showed improvement in their symptoms for them were weight loss and/or diet. However, there was no specific amount of weight loss in which
they found improvement. Two of the most common diets reported that participants related to symptom relief were the ketogenic diet and a dairy-free plant-based diet. Some of the reported symptom improvements were weight loss 4 (4%), regulated periods 1 (10%), lighter periods 3 (30%), increased energy 2 (20%), and improved fertility 1 (10%).

Table 4

Diet Interventions Attempted by PCOS Participants (N=10)

<table>
<thead>
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<th>Diet</th>
<th>White</th>
<th>Black</th>
<th>Composite</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Ketogenic</td>
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</tr>
<tr>
<td>Plant-Based</td>
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</tr>
<tr>
<td>Dairy-Free</td>
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<td>2 (40)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>General Healthy Eating</td>
<td>2 (40)</td>
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<td>4 (40)</td>
</tr>
<tr>
<td>Juicing</td>
<td>0 (0)</td>
<td>2 (40)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Multi-level Marketing</td>
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<td>1 (20)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Weight Watchers</td>
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<td>1 (20)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Gluten-Free</td>
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<td>1 (20)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Low carbohydrate, High Protein</td>
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<td>1 (20)</td>
<td>1 (10)</td>
</tr>
</tbody>
</table>

Weight loss was suggested to most participants. Diet and exercise are usually a part of the weight loss journey. However, 6 (60%) participants did not mention exercise very often during the interview.

Only one participant reported that a healthcare worker gave her general exercise instructions but did not specify workout examples or frequency of how many days per week to do the exercises. When asked about instructions this was her response.

BW3: “No, just diet and exercise... The one by the grad school’s town said like, “Oh, 30 minutes a day” Like, that was the extent...They have things like... the exercise
they were talking about...like, what is it called...I think it’s called low impact-something something. It’s like, L-I-S-S” is the acronym, but I can’t remember what it stands for anymore. But it’s like the opposite of HIIT workouts...I remember seeing on the Tiktok account...was that low impact works better for PCOS gallies. So...I can’t recall why. But that stuck with me...so that I can remind myself that whenever I do start working out.”

Another patient was told to lose weight and although exercise was not reportedly mentioned by the health care provider, concerns on how to exercise to promote weight loss started to grow. Her pre-existing foot injury made her feel that weight loss could not be achieved because she felt her injury made exercise impossible. When she visited a podiatrist, she felt dismissed by this doctor too.

WW3: “I mean, I even went to a foot doctor once and she was like, “well if you lose weight, it would help with your foot problems.” And I’m like, “but I have foot problems, I can’t walk.” That’s kind of what we need to address in order. I can’t walk. I can’t walk.”

One participant mentioned implementing basic exercises but reported that her Registered Dietitian didn’t deem it a top priority at the moment.

WW2: “I’m trying to implement some workouts and it’s like very basic, like 10 jumping jacks, 10 setups, and 10-second plank...something like that...something basic. I’m trying to insert those. But right now, I am trying to get my mind wrapped around what to eat, when to eat, how to eat it. Um, sometimes the workouts just don’t work. But my dietitian basically looked at me and said, try to get six months down the road, just worrying about the diet and just do the diet and the meds...and six months down the road, you’ll lose enough weight and you’ll feel comfortable and kind of in a rhythm with
everything and then you can start entering some...some weight loss or another weight loss...workouts. So that’s basically all I’m worried about right now is the meds and the diet.”

Participants have learned that PCOS may cause infertility through health care professionals, educational pamphlets, and/or their research using the internet and social support groups. Yet only 3 (30%) participants were given a prognosis for pregnancy.

BW2: “The only connection that they made is that I would have difficulty with weight loss and I might—shoot—not even might...she said, most likely I would need help with fertility.”

WW3: “I mean, I understand the stuff that I’m on now, the progesterone and what it is there for. I don’t think it’s fun. But I do still take it because I at least understand that it’s... you know...while I’m trying to get pregnant, this is what I’m going to have to do. You know, or at least for the time being. As I’m approaching 39, I’m getting a little more anxious about my age and whether I’m even going to be able to have kids and that kind of thing. But she told me we weren’t going to have that. She said right now just try not to stress out because she said that’s the worst thing when you’re trying to have a kid...just so you know...she’s like, let’s wait till your 39. If you don’t have a kid by when you’re 39, which is coming up. *laughs* She said then we’ll have discussions about what we can do to access.”

While some participants (30%) were diagnosed under the age of 18, although they may have been aware that infertility was a possibility, but reported that their healthcare practitioners chose to not focus on infertility due to their age.
Life Impact

PCOS is a condition of hormonal imbalances. These imbalances can cause symptoms that can affect a person’s mental and physical health as well as their overall well-being. Many of the participants felt that PCOS made an impact on their lives, while others did not feel the same.

One participant reported that before the beginning of her period that she would have debilitating pain that impacted her ability to perform simple tasks for at least three days.

WW1: “It would be for about three or four days before my period would eventually start...I would just not be able to move, basically, for those three or four days.”

One of the participants reported that PCOS caused her ovaries to enlarge greatly in size causing much discomfort. This same participant stated that she experiences worsening symptoms in her mental health and gastrointestinal system, which had an impact on her life and led to needing medication to remedy these symptoms under the age of 18.

WW2: “They started taking other tests and they did an ultrasound on my ovaries and they found that I had about triple the size of a regular ovary on each side.”

WW2: “They ruled it as PCOS... put me on ...with the symptoms and whatnot. And they were able to get every...all the symptoms...gastro symptoms...mental health symptoms...everything was basically... Was basically being controlled by my PCOS and was being remedied by the medicines they put me on.”
While another participant stated that she suffers from intense cramping and pain and other symptoms that greatly impact her life, she mentions being petrified about having PCOS-related accidents to the point that she has to keep sanitary napkins in multiple locations.

WW3: “Like, you know, once every two or three months, I had to stop my life at one or two days, while I had those intense cramps and pain, and sometimes a real bad headache will come along with it. I used to suffer from migraines. And I realized later on...I didn’t realize there was a correlation. But later on, I realized. So, a lot of the migraines were triggered by you know, hormones and things like that”... “I have on occasion had like real bad blood clots which can be worse than...like...you know...even just because they don’t stay on pads. *laughs* They don’t... yeah. Yes, so blood clots can be pretty bad. I still get those on occasion. I don’t know. I have, like sanitary napkins everywhere. Because I’m like petrified and like, If I feel like a little bit of a cramp, I put one on because I’m like, I’m petrified. I’m going to have this big thing and may have this big accident. You know, but you never know. You never know when it’s going to come.”

WW5 “So, my periods were always really bad, but I just thought that’s how they were. So, they were a week-long...a ton of cramping...really bad nausea, sometimes at the point of vomiting. Acne is a big one and still something that I struggle with.”

BW4: “whenever I would... Whenever I did get a period, it will be like on the scale of one to ten, like thirty! Like, lasting for... Sometimes like a month, sometimes longer than a month, and just cramping pain, just--just horrible.”

