2022

Knowledge and Experiences of African American Women with Polycystic Ovary Syndrome

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Walden University
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Abstract

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MS, Mississippi University for Women, 2009

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Health Education and Promotion

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Abstract

While polycystic ovary syndrome (PCOS) is a nationwide phenomenon, African American or Black women often have little to no information on the education and support available to manage the condition. PCOS is one of the most poorly understood disorders among patients which has led to limited resources and management. The lack of education could contribute to increased risks to many health issues for African American women with PCOS. The purpose of this basic qualitative study was to explore and examine the level of health knowledge related to PCOS among African American women living in or around the Northern Region of Mississippi. Questions were asked about the health related knowledge of PCOS, symptoms and experiences of PCOS, and self-help ways to manage PCOS. Using a thematic approach, this study was designed to capture new data for the development of appropriate education tools and resources for African American women with PCOS. The major themes arising from the data concerned the importance of the following: (a) no prior knowledge of PCOS before diagnosis, (b) African American women shared similar responses to PCOS diagnosis, (c) doctors or medical professionals did not provide sufficient advice or education about PCOS, (d) African American women found online support groups helpful, and (e) more tools and resources need to be available. The inclusion of all these elements is recommended for future programs. The social change implication is that these recommendations could be helpful in developing better education programs and resources to reduce barriers and help African American women improve the management of PCOS and quality of life.

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Dedication

Approximately six years ago in 2016, I lost my job as a health educator and at that moment I really didn't know what to expect. My first response was to just find another job in my career field and continue growing as a health educator. Little did I know that finding a new job in my area would be so hard. After the first few months, I started to question if I was going to be able to find something that would even suffice to what I was looking for. Finally, I found an adjunct instructor position at Coahoma Community College. Although I had previous experience teaching at a community college this divine connection felt different than before. I was able to connect and make a long lasting relationship with a lady named Dr. Shirley Taylor and she took me under her wing and exposed me to more areas of academia. I never really thought about having a career in academia but after watching and listening to Dr. Taylor, my heart became passionate to educate students.

Unfortunately, my teaching position at Coahoma Community College was not very long and I still hadn't found a full-time job in my career field. One day, I was just sitting and thinking and I was reminded of the time I mentioned going back to school to get my Ph.D. Well, at this point nothing was stopping me from enrolling and I really didn't have anything else to lose. So, I prayed about it and told God that if it was in his will for me to go back to school then make this process and journey as easy as possible and I would do the work. I finally enrolled into Walden University, pursing a Ph.D. in Health Education and Promotion.

Upon embarking on this new journey, I wasn't sure if I was even capable to handle everything that it was going to entail. I knew that this was going to be a long, time-consuming, and tedious journey but I understood it would be worth it in the end. Throughout this endeavor, there have been many life challenges that have come along to make this goal seem so unreachable. Days were long and nights were even longer but I continued to progress through and complete all the coursework. This opportunity has allowed me to learn, grow, and advance in Health Education and Promotion and this experience has been remarkable.

I dedicate this dissertation first to my Lord and Savior, Jesus Christ. I thank God for the grace and strength that was given to me throughout this process. This dissertation is also dedicated to the late Lorine Dancy, my "Granna", Debra Vance, Kierra Ransey, and Carlitha Hunt. And last but certainly not least, this dissertation is dedicated to my parents, WC and Lerine Brim. The sum total of my journey is embodied in the following scriptures: "Cast thy burden upon the Lord, and he shall sustain thee: he shall never suffer the righteous to be moved." Psalms 55:12 (KJV); "But they that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles; they shall run, and not be weary; and they shall walk, and not faint." Isaiah 40:31. (KJV)

Acknowledgments

First and foremost, I would like to thank God for the ability, insight, and strength to accomplish such a momentous and extremely challenging task. “To God Be the Glory.” I would like to extend my sincere thanks and gratitude to Dr. Nina Bell, for her extraordinary expertise, patience, leadership, kindness, encouragement, and her faith in me throughout this journey. I would also like to thank my other committee members: Dr. Kayte Miller for her knowledge and precision that provided the necessary guidance needed to help progress and continue to move forward. I want to thank Dr. Theresa Gibble for stepping in halfway through and providing her keen eye and input to ensure my dissertation met quality standards. I would like to thank each of my professors for their accessibility. I would also like to thank Walden University’s Library and Word Support Staff for their guidance and readiness to assist in every way. I am extremely thankful for my research participants who willingly shared their information and experiences, without them this dissertation would have been impossible. I am so grateful!