In one case, the participant has routinely prepared herself and her treatment regimen as she awaits the start of her menstrual cycle.
“I’m able to kind of when to expect it within a time frame so I can start getting ahead of it, take some ibuprofen...make sure my heating pad is ready to go. I’ll bring my heating pad to work and everything like that. Just drink lots of water and that’s basically the best thing I could do for myself because there’s still some days where I’m like, “oh my God, this is unbearable.””

For other participants, PCOS impacts their lives daily and for one, the meaning of PCOS was equivocal to a death sentence.

“No, actually, it affects everything in my life and I think about it, probably more than most people know. But I mean, I think about it probably at least a couple of times a week...If not daily, you know because it can affect the whole bunch of things.”

“I’ll never forget like she told me I had PCOS. Like, I just remember, like crying...I was like, so sad. I felt like I had some deathly disease.”

**Mental Health**

Two of the most common symptoms of PCOS is depression and anxiety. (Chaudari, Mazumdar, & Mehta, 2018). The hormonal imbalances of PCOS facilitates rapid changes in emotions. Almost all participants (90%) indicated that they have felt anxiety.

In one circumstance, the participant acknowledged that fact hormones change before starting menstruation, but felt her changes were a little more intense because of PCOS.

“You definitely feel a little sad sometimes. Because you know, hormones are out of whack. So, your emotions are going to be out of whack too” ...” Once my birth control regulated my cycle, to where I got it, like a week, a month, normally. I would feel
very sad the night before my cycle started. And it was just like, I would cry for like the littlest things. In my head it was big’” ... “and I know that a lot of women relate to that, but I, feel like it’s a little much for me.”

In the survey administered to each participant, questions to assess mental health issues such as depression and anxiety were asked. The results are exhibited in Table 5.

Table 5

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>White Responses (n %)</th>
<th>Black Responses (n %)</th>
<th>Composite (n %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little to no interest or pleasure in doing things for 2 weeks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1(20)</td>
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<tr>
<td>Several days</td>
<td>2(40)</td>
<td>2(40)</td>
<td>4(40)</td>
</tr>
<tr>
<td>More than half the days</td>
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<td>1(20)</td>
<td>1(10)</td>
</tr>
<tr>
<td>Nearly everyday</td>
<td>2(40)</td>
<td>1(20)</td>
<td>3(30)</td>
</tr>
<tr>
<td>Feeling down, depressed or hopeless for 2 weeks</td>
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<td></td>
<td></td>
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<tr>
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<td>0(0)</td>
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<tr>
<td>Several days</td>
<td>2(40)</td>
<td>2(40)</td>
<td>4(40)</td>
</tr>
<tr>
<td>More than half the days</td>
<td>3(60)</td>
<td>0(0)</td>
<td>3(30)</td>
</tr>
<tr>
<td>Nearly everyday</td>
<td>0(0)</td>
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<td>2(20)</td>
</tr>
<tr>
<td>Nervous, anxious, &amp; on edge for two weeks.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>0(0)</td>
<td>1(20)</td>
<td>1(10)</td>
</tr>
<tr>
<td>Several days</td>
<td>1(20)</td>
<td>1(20)</td>
<td>2(20)</td>
</tr>
<tr>
<td>More than half the days</td>
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<td>5(50)</td>
</tr>
<tr>
<td>Nearly everyday</td>
<td>0(0)</td>
<td>2(40)</td>
<td>2(20)</td>
</tr>
<tr>
<td>Not being able to stop or control worrying for two weeks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>0(0)</td>
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<td>Several days</td>
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<td>More than half the days</td>
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<td>1(20)</td>
<td>1(10)</td>
</tr>
<tr>
<td>Nearly everyday</td>
<td>2(40)</td>
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<td>3(30)</td>
</tr>
</tbody>
</table>

Three (30%) participants reported experiencing anxiety, depression, or emotional havoc caused by PCOS. One (10%) mentioned having depression that stemmed from trying to conceive. Two of the White participants reported either receiving mental health counseling or being given the option whereas the two Black participants reported having
mental disturbances, but did not mention receiving counseling or being provided the option to see a counselor.

Support Systems

Since some participants began their PCOS journey in their adolescent years, their parents and even grandparents played an active role in their healthcare and support. For the most part, family played a positive role, but in some instances, participants expressed having unfavorable experiences with family support related to their PCOS journey.

WW2: “I did notice in the beginning, the meds, the antidepressant man is that they started me on, I can’t remember what they are called but I didn’t feel a difference. That was my main thing was I wasn’t feeling the difference. Or that…and my mom and my grandmother both, basically, almost had a sworn document stating that they were seeing it - they were seeing changes every time we’d go to the doctor, whether it was my mom taking me or my grandmother. I would tell my…I’ll tell my PA I did not. I don’t… I don’t see a difference. I don’t feel like they’re working. And whether it was my grandmother or my mom, they’d look at me and say “it’s working, is working. We see so many changes in you” I’m like “I don’t. I don’t care what you say” *chuckles.*”

WW3 “So, my mom does try, my mom is her…well not now. My mom … My mom is menopausal, well, post-menopausal but my mom has always been like super clockwork. Like, she could tell you exactly when she was ovulating and everything. And she was like - she planned out each of her kids to the letter and knew exactly when and completely - it all worked for her. I was like, “oh, that must be nice”. Know exactly when things are going to happen because that doesn’t happen for me. So, I think in some ways, my mom
tries to help me. But, it doesn’t always come across. I guess because she doesn’t understand it. It’s okay. She doesn’t have to understand it.”

Due to the reported lack of guidance provided by healthcare professionals participants felt the need to seek information about PCOS on their own. When it came to support groups, 3 (30%) participants reported being a part of official Facebook groups. They reported that these groups provided a platform to discuss medications, diets, supplements, and PCOS in relation to other conditions. One participant reported being a part of the Facebook group “Black Girls with PCOS” which provided many benefits on her journey.

BW2: “So, I ended up-- from my friend...And mind you...just to put the time with it. So, I got diagnosed in 2016. Me and my friend had a conversation about PCOS in 2019. So, I had lived with it for three years, completely ignorant. And then this same friend recommended a group on Facebook called “Black Girls with PCOS” and it wasn’t until I got in that group, I promise, I was in there probably for hours just scrolling and reading posts, realizing, one, that I’m not alone - that I wasn’t alone in it, right?...because it’s not something that’s open and talked about in the way that it sounds. So, I ended up not...um... not...going down there (through the “Black Girls with PCOS group posts), reading through there, right? And so, I was finding things about specific foods to stay away from, you know, obviously cutting back on sugar--- just all these other more natural herbals, “take this vitamin”, you know, whatever else, finding out about those things... kind of through that group. So that was the majority of where my information came from.”
Religion/Spirituality

With regards to religious beliefs and spirituality, 3 (30%) indicated they were a part of a spiritual community while 7 (70%) of the participants indicated they were not. Interestingly, 7 (70%) of the participants stated they had spiritual/faith-based beliefs while 3 (30%) total participants stated they did not.