I would like to thank my parents, WC and Lerine Brim, for their encouragement, enthusiasm, financial support, taking care of my children, and constant push toward my completion. I would also like to thank my siblings, Ketra McCoy who was always there as a sounding board and consistent supporter whenever needed and Cedric Brim for always checking to make sure I was still pushing forward. A very special thanks to Demetria Hereford, my other sister, who always was there willing to assist and help in any way. I want to thank my friends/extended family, La’Shonda McKinney, Kristie

Davis, Veronica Anderson, Nicole Judon, Ingrid Lowery, and Demario Carouthers, for all of their encouraging words, random phone calls, text messages, and continuous motivation to help me stay focus until the end. To my reasons for not giving up and making this journey worth it, I want to thank my children, Ckylar and Ckyree Vance. Mommy loves you so much and I appreciate your hugs and kisses that kept me smiling.

This journey has truly been an experience educationally and spiritually. Many other people have contributed to the success of this journey through love, support, or encouraging words. I am thankful for my Pastor, Bishop Kelvin Ransey; and First Lady Deborah Ransey for their many prayers and encouragement that kept me sane. I want to thank a very special friend, Donald Cole II, for always allowing a space for me to vent and speaking positive affirmations along the way. Many thanks to my employer, for allowing a flexible schedule to be able to contribute many hours toward this dissertation which would have been impossible in a traditional setting.

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Chapter 1: Introduction to the Study

Introduction

Polycystic ovary syndrome (PCOS) is a condition that affects adolescents and women in the reproductive stage (Escobar-Morreale, 2018). PCOS causes girls and women to have increased male hormones, infertility, irregular cycles, ovarian cysts, and obesity (Escobar-Morreale, 2018). These symptoms can also lead to heart disease, diabetes, and other health risk diseases. Although there is no cure for PCOS, research has been conducted to help find ways to minimize the symptoms and find the best treatments to reduce long term problems. Research also has shown that improved dietary intake and exercise helps to reduce weight and improve the chance of fertility (Brennan et al., 2017). According to the Centers for Disease Control and Prevention (CDC, 2020), PCOS affects as many as 5 million women of reproductive age in the United States. PCOS can lead to several complications and is an independent risk factor for cardiovascular disease, Type 2 diabetes, and obesity. Making lifestyle changes, exercising, and taking medication can help reduce risks and control PCOS (CDC, 2020).

PCOS is a chronic condition that requires prolonged lifestyle management (Kozica et al., 2013). In recent research, it was noted that PCOS is one of the most poorly understood disorders among patients which has led to limited resources and management (Escobar-Morreale, 2018). According to Kozica et al. (2013) there is no research available exploring self-help in women with PCOS and it is crucial to explore self-help behaviors in PCOS to guide future interventions. Women with PCOS have a higher prevalence of depression and anxiety, reduced quality of life, and self-esteem associated with socialization and body image satisfaction (Kozica et al., 2013). It has been found and suggested that treatment should always be personalized and altered to the needs of the individual patient based on race and ethnicity (Escobar-Morreale, 2018). Although there has been a modest amount of research on PCOS in women of different races and ethnicity, emerging research suggests that there could be more research done on each race and ethnicity alone (Chan et al., 2017).

In addition, more research found that there is a lack of structured education programs in women with PCOS which could increase understanding of the condition and promote self-management strategies for a lifestyle change (Mani et al., 2015). Conducting this research could benefit African American women with PCOS who lack the knowledge and support to help the management of their condition. There is limited research and information on education and support specifically tailored for African American women with PCOS. Hence, this study aided in filling the gap in research by specifically focusing on the knowledge and experiences among African American women about health knowledge related to PCOS and how that affects self-help methods.

Dunfey (2017) defined social change as human interactions in relationships that can bring changes in cultural and social institutions. As a researcher, one lesson one learns is that social change will always require a constant change. It depends on the direction in which social change is created and shaped to see the change needed in communities, society, and the world. My findings could promote social change by using ideas, education, and personal experiences to enhance or impact other people's lives in a positive way. This research study could be the beginning of developing and implementing programs and support groups for African American women with PCOS on a larger scale and providing the necessary resources and materials to better manage the condition.