_BW1:_ “I’m a Christian and the hope that one day I will not struggle anymore with my symptoms or the stress that comes with the future—when I leave this earth. It also gives me the ability to be confident in myself, know there’s more to my life than my condition.”

_BW2:_ “Reminder that ‘all things will work together for the good.’”

All of the participants indicated that there was nothing in their beliefs that would prohibit them from considering artificial insemination. Only 1 (10%) of the participants reported having restrictions that healthcare workers should know about when providing medical care (such as not wanting to take birth control for religious/spiritual reasons) whereas 9 (90%) did not.

All of the participants varied in their religious and spiritual beliefs. They agreed taking birth control was a treatment option that may have helped manage the symptoms of PCOS, but also believed that the medication would interfere with “God’s temple”. Therefore, presenting a difficult choice.

_WW4:_ “So there...you can either lose weight or you can get on birth control. And I personally don’t believe in taking birth control because my body is meant to be how God made it, right? So, birth control and all these other things, like, I don’t believe in
putting into my body on a regular basis” … “And they basically just said “well, I mean, lose weight or take the birth control. Up to you.”

One of the participants mentioned that their faith played a role in them refraining from taking medications and there have been some benefits from that decision.

*Per survey, BW1:* I don’t take medicine- I haven’t in years and because of my faith. I believe my symptoms have dramatically decreased since I stopped.

Those facing infertility believe it is a very private concern and discussing reproductive health is not a topic readily discussed in some religions.

*WW3:* “So, I don’t know if I am just in a bubble where nobody talks about or, or if it’s a cultural thing. I feel like...so I grew up Catholic. And I feel like reproductive health was something that just wasn’t talked about. And I don’t know if that might be part of the reason why it just-- you didn’t talk about it” … “People had sex and they had kids, but that was kind of like, when you get married, you’ll have to worry about that” …” And then I got married and nobody still wanted to talk about it… Um, so I feel like...I’m not really a practicing Catholic anymore. But I feel like some of the cultural implications of...kind of, like, if you have a problem, you just kind of have to deal with it in your own home, and we’re not going to talk about it. I think that might have pushed me along to where I either wasn’t looking for it...or I was just assuming I’m in this by myself kind of thing,” …Although, religion and spiritual beliefs may cause certain issues with seeking medical intervention it also, may play a part in those who seek comfort, community, and guidance when dealing with the challenges of living with the condition. In the survey, when asked, “What are your sources of hope, strength, comfort, and peace during the days that the symptoms of PCOS are challenging?”
The survey allowed participants to provide short answers to additional questions such as identifying their sources of hope, strength, comfort, and peace during times they were experiencing challenges with their PCOS condition. Many of them, whether Black or White indicated that they drew strength from their family, significant other, and friends. This was reflected in statements such as those in WW3 and BW2.

WW3: “My husband is wonderfully supportive. He can tell days when I just can’t do what I normally do and helps fill in where I’m lacking. Sometimes I feel like just telling someone how I feel helps. Knowing that these periods will eventually pass helps. In recent years, I’ve learned that many people I know actually have PCOS, so it helps not to feel alone.”

BW2: “Faith, friends, and community are my sources of hope, strength, comfort, and, peace during the days that the symptoms of PCOS are challenging.”

While others found strength in music, reading, social media, and meditation. Others chose not to respond to the question, 3 (30%), and one indicated that she had lost faith.

WW3: “Honestly lost my faith as I’ve gotten older, and I haven’t had much solace from it.”

Cultural Comparisons and Differences

When asked about cultural differences between White women and women of color with PCOS one of the participants reported that body image and acceptability have cultural implications which may have a negative impact on a woman’s life.

WW3: “I do feel like in culture in general, a heavier African American woman is more acceptable than a heavy Caucasian woman... I don’t know if it’s the same in every
culture, but I feel like in general, you see more African American women, at least a little more filled out. I’m not saying necessarily completely full, right? But you know at least a little more than just a skinny pole. Right, and it’s a more accessible thing. So, I think from that perspective, you know, I’m not saying I wish I was a different culture because I wouldn’t say that, but you know.”

When the White participants were asked how they felt about other women with PCOS’s experiences compared to their experiences, four (80%) noted dismissiveness in their experiences but expressed that there may be other factors that affect women of color.

WW1: “Oh, I think that it’s completely different. I know that as a Caucasian…as a white person, and as a white, female passing person. My complaints are held to a higher standard than a lot of black or other people of color...women’s complaints are... Like, I know that. If I go to the doctor, and I push hard enough, I’m going to get it. I’m going to get answers. Rather than just being told that I’m being aggressive or emotional or things like that”... “I think that in general, women of color have had their voices silenced for far too long... it...especially in medicine. I mean, we have historical...we can look every day around us and we see that for like the death rate...the mortality rate of childbirth is so much higher in women of color than white women. We see all the time that women of color aren’t getting the help they need because they’re being ignored by doctors. And I don’t think that there is a way to ever claim that there is equality in any of that without very distinct change in the medical field. And especially when it comes to pain. Because so many doctors are still under the assumption because they were taught
60 years ago, even up ’til 10-20 years ago, the black woman had a higher threshold of pain than anybody else.”

One participant went so far as to say that women in the circles she travels have had similar experiences and they too have felt “pushed out” of doctor’s offices which left them feeling like they were on their own to manage their condition.

WW4: “I feel like it could be more in the aspect that even I have been pushed out of a doctor’s office and not really sat down and talked to like, “Hey, this is what you can do to help yourself”, right? And I know, obviously, I went to an HBCU. So, I have friends that I went to school with, that has similar issues or endometriosis, or similar, like reproductive issues, and they kind of had the same experience. And I’m like, well, that’s kind of messed up because women, PERIOD, are being pushed out of the doctor’s office. So, I can only imagine if I was, if there’s a doctor out there with prior prejudices to you know, like, it could have been 10 times worse for that person”...” Um, Overall, you know, it takes time to manage, but I feel like everybody feels like...no...not...not everybody feels like ... Everybody learns how to manage things on their own, period, but some people might not have the same resources as I did.”

While another participant acknowledged that being white helped her to receive better treatment than women of color because she had the privilege of having healthcare access.

WW5: “I don’t know this for sure, because I haven’t read any research or anything, but I’m sure that it affects...like the symptoms and stuff affects us in similar ways. But I will say that I know that I have a lot more privilege and access to care providers that will probably listen to me more than women of color. And, you know, I will
more than likely get better treatment from them because of the healthcare disparity in our country. I mean I think that our whole healthcare system needs an overhaul. And I think that it is starting with listening to women but especially black women, and women of color and how they’re treated by the health care system especially when it comes to reproductive health.”

When the Black participants were asked how they felt about other women with PCOS’s experiences compared to their experiences these were some responses. Four (80%) of the Black participants noted dismissiveness and/or poor guidance in their experiences.

Some Black women felt as though the healthcare practitioners, did not listen to them and especially did not take them seriously when they discussed their medical concerns. One Black participant indicated that her practitioner was white and she found the physician to be supportive. However, she was quick to point out that her experience could very well be different for most women of color.

BW1: “I would say that I don’t see anything - I don’t see any differences. I only have one other friend who has PCOS; and, she’s white. And so, it was nice to have someone to kind of relate to. But I don’t see any differences in terms of experience. It’s not like, you know, I was in an atmosphere that wasn’t supportive or anything like that. So that’s good. But yeah, I don’t...I haven’t personally experienced any common...like...significant differences on being treated or like anything...or, you know, just communicating about it with my friends and things like that”... “But yeah, I mean, I definitely know that there...that there...a lot of my Black, my Black girls...girlfriends...like they have gone through, you know, just different experiences with
their doctor. So, I would say, I’m positive *chuckles* there--- has been situations where someone has gone in and has similar situations to me and has been treated differently. So, if...I never want my own experience to be like, “oh, well, this happened, so everything’s fine”, you know? So, yeah. So, I would say not to count my experience because I’m sure that is not the majority *chuckles*...”So yeah, I mean, my experience has been fine. I wouldn’t really change anything. But I mean, you always have to take into account that there’s...there’s obvious disparities with Black women and doctors and things like that. So yeah. I always had to keep that in mind.”

On the other hand, one participant complained more about not receiving the information/knowledge needed to navigate PCOS. Specifically, stating that she and others like her have felt that practitioners they sought care and guidance from have fallen short in providing them what they felt was needed to cope with the condition and better plan for their future.

BW2: “The truth of the matter is... I don’t know. Because I don’t know any white women with PCOS. And I don’t know, I haven’t been exposed to white women who talk about it. What I do know is every person that I know even outside of the Facebook group that I’ve come to know that have had the diagnosis secretly, they’ve been Black. And all of us share similar medical experiences not feeling like we received the knowledge that we should have...not...or honestly just feeling like we’re pretty clueless about what it is, how it really affects our body, what we really can expect, what we look forward to and what we shouldn’t. All of those things... Like even in the questions offered today, I’m 1000% positive that most of us would answer similarly”... “Every person that I know is...I’m like, “oh, there’s a group on Facebook you should join the group”. When
they…these are not medical professionals, you know, but these are just like-minded Black women who realized that when it comes down to medical care, and just concern we’re not receiving the information…or the care…or the due diligence that we should”…

“because I have been specific about changing my health care to a lot more holistic care, herbal care, natural care, definitely BLACK care… just because I feel like they handle us a lot differently than white physicians… For instance, Black women and infertility rates, you know…and just finding out how many are connected to PCOS and the knowledge of…and maybe if you would have…we could have done some things differently, you know? So just all of that to say, yes, I do feel like there’s a difference. And I do feel like if we knew earlier and had more information, it would help us be able to manage the diagnosis a lot better.”

One participant indicated that it was not about who was white and who was a woman of color in terms of treatment received. Rather, it was about the character of the person providing the healthcare and their responsibility to provide equitable treatment.

BW3: “It’s really frustrating, because, like, you’re just trying to navigate through life, especially as like, a woman of color. You know what I mean? Like, you have to think about was it just put on me. Or like, what I get more help…if you know… We ain’t gonna finish that sentence! *chuckles* You know, it makes you think that….you know…you…you kind of have to vet people… because I made sure when I called my insurance…this is over sharing … When I called my insurance, I was like I need a Black woman. There’s no… there’s no excuses.”…”I feel that that’s important. Because the kind of…the character of your doctor….because…honestly…it’s not even about skin
color. It’s about how they care about people. So, the character of the doctor. I think…if I had a different character, I would have been more educated on what PCOS is.”

“Just because, like, you know, like for example, like cancer doesn’t know what….what race you are. So, I’m going to assume PCOS is similar. And I only say similar instead of saying same because…how does…Black women are treated in healthcare, period? Like, I can’t skip over that because I’m sure that all of the research on PCOS…not all, most, of the research of PCOS, were not done on…you know African American women. Um, I will say that they’re both similar. Hard things to deal with. They’re both…they’re…both are trash. You know, no one … No one wants to feel like their hormones out of whack. No one wants to have irregular cycles…to feel infertile … To…you know…like…that … That for a woman, period, I think it’s just not okay.

However, do I think that women of Caucus descent might be set up for success a little bit more? Yes.” “How long someone went without a diagnosis, and if things could have been maintained better… How they have been caught sooner? How doctors don’t listen to Black women when they say they’re in pain. Um, how?… Because that having a cycle for two months was ridiculous, period…and for me to have to sit there at 17 years old, and think that’s okay….Because I didn’t want to tell that doctor! Then why do people not think about that? There’s no…like…there’s a whole layer of that goes into it…an African American woman side versus a white woman side. But, however, the diagnosis in and of itself…is just…is still bad on both ends… I’m not trying to discredit anyone’s feelings.

But those things that I mentioned are very valid experiences that most, period, if not all black women go through with any diagnosis. Not just PCOS. Just doctors, period.”
BW4: “Um, I feel like automatically….I just always feel like black women, in general, get the shorter end of the stick when it comes to anything. So, both of my doctors are white. So, I can’t necessarily say…I will hope that they wouldn’t do this on purpose…but they probably are just dismissing because it’s just…it’s so common with us. And I feel like they will be more likely to help their own as opposed to trying to help us.”

The participants suggested that the healthcare practitioners did not truly understand PCOS and how it affected female physiology. Some went on to say that there may be an age, gender, and even sometimes a racial component in the dismissiveness and lack of guidance. One of the participants even acknowledged feeling more comfortable with a female healthcare practitioner than a male.

WW4 “I feel like the medical profession unless you’re a nurse like as far as doctors go, it’s still kind of like a male-dominated atmosphere. And I’ve read stories about, you know, maybe not doctors in particular; but men, period, just not knowing how a woman’s body works. And it’s just mind-blowing. So, I can imagine, you know; yes, these men might have medical knowledge, but do they truly understand our bodies and how they work, right?”

Overall, it appears most of the participants had received care from male physicians and because of their disposition, they felt like most could not relate to what they were physically and emotionally experiencing. With that said, one participant summed it up by saying they just didn’t believe the doctors understood what it meant to have PCOS as a woman.

WW3 “And…But I don’t feel like some doctors really understand what it means to have PCOS.”
For the most part, all of the participants shared similar experiences regardless of race. Although some participants mentioned that race may have or could have played a role in this treatment, they felt that all women with PCOS probably receive similar treatment. Many attributed this to PCOS being a female reproductive issue which may not be perceived as a condition of utmost importance to male practitioners.