Background of Study

PCOS, from a biomedicine perspective, is considered an endocrine disorder that impacts women of reproductive age (Wolf et al., 2018). It is normally caused by a hormonal imbalance that is characterized by hyperandrogenism (HA), ovulatory dysfunction, and polycystic ovarian morphology (PCOM; Azziz et al., 2016). PCOS is an overly complex disorder with reproductive, metabolic, and psychological features and can lead to several complications. For instance, PCOS is an independent risk factor for cardiovascular disease (CVD), Type 2 diabetes, and obesity (Azziz et al., 2016). Since the etiology of PCOS is not completely understood, the known cause has not been found although genetic components have been identified (Wolf et al., 2018). PCOS was first defined in 1935 by Stern and Leventhal identifying women with obesity, hirsutism, and chronic oligo anovulation (OA; Goldrat & Delbaere, 2018). The clinical appearance is heterogenous and can be in several phenotype categories depending on the presence or absence of characteristic features such as infertility, hirsutism, acne, obesity, and menstrual dysfunction (Rao et al., 2020).

According to the CDC (2020), PCOS affects women of reproductive age between 6% to 12% (as many as 5 million). It has been reported that women with PCOS seem to produce higher amounts of male hormones which leads to a disruption in menstrual cycles, so women experience fewer periods (Escobar-Morreale, 2018). PCOS is a syndrome with the group of symptoms affecting the ovaries and ovulation. Common symptoms of PCOS include the following: severe acne on the face, chest, and back, weight gain, darkening of the skin, obesity, thinning hair, oily skin, infertility, multiple sacs in the ovaries, irregular menstrual cycles, skin tags, and excess hair (American College of Obstetricians and Gynecologists [ACOG], 2020). The National Institute of Health (NIH, 2017) explained that since oily skin, acne, and excess hair are not considered serious problems to many women, the symptoms are rarely mentioned during health care visits. Black women with PCOS tend to have more issues with increased rates of hirsutism, obesity, and risk factors for infertility (Black Women's Health Imperative, 2017).

African American women with PCOS also have a higher risk of developing cardiovascular disease and metabolic syndrome (Black Women's Health Imperative, 2017). This is significant because African American women suffer higher rates of heart disease compared to White women and Black women have one of the highest prevalence of high blood pressure, Type 2 diabetes, and obesity in the United States compared to their counterparts (Marinos et al., 2017). Research has found that women of color suffer from PCOS more often than White women and since Black people have a higher rate of morbidity and mortality due to CVD and diabetes, it is important to understand racial and ethnic differences among women with PCOS (Basile, 2020). Although there has been a modest amount of research on PCOS in women of different races and ethnicity, emerging research suggests that there could be more research done on each race and ethnicity alone (Chan et. al., 2017). This study aided in filling the gap in research by specifically focusing on the knowledge and experiences among African American women about health knowledge related to PCOS and how that affects self-help methods.

Problem Statement

PCOS is a hormonal endocrine disorder that causes several different symptoms in women and affects up to 10% of reproductive-aged women globally (Lin et al., 2018). According to the CDC (2020) PCOS affects as many as 5 million of the U.S. women of reproductive age. PCOS can lead to several complications and is an independent risk factor for cardiovascular disease, Type 2 diabetes, and obesity (CDC, 2020). One problem with PCOS is that it is one of the most poorly understood disorders among patients which has led to limited resources and management (Escobar-Morreale, 2018). Secondly, the lack of education could contribute to increased risks to many health issues for African American women with PCOS. In this study, I focused on the present knowledge and experiences in African American women with PCOS that could be due to the lack of PCOS education.

Chan et al. (2017) found that Black women with PCOS had metabolic syndrome components significantly higher than White women. In another study, researchers also found that young Black adolescents and adult women with PCOS had significantly increased prevalence of low high-density lipoprotein, high glucose, and the general CVD risk was increased compared with White women with PCOS (Hillman et al., 2014). Some evidence has shown that the prevalence of PCOS and metabolic outcomes vary by race and ethnicity which could create race-ethnic differences in health-related knowledge and beliefs in PCOS (Lin et al., 2018). The prevalence of PCOS was investigated in several studies in different continents and the results concluded that Black women, the majority being African American, tended to have the highest risks of developing PCOS compared to White females living in the United and Europe and females residing in the Middle East (Ding et al., 2017). It was suggested that there is an urgent need for the establishment of ethnicity-specific guidelines for this condition that could help prevent the under or over diagnosis of PCOS. Researchers explained that further research should be conducted in the prevalence of PCOS in different community ethnic populations to collect sufficient data occurrence extrapolation (Ding et al., 2017). There is still little to no statistical data among Black women with PCOS and there is little to no research found on PCOS and African American women specifically.