The symptoms across races were comparable although some exceptions that may need further research. Most participants reported experiencing a degree of body fat discrimination regardless of race and mentioned that this may have led to the dismissiveness and limited treatment options given by the healthcare providers. Most participants were not referred to a Registered Dietitian; none of the Black participants were referred or given the option to see one, which frustrated some of the Black participants. The lack of guidance, support, and information provided coupled with the encouragement to lose weight led to people receiving information and support from sources outside of healthcare to help with their symptoms. Although this provided comfort and a sense of community, this led to some not-so-favorable or sustainable diet choices. Overall, the participants, regardless of race, have had difficulty on their PCOS journey and have voiced the need for improvements in healthcare to help women navigate their PCOS journeys more effectively.
CHAPTER 5

DISCUSSION

When diagnosed with PCOS, patients seem to start showing symptoms either before or during puberty (Tsikouras, 2015), but may not be officially diagnosed until much later. This was the case for many of the participants, 7(70%), did not receive a formal diagnosis until they were 18 years of age or older. Various studies have reported the prevalence of PCOS in adolescence as 9-15% (Naz, Ramezani, & Ozgoli, 2019). Although, symptoms such as anovulatory/oligo ovulatory cycles, hyperandrogenism, and polycystic ovarian morphology can appear in teens. However, the constant fluctuations in hormones during puberty may make these symptoms unfavorable to use as diagnostic criteria. This may be due to the symptoms possibly resolving once hormones begin to regulate the menses as the teen ages. Therefore, diagnosing adolescents based on criteria used to diagnose adults could result in unnecessary interventions (Mohammad & Seghinsara, 2017). Further research is needed to develop standard diagnostic criteria for adolescents.

Diagnosing patients early can help healthcare providers provide adequate support to this vulnerable population. This can be impactful as the adolescent stage is a pivotal moment in psychosocial development and is related to self-esteem/self-image. Dealing with any fertility disorder can disrupt an adolescent girl’s psychosocial development. Dealing with PCOS can disturb the joys of adolescence due to the stigma associated with
hyperandrogenism which could be more intensely felt in this age group. This in turn could impair the psychosocial development of adolescent girls (Naz, Ramezani, & Ozgoli, 2019).

The PCOS symptoms experienced by the participants were consistent across racial lines, with some exceptions. The most common symptom was irregular periods which was experienced by 8 (80%) of the participants. Amenorrhea or oligomenorrhea ovulatory cycles (irregular periods) are the main symptoms and defining criteria used to diagnose someone with PCOS (Mohammad & Seghinsara, 2017). This was supported by the participant-reported symptom frequency in this study. The data in this study showed that 80% of the White participants reported pain and 2 (40% of Whites) reported GI-related symptoms more than their Black counterparts. Only 1 (20%) Black participant reported having pain while none reported having any GI issues. There was no research to support these comparisons between Black and White populations diagnosed with PCOS. This may be an area in need of additional research.

It is important to note that 3 (60%) Black participants reported hair growth more than their White counterparts (20%). In general, it has been reported that non-Hispanic Blacks and Mexican Americans in the United States have a higher rate of hyperinsulinemia compared with non-Hispanic Whites which is independent of obesity (Engmann et al., 2017). Although Engmann et al. (2017), reported no observed differences in insulin resistance between non-Hispanic Blacks and non-Hispanic Whites with PCOS, the authors mentioned that there were several other studies that indicated that hyperinsulinemia and insulin resistance were more prevalent among Blacks, Mexican-Americans, and Caribbean Hispanics compared to White women with PCOS (Engmann
et al., 2017). Hyperandrogenism could lead to an increased frequency of hirsutism which could also be caused by hyperinsulinemia. More research is needed to assess whether there is an increased occurrence of hirsutism in women of color and a correlation with insulin resistance.

Due to PCOS’s multifaceted features, there is no consistent treatment plan for all women with PCOS. However, implementing lifestyle modifications, hormone-regulating contraceptives, and other drugs like inositol, clomiphene, eflornithine, finasteride, flutamide, letrozole, metformin, spironolactone has been reported to alleviate symptoms associated with PCOS (Tabassum et al., 2021).

In terms of lifestyle modifications, weight loss and diet, and exercise were mentioned by the participants. The two most common interventions that the participants reported that showed improvement in symptoms for them were weight loss and/or diet. However, there was no amount of weight loss in which they found improvement in their symptoms. Research states “Lifestyle intervention targeting at least 5 to 15% weight loss is the recommended first line of treatment for women with PCOS and overweight or obesity, though there is no established weight or weight loss threshold to induce ovulation or resumption of menstruation in women with PCOS and overweight/obesity” (Gorczyca et al., 2022). Two of the most common diets reported that aided in symptom relief were the ketogenic diet and a dairy-free, plant-based diet. Weight loss was reported by 4 (40%), a regulated period was reported by 1 (10%), lighter periods were reported by 3 (30%), increased energy was reported by 2 (20%) and improved fertility was reported by 1 (10%). Although the Ketogenic Diet has benefits such as weight loss, improving
lipid profiles and insulin resistance (Che et al., 2021), the ketogenic diet is not a long-term solution because ketosis shouldn’t occur over long periods (Merra et al., 2017).

Evidence is emerging to demonstrate that low glycemic diets aid in glycemic control, lipid control, and weight loss. This is influencing Registered Dietitians and patients to use this diet strategy to better manage PCOS symptoms. Another recommended diet is the Mediterranean Diet. The Mediterranean Diet is rich in antioxidants and has a low glycemic load and has been reported to improve insulin resistance in women with PCOS (Calcaterra et al., 2021). When compared to a normal glycemic diet, a low glycemic diet improves ovulation in patients with PCOS. Even implementing a low GI diet for a short period could increase insulin sensitivity (Che et al., 2021).

One study found that increased frequency and duration of exercise had a significant association with the achievement of health goals (Arentz et al., 2021). Most, 6 (60%) of the participants did not mention exercise at all during their interviews. Only one participant mentioned that a healthcare worker gave her general exercise instructions but did not specify workout examples or frequency of how many days per week to engage in exercises. This could be an issue because exercise has not been routinely encouraged in healthcare settings as a means to manage symptoms. However, it has been shown that exercise therapy can be quite effective in managing PCOS in overweight and obese individuals. It has been argued that exercises and physical activities that do not have adverse side effects should be practiced as the first-line treatment for PCOS (Rajkumar et al., 2022).
Medical interventions were also mentioned by most participants. Of the participants, seven (70%) were prescribed birth control pills. This is a common treatment as to birth control and/or progesterone therapy are typically used to promote menstrual cycles and hormone regulation in PCOS patients (Williams, Mortada, & Porter, 2016). Only one (10%) found this effective in managing her symptoms whereas six participants (60%) felt this intervention was not helpful due to side effects, no impact, and in some cases, no reason was mentioned. Metformin was recommended to (40%) of the participants. This medication is often prescribed for regulating blood glucose levels, combating insulin resistance, and promoting weight loss. Of those that were prescribed metformin (40%) chose to discontinue the medicine due to side effects, not providing improvement, or not being needed. Metformin does have adverse effects such as gastrointestinal upset, lactic acidosis, and an increase in homocysteine levels associated with atherosclerosis (Williams, Mortada, & Porter, 2016), so these effects should be considered and monitored when prescribing this medication to treat PCOS.