Most women have a basic understanding about PCOS, and the associated symptoms and health risk related to the condition (Lin et al., 2018). Additionally, there is little to no research on the perceived knowledge about PCOS among African American women with PCOS. Lin et al. (2018) expressed that there is limited understanding about the actual health- related knowledge and beliefs among women with PCOS and conducted a study addressing the knowledge gap between women with PCOS and a comparison group. The participants were 475 U.S. residents between the age 18-38 years old and were predominately White, yet the study did include 18 Black women with PCOS and 14 Black women without PCOS (Lin et al., 2018). However, the study did not report results from different ethnic backgrounds regarding knowledge or beliefs. The lack of information, education, and support provided to women with PCOS has been associated with poor health quality of life and less motivation to engage in managing the condition (Hadjiconstantiou et al., 2017). Specifically, there has been no research conducted exploring the education and support on African American or Black women with PCOS alone.

Purpose of Study

The purpose of this basic qualitative research design study was to explore and examine the level of health knowledge related to PCOS among African American women with PCOS. By examining this phenomenon, I sought to understand the existing knowledge, experiences, and self-help methods used among African American women with PCOS. In return, it could lead to the development of health education and promotion interventions to increase education and reduce barriers among African American women with PCOS to promote self-help methods that will aid in lifelong management. Black women who have been diagnosed with PCOS were interviewed to gain more understanding on the participants current knowledge and experiences with the diagnosis. More discussion on the methodology of the study is detailed in Chapter 3.

Research Questions

RQ1: What is the current health-related knowledge of PCOS in African American women with PCOS?

RQ2: What are the symptoms/experiences of African American women with PCOS both before and after diagnosis?

RQ3: After diagnosis, how have African American women managed PCOS symptoms in terms of self-help?

Theoretical Foundation

The theory for this framework was based on the health belief model (HBM). The HBM consists of six constructs which include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (Jones et al., 2015). If American African women understand their condition and become knowledgeable about the severity of it, then that could produce a positive outcome and increase self-help methods (cues to action) that would decrease the associated risk of health diseases (i.e., CVD, diabetes, stroke). Understanding and increasing PCOS education in Black women could decrease poor perceptions (perceived susceptibility) about developing adverse health outcomes. As well as increasing perceived control and beliefs caused by perceived barriers (ability to eat healthy, exercise, reduce weight, and control symptoms) to help manage and reduce symptoms of PCOS. This could be done by assessing the value that is placed on engaging in health promoting behaviors (perceived benefits) among African American women with PCOS. Furthermore, the increase of PCOS education in Black women could improve the confidence and ability (self-efficacy) to change health behaviors that could result in a lifelong management of the condition. In addition, HBM constructs can be used to develop an instrument to assess PCOS related health knowledge, beliefs about health outcomes and confidence in lifestyle behaviors, and current self-evaluation of lifestyle.

Nature of Study

The nature of this study was a qualitative approach using a basic qualitative research design. I used this approach to better understand the level of knowledge among

African American women with PCOS to help reduce barriers and increase health education and awareness. This basic qualitative research design attempted to uncover the participants' experiences, the meaning the participant ascribes to those experiences, or a process. Qualitative research was the best method for this study because it grants the permission for the collection of data to be analyzed for themes and perspectives of participants, an ideal posed by Creswell (2013) as a key component of qualitative studies.

A basic qualitative research design was used to guide the research to obtain broader understanding of the knowledge and experiences of the barriers, issues, and culture behaviors associated among this ethnic group with PCOS. I conducted face- to-face in person and via an online platform (Zoom) semistructured interviews, which was the preferred method of choice. I used open-ended questions to gain a deeper understanding of the participants knowledge and experiences of PCOS. The knowledge acquired during these interviews translated into new knowledge for the planning and implementation of new resources, materials, and programs to support African American women with PCOS.