Most, 6(60%) participants experienced dismissiveness by their healthcare practitioners. In this study, dismissiveness mostly came from a place of weight bias and limited treatment options. Weight stigma is prevalent in healthcare settings and has been observed among physicians, nurses, medical students, and dietitians (Tomiyama et al., 2018). When discussing their PCOS symptoms, fifty percent of participants felt that their size was a major focus of healthcare practitioners and their body size influenced the practitioner to dismiss their PCOS-related concerns. Implementing lifestyle changes such as diet and exercise can enhance weight loss and improve PCOS symptoms. However, women with PCOS who are overweight (Pataky et al., 2018), receiving the medical care
necessary to manage their symptoms effectively may be hindered by practitioners’ anti-fat bias and preconceived ideas (Tomiyama et al., 2018).

It has already been reported that patients with higher BMI is avoid seeking medical care due to discomfort from being stigmatized (Tomiyama et al., 2018). Furthermore, weight loss attempts are less successful when patients perceive that their primary care providers judge them based on their weight (Tomiyama et al., 2018). More compassion and education provided by healthcare providers could lead to better care. Public health supports the notion that healthcare practitioners should provide a more weight-inclusive environment. By creating a more welcoming atmosphere and being more weight-inclusive, healthcare providers could facilitate the implementation of healthier behaviors/habits rather than stress weight loss, alone (Tomiyama et al., 2018). This could provide a sense of support, build rapport between the provider and overweight/obese patient, and may increase self-efficacy and encourage healthy behaviors. This information is important because even though all of the participants in this study fell below the obese BMI category they still expressed experiencing discrimination and dismissiveness due to their weight. Additionally, some noted that if they were smaller, they might have had a different outcome with better quality care. Therefore, healthcare providers should acknowledge their weight biases and provide more weight-inclusive care to foster a healthier environment for overweight and obese patients with PCOS. This may encourage patients to feel comfortable with sharing health-related concerns and improve self-efficacy when treating PCOS.

Poor guidance was a prominent issue noted by the participants; not receiving adequate care was a strong feeling. Specifically, participants indicated they did not
receive adequate information about their PCOS diagnosis. A previous published study concluded that there is a need for psychological support and education at all times, but specifically at the time of diagnosis (Hadjiconstantinou et al., 2017). Another issue that stemmed from poor guidance was that weight loss was encouraged yet they were not given specific instruction on how to implement changes to promote weight loss, nor were they given other resources such as educational handouts, and referrals. It was noted in one study that physicians often engage in less health education with patients with higher BMIs (Tomiyama et al., 2018). Additionally, women with PCOS have found a lack of community services and support to support lifestyle interventions to support adequate management of their symptoms (Arentz et al., 2021). In one study, women with PCOS agreed that primary care physicians were able to prioritize PCOS medical needs but they still have neutral feelings about their primary care provider’s qualifications to treat PCOS. The PCOS group’s responses to their primary care provider’s efforts to treat and advise on PCOS concerns suggested they experienced more neutral feelings in their interactions with their primary care physician. The results from the mixed model confirmed that the PCOS group felt their primary care physician placed less effort on PCOS issues compared with general health concerns (Lin et al., 2018). This study also shows that women with PCOS only sometimes receive some information about PCOS, but the information PCOS provided is often limited (Lin et al., 2018).

Most participants in this study disclosed that their healthcare providers did not provide information about the correlation between PCOS and other chronic conditions such as T2DM and CVD. Due to the numerous complications associated with PCOS and their severity, prevention and treatment are important to improve the quality of life and
prevent health complications of women of all ages with PCOS (Havelock, 2018). This is why it is so important for healthcare providers to be knowledgeable and forthcoming with this information to not miss the opportunity to combat those complications earlier.

The hormonal balances of PCOS lead to symptoms that impact the participant’s mental and physical health as well as their overall well-being. Some of the life-impacting symptoms mentioned in the interviews included pain, heavy periods that may cause clothing accidents, nausea/vomiting, anxiety, and depression, as well as difficulty trying to conceive. Due to the physical changes from PCOS, it has been noted that this could induce psychological issues that may affect self-esteem (Rajkumar et al., 2022). Therefore, it is important to emphasize adequate clinical attention to effectively address and deal with these physiological changes (Rajkumar et al., 2022).

Anxiety was felt by almost all participants with several reports of experiencing anxiety, depression, or emotional havoc related to PCOS. A previous research study indicated that anxiety and depression, physical quality of life, and sexual function in women appear not to be associated with PCOS status. However, PCOS status seems to be associated with impaired mental quality of life (Karsten et al., 2021). Yet a different study confirmed previous reports about the severity of PCOS and the negative impact it may have on women’s well-being, including high levels of psychological distress, depression, and anxiety (Hadjiconstantinou et al., 2017).

Since some participants began their PCOS journey in their adolescent years, their parents and grandparents played an active role in their health care and support. Generally, family played a positive role in support, yet some participants did express having unfavorable experiences with family support. The literature states that adolescents with
PCOS can choose isolation to counteract others’ reactions around them. It has been noted that providing a sense of community may lead to better outcomes with behavior whereas criticism can lead to low self-esteem, increased anxiety, and depression, resulting in abandoning social relationships. (Naz, Ramezani, & Ozgoli, 2019). Therefore, implementing counseling programs that may teach adolescents adaptive coping strategies are recommended to prevent future mental health problems. Mental health assessment and treatment should be imperative in PCOS treatment, especially with adolescent girls.

Due to the reported lack of guidance provided by healthcare professionals participants felt the need to seek information about PCOS on their own. “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 a greater frequency of arguments with their physicians. Tomlinson et al. (2017), identified conflict stemming from disagreements about whether PCOS symptoms subside with age and on the necessity of specialist referrals (Lin et al., 2018). Collectively, results across studies reveal that healthcare providers should address different aspects of social support (informational and emotional) to improve the PCOS patient-provider relationship” (Lin et al., 2018).

When it came to support groups, 30% of participants reported being a part of official Facebook groups and that these groups provided a platform to discuss medications, diets, supplements, and PCOS in relation to other conditions. It has been mentioned that support is important so forming social connections such as social media groups, in-person support groups, family, significant others, friends, etc. could provide a
sense of community and support which could help promote better physical, mental, and social outcomes.

With regards to religious beliefs and spirituality, 30% indicated they were a part of a spiritual community while 70% total participants indicated they were not. Only 20% reported having faith or spiritual beliefs play a role in refraining from taking PCOS-related medications such as birth control. Religions have varying stances on birth control and other PCOS treatments such as IVF, so it is difficult to predict who may have beliefs that may impact treatment plans of the healthcare providers. Spiritual beliefs are a part of the core being of a person so it is important to consider that and make note of potential barriers that may have when providing care.

As mentioned in the article “A Woman’s Work: Roles of Women in World Religions” discussed in the Review of Literature, various religions have similar roles for women which are being a wife and child-rearing. Yet none of the participants reported that their religious or spiritual beliefs had an impact on potential infertility as a result of PCOS.

One participant did report that she felt that her Catholic background may have played a part in not seeking outside support for her PCOS symptoms. She attributed this to the conservative nature of Catholicism and how intimacy and sexual/reproductive issues are not discussed outside of her household. Instances like this are supported by one study that sought to ascertain the most dominant barriers and facilitators to individuals’ help-seeking attitudes. Among the barriers hindering individuals’ help-seeking, Lack of knowledge was the most dominant barrier (45.9%) which was followed by concerns regarding concealment from one’s family and community (36.0%) (Dune et al., 2021).
Examining these barriers across religions can lead to better strategies to encourage knowledge and comfort to utilize resources and support systems which could lead to better symptom management of PCOS.
In this study, Black and White participants shared similar healthcare experiences related to their PCOS diagnosis. Regardless of race, participants mostly felt as if their healthcare providers did not provide adequate care. There was a common theme of dismissiveness and poor guidance when it came to PCOS-related care. Many of the participants were not given any information about the condition or other complications/conditions that could be associated with PCOS. This led to growing frustration and the need to seek additional information from non-medical professionals via social media groups. The social media groups enabled the women to acquire information about PCOS and share their experiences with the condition and with healthcare practitioners. It is important to note that Black participants were more inclined to join and participate in social media groups compared to their White counterparts.

The participants were, for the most part, told to lose weight and/or utilize medication management to treat their PCOS-related symptoms. As mentioned before, due to the lack of guidance, the participants either explored dietary options based on social media recommendations or general internet searches about PCOS diets. The most common medications mentioned were birth control and metformin. Although for the most part, participants reported being at least 75% compliant with their medication regimen.
they felt that the medications were either not helpful, caused unwanted symptoms, or went against their personal beliefs.

When it came to diet therapy, the most common diet followed by White women was the ketogenic diet and a plant-based dairy-free diet by Black women. These diet recommendations and instructions (if applicable) came from general internet searches and/or social media groups. Although healthcare providers generally recommended weight loss to help improve PCOS symptoms, no guidance was provided on how to achieve this task. In addition, they did not refer most of the participants to a Registered Dietitian/Nutritionist (RDN) to better help guide the participants on a weight loss journey.

Regardless of race, participants experienced similar barriers. When it came to seeking medical treatment, there was dismissiveness when symptoms and concern about said symptoms were presented to the practitioner. There were also limited resources and information provided on how to treat PCOS. However, it is important to note that when it came to healthcare providers providing a referral to an RDN, none of the Black participants were referred. This shows a potential additional barrier and additional research with providers is needed to determine why they were not referred. Additionally, although the Black participants reported having anxiety, depression, and/or mental health disturbances related to PCOS, none of the participants reported that they received additional mental health resources or support from healthcare providers.

This study helps to provide qualitative data on how the overall experiences of women with PCOS compares and contrasts experiences by race. This study shows that there were common themes across the participants’ experiences, regardless of race.
Generally, the participants felt that there was a lack of PCOS resources provided by their healthcare providers. However, the Black participants received fewer referrals and options such as seeking mental health and dietary counseling compared to their White counterparts. This may shed light on how to better provide information and adequate care from not just a stance of equality but equity.

When the participants were asked about how their experiences compared and contrasted with their counterparts, there was a consensus that symptoms and frustrations with the level of care were similar regardless of race. They mostly attributed this due to PCOS being a female reproductive health issue. Although this was stated, there was mention that racial discrimination may also create more barriers if healthcare providers have unaddressed racial biases. This can result in a poorer level of care, limited resources, and more dismissiveness.

Limitations of this study include that there was only a single survey with a single interview conducted with each participant. Conducting more than one interview may have led to the participants feeling more comfortable sharing additional information about their PCOS journey and symptoms. Also, inquiring about other cultural factors beyond race such as religious/spiritual background, geographical region, and social influences may have provided additional information about their experiences.

**Future Work**

Future research about PCOS diagnosis in adolescents is needed. Providing health education earlier may inform the youth about their bodies leading them to voice concerns to caretakers about early, abnormal, and absent menstrual cycles for their age of development. Also, developing protocol for menstruation in pediatric healthcare settings
that determine when a child needs to be referred to an OBGYN for further guidance on reproductive health. This may assist with more appropriate diagnostic criteria and treatment for this age group leading to an earlier intervention. Exploring the knowledge and biases of healthcare providers when it comes to providing information on reproductive health conditions such as PCOS is needed. Research has confirmed that women, especially, if overweight or obese feel as though their healthcare providers do not have the knowledge base about PCOS to properly inform them. Also, they have biases when it comes to women’s health and fat discrimination that may affect the level of care given to said individuals. This was confirmed in this study.

Exploring the factors of race, ethnicity, and symptoms, experiences, and symptom management could advance treatment plans. This could highlight additional potential barriers and biases across racial lines which could lead to the development of adequate resources and equitable care.
APPENDIX A

OPERATIONAL DEFINITIONS
**Polycystic Ovarian Syndrome (PCOS):** A hormonal disorder causing enlarged ovaries with small cysts on the outer edges.

**Women of Color:** A woman whose skin pigmentation is other than and especially darker than what is considered characteristic of people typically defined as white; a woman who is of a race other than white or who is mixed race.
APPENDIX B

RESEARCH MATRIX
## Research Matrix

<table>
<thead>
<tr>
<th>Purpose Statement</th>
<th>Objectives</th>
<th>Focus areas</th>
<th>Analysis Plan</th>
</tr>
</thead>
</table>
| The purpose of this study is to describe the unique experience of women of color who have been diagnosed with PCOS, assess the strategies they have used to manage their condition, and the difficulties they have endured while seeking medical treatments. | 1. To describe the symptoms of women of color with PCOS prior to seeking medical treatment. | Symptoms at diagnosis  
Current symptoms | Grounded Theory |
|                                                                                 | 2. To describe healthcare experiences of women of color with PCOS in relation to: | a. Treatment options offered  
b. prognosis for becoming pregnant  
c. payment of services  
d. demeanor of healthcare practitioners towards patients during initial visit and thereafter | Grounded Theory |
|                                                                                 | 3. To describe and assess the strategies that have been used to manage their condition | a. medication regimen  
b. diet  
c. Exercise  
d. Counseling  
e. Support Groups | Grounded Theory |
|                                                                                 | 4. To describe the barriers women of color with PCOS have had in seeking medical treatment | Cultural Aspects (food and diet barriers)  
a. Family support  
b. Healthcare access  
c. Healthcare availability | Grounded Theory |
APPENDIX C

TOOLS
Guiding Questions

1. When did your PCOS journey begin?
   a. How did your PCOS journey begin?
   b. What were some symptoms you had and how severe were they?

2. Can you describe your doctors’ visits at time of diagnosis? How did you feel?
   a. Do you feel that the doctors and nurses were helpful?
   b. How has your experience with healthcare professionals changed since diagnosis?

3. Are you aware of the relationship between PCOS and of other conditions such as Metabolic Syndrome, CVD, and T2DM? If so, what did they say?