Definitions

African American: The U. S. Census Bureau (2010), reported that African Americans can be referred to also as Blacks or Negros. This designation dictates a social and racial significance within society among other denominations of people. African American and Blacks will be used interchangeably throughout the paper.

Diagnosis criteria for PCOS: Characterized by the clinical presence of HA, OA, or PCOM under the Rotterdam criteria (citation).

Endocrine disorder: An endocrine disorder is a disease related to the endocrine glands of the body. (U.S. Department of Health and Human Services, 2021).

Health belief model (HBM): The HBM is a commonly used theory that is used in health education and health promotion. The six concepts of the HBM are that health behavior is determined by personal beliefs or perceptions about a disease and how to decrease the occurrence (Glanz et al., 2008).

Hirsutism: Hirsutism is defined as excessive growth of terminal hair in women in a male-like pattern; it is the most commonly used clinical diagnostic criterion of hyperandrogenism (Azziz et al., 2016).

Hyperandrogenism (HA): HA refers to the excessive presence of the male sex hormones testosterone, androsterone, and androstenedione in women and the effects that they have on the female body (Azziz et al., 2016).

Metformin: Metformin is a drug approved by the U.S. Food and Drug Administration as a prescription medication to treat diabetes (Dinsmoor, 2019).

Metabolic Syndrome (MetSyn): MetSyn is a cluster of conditions that occur together, increasing the risk of heart disease, stroke, and Type 2 diabetes. These conditions include increased blood pressure, high blood sugar, excess body fat around the waist, and abnormal cholesterol or triglyceride levels (Williams et al., 2016).

Misdiagnosis: A misdiagnosis is when a doctor has diagnosed a person with the wrong medical condition (Witchel et al., 2020).

Missed diagnosis: A missed diagnosis is referred to as failure to diagnose or delayed diagnosis, occurs when a doctor fails to identify a medical condition at the time they are presented with it (Witchel et al., 2020).

Oligo anovulation: Oligo anovulation is type of ovulatory dysfunction and is when ovulation occurs infrequently or irregularly and usually is classified as having eight or fewer periods in a year (Azziz et al., 2016).

Overdiagnosis: Overdiagnosis occurs when a diagnosis is “correct” according to current professional standards but when the diagnosis or associated treatment has a low probability of benefiting the person diagnosed (citation).

Ovulatory dysfunction (OD): OD is defined as abnormal or irregular (less than nine per year) menstrual periods or absent ovulation (Escobar-Morreale, 2018).

Phenotypes: Phenotypes are the clinical characteristics produced by the interaction of heredity and environment in a disease or syndrome (Goldrat & Delbaere, 2018).

Phenotypes of PCOS: The phenotypes of PCOS are described on the presence of clinical HA, oligo ovulation and polycystic ovaries (Williams et al., 2016).

Polycystic ovarian morphology (PCOM): PCOM is defined as a follicle number per ovary of ≥ 12 and/or an ovarian volume of >10 cc in at least one ovary (Azziz et al., 2016).

Polycystic ovary syndrome (PCOS): PCOS is an overly complex disorder with reproductive, metabolic, and psychological features (CDC, 2020).

Reproductive age: In women, reproductive age is those years of life between menarche and menopause, roughly from ages 12 to 49 (CDC, 2020).

Rotterdam criteria (ROT): The diagnosis criteria of PCOS showing two of three following conditions OA, PCOM, and HA (Goldrat & Delbaere, 2018).

Underdiagnosis: Underdiagnosis refers to when doctors diagnose (a condition or disease) less often than it is actually present (Witchel et al., 2020).

Assumptions

The following assumptions underlined this study. I assumed that all participants were willing to participate because they were sincerely interested and concerned about their health and provided their answers freely and honestly. I also assumed all participants understood the purpose of the study and that the written and verbal content of the protocol was clear and easily understood by participants. Another assumption was that the inclusion criteria of the sample were appropriate and assured that the participants have all experienced the same or similar diagnosis. My final assumption was that participants were willing to discuss and share their experiences because they believed it will help develop better resources to help manage their condition.

Scopes and Delimitations

In this study, I aimed to explore the knowledge and experiences of African American women with PCOS. The study was limited to African American women living in or around the Northern Region of Mississippi. The primary focus of the study was to gain a better understanding of the level of knowledge of PCOS among African American women and to understand their experiences. The location of the study took place in a private and safe environment which was conducive both for the interviewer and interviewee. The data collection of the study took 4 weeks. This was a qualitative study using a basic qualitative research design conducting semistructured interviews using opened- ended questions. The participants pool was a purposeful sample selecting African American women who had a diagnosis of PCOS for 3 years or more.