4. If so, how were you made aware of the relationship between PCOS and these other conditions?

5. What instructions have you been given in order to treat this condition?

6. Where and how were these instructions and/or information given?

7. Can you describe your medication regimen with names and dosages included?

8. How compliant are you with your medication regimen?

9. Have other treatment options been mentioned to you as a way to treat PCOS?

10. If yes, did they specify why the option(s) will help?
    a. Did they tell you how to implement the changes?
    b. Did you receive any nutrition education on how to treat PCOS?

11. If yes, what instructions were you given?
    a. Were you referred to a Registered Dietitian?
    b. Did you feel that they made a diet plan that was culturally appropriate and realistic?

12. Have you tried any dietary therapy (diet changes, etc.) to treat your PCOS?
    a. If so, describe them.
    b. If you’ve tried them how did they help with your symptoms?

13. How do you feel as a woman of color with PCOS?
14. Do you feel like your experience is similar or different to women that are not of color?
   a. If similar- How so?
   b. If different- How so?
   c. How would you like for this to change?

15. Over the last two weeks, how often have you been bothered by having little interest or pleasure in doing things. Would you say this happens...
   a. Never
   b. For several days
   c. For more than half the days
   d. Nearly everyday

16. All of the last two weeks, how often have you been bothered by feeling down, depressed or hopeless? Would you say this happens...
   a. Never
   b. For several days
   c. For more than half the days
   d. Nearly everyday

17. Over the last two weeks, how often have you been bothered by feeling nervous, anxious or on edge? Would you say this happens...
   a. Never
   b. For several days
   c. For more than half the days
   d. Nearly everyday

18. Over the last two weeks, how often have you been bothered by not being able to stop or control worrying? Would you say this happens...
   a. Never
   b. For several days
   c. For more than half the days
   d. Nearly everyday

19. In general, how satisfied are you with the healthcare you received? Would you say---
   a. Very Satisfied
   b. Somewhat satisfied
   c. Not at all satisfied
20. Are Hispanic, Latino, or Spanish origin?
   a. If yes read: Are you
      i. Mexican, Mexican American, Chicano/a
      ii. Puerto Rican
      iii. Cuban
      iv. Another Hispanic, Latino/a, or Spanish Origin
   b. No

21. Which one or more of the following would you say is your race?
   a. Black or African American
   b. American Indian or Alaska Native
   c. Asian
      i. Asian-Indian
      ii. Chinese
      iii. Filipino
      iv. Japanese
      v. Korean
      vi. Vietnamese
      vii. Other Asian
   d. Pacific Islander
      i. Native Hawaiian
      ii. Guamanian or Chamorro
      iii. Samoan
      iv. Other Pacific Islander

22. Are you...
   a. Married
   b. Divorced
   c. Widowed
   d. Separated
   e. Never Married
   f. A member of an unmarried couple

23. What is the highest grade or year of school you completed?
   a. Never attended school or only attended kindergarten
   b. Grades 1 through 8 (Elementary)
   c. Grades 9 through 11 (Some Highschool)
   d. Grade 12 or GED (High school graduate)
   e. College 1 year to 3 years (Some college or technical school)
   f. College 4 years or more (College graduate)
24. Are you currently...?
   a. Employed for wages
   b. Self employed
   c. Out of work for 1 year or more
   d. Out of work for less than 1 year
   e. A Homemaker
   f. A Student
   g. Retired
   h. Unable to work

25. About how much do you weigh without your shoes?

26. About how tall are you without your shoes?

27. What are your sources of hope, strength, comfort and peace?

28. What do you hold on to during difficult times?

29. Are you apart of any religious or spiritual community?

30. Does it help you? How?

31. Do you have any personal spiritual beliefs?

32. What aspects of your spirituality or spiritual practices do you find most helpful?

33. Are there any specific practices or restrictions that healthcare practitioners should know about in providing your medical care?

34. Have your beliefs influenced how you take care of yourself with PCOS?

35. Do your religious or spiritual beliefs prohibit you from considering artificial treatment for PCOS?
APPENDIX D

RECRUITMENT FLYER
What is this study about?

- The purpose of this study is to describe the unique experience of Women of Color who have been diagnosed with PCOS, assess the strategies they have used to manage their condition, and the difficulties they have endured while seeking medical care.

Why Participate?

- You may help Women of Color with PCOS in the future.
- You will be compensated for participating in the study.
- You will contribute valuable information that may advance Women’s Health for women with different cultural/ethnic backgrounds.

Who can Participate?

- Women between the ages of 18 and 50 with a PCOS diagnosis.
- Women that have PCOS related symptoms (absent/irregular periods, excessive body hair, facial hair, acne, etc.)
- Those who are able to participate in a 30 minute to 1 hour virtual interview that will be recorded (via Zoom, Skype, etc).

PARTICIPATE IN A PCOS RESEARCH STUDY

Help advance research around understanding and treating PCOS in Women of Color.
APPENDIX E

HUMAN USE APPROVAL LETTER
MEMORANDUM

TO:        Catherine Fontenot, Ph.D., R.D., L.D.N.
FROM:      Dr. Walter Buboltz, Professor/Elva L. Smith Endowed Professor  
           buboltz@latech.edu
SUBJECT:   Human Use Committee - Review DECISION
DATE:      March 23, 2022

In order to facilitate your project, an EXPEDITED REVIEW has been completed for your proposed study:

HUC No.:    1398, 22-070
TITLE:      Our Pears Matter: Exploring PCOS Using the Lens of Women of Color and Caucasian Women

HUC DECISION: APPROVED

The proposed study’s procedures were found to provide reasonable and adequate safeguards against possible risks involving human subjects. The information to be collected may be personal in nature or implication. Therefore, diligent care needs to be taken to protect the privacy of the participants and to assure that the data are kept confidential. Informed consent is a critical part of the research process. The subjects must be informed that their participation is voluntary. It is important that consent materials be presented in a language understandable to every participant. If you have participants in your study whose first language is not English, be sure that informed consent materials are adequately translated or translated. Since your reviewed project appears to do no damage to the participants, the Human Use Committee grants approval of the involvement of human subjects as outlined. Projects should be renewed annually. This approval was finalized on March 23, 2022 and this project will need to receive a continuation review by the IRB if the project continues beyond March 23, 2023. ANY CHANGES to your protocol procedures, including minor changes, should be reported immediately to the IRB for approval before implementation. Projects involving NIH funds require annual education training to be documented. For more information regarding this, contact the Office of Sponsored Projects.

You are requested to maintain written records of your procedures, data collected, and subjects involved. These records will need to be available upon request during the conduct of the study and retained by the university for three years after the conclusion of the study. If changes occur in recruiting of subjects, informed consent process or in your research protocol, or if unanticipated problems should arise it is the Researchers responsibility to notify the Office of Research and Partnerships or IRB in writing. The project should be discontinued until modifications can be reviewed and approved.

Thank you for submitting your Human Use Proposal to Louisiana Tech’s Institutional Review Board.

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