Delimitations to this study included that only African American women with PCOS were selected for this study. The participants also had to have a confirmed diagnosis from a physician. I used the HBM to develop an instrument to assess PCOS-related health knowledge, beliefs about health outcomes and confidence in lifestyle behaviors, and current self-evaluation of lifestyle. I used a basic qualitative research design to uncover the participants' experiences, the meaning the participant ascribes to those experiences, or a process.

Limitations

Potential limitations included the difficulty recruiting participants for interviews. Recruitment of participants was not very challenging although it was anticipated due to the sensitivity of the topic, privacy about medical diagnosis, COVID-19, clinics not allowing flyers posted, and fear of embarrassment. Researcher bias was another potential limitation due to the personal experience of the topic (see Ross & Zaidi, 2019). I minimized interview bias by remaining neutral in facial expressions, body language, and tone of voice. I refrained from offering opinions and recorded all interviews and kept notes or a journal of the interview process (see Ross & Zaidi, 2019). The findings were not a representative of all African American women diagnosed with PCOS; however, the results provided insight to the experiences from some Black women diagnosed with PCOS. I developed the instrument. Developing open-ended, simple, clear, concrete, and neutral questions can reduce biased questions (Ross & Zaidi, 2019). Creswell (2013) stated that a self-developed interviewing instrument is a potential weakness that may affect the validity and accuracy of the data. Lastly, the potential emotional vulnerability that arose among respondents was another limitation. Emotional vulnerability can be a limitation due to feelings of being rejected, shamed, or judged as inadequate (Emerald & Carpenter, 2015). The respondents experienced overwhelming emotions while sharing their experience with me but did not experience feelings of uncertainty to exposure.

Significance

In this study, I explored and examined the knowledge and experiences among African American women with PCOS have about health education and promotion interventions related to PCOS education. I sought to understand how PCOS education can be further developed and improved to reduce barriers and increase PCOS awareness among African American women. The different forms of self-help methods used among African American women with PCOS in relation to their knowledge, experience, and management were also explored. PCOS can increase a women's risk of developing Type 2 diabetes, heart disease, and high blood pressure (CDC, 2020). African American women with PCOS have a higher risk of developing cardiovascular disease and metabolic syndrome (Black Women's Health Imperative, 2017). This is significant because African American women suffer higher rates of heart disease compared to White women (Marinos et al., 2017). Black women have one of the highest prevalence of high blood pressure, Type 2 diabetes, and obesity in the United States compared to women of other races (Marinos et al., 2017). The lack of appropriate health education interventions and PCOS awareness among African American women with PCOS could influence self-help methods related to their individual experience. This study has the potential to encourage education programs in communities to increase knowledge and bring awareness among African American women with PCOS to reduce symptoms and lower the risk of associated diseases.

I intended to uncover any relevant data concerning African American women with PCOS and how resources can be developed to help them better manage their condition. Also, findings suggested that it is extremely important to address the lack of education and support in African American women with PCOS could lead to the implementation of intervention programs. This could possibly lead to a reduction in the economic effect of PCOS that surpassed $4 billion dollars in 2004 (Azziz et al., 2016). This study could shed light on how PCOS research is underfunded. Results from Brakta et al. (2017) showed that PCOS was less funded than three other disorders and more individual research grants were awarded to the other disorders. The overall public health implication is that it will add to the knowledge base across the public health sector and toward the goals of future research. The new data can be simulated through PCOS health education programs to enhance new methodologies that can promote vital changes to accomplish better management of PCOS among African American women and the community.

This study provided insight to varied experiences of African American women with PCOS. The knowledge of certain contributing factors such as their beliefs, culture, and social environment can have a substantial impact that can promote positive behavior modifications. Additionally, the findings concurred with the literature that the lack of research, education, and support among African American women with PCOS needs to be addressed to reduce health risks associated with PCOS and promote healthier outcomes. The information gathered from participants was useful knowledge to promote effective positive change by understanding the elements needed to develop and implement sustainable PCOS health education programs. The intent was that the results gathered could also help to engage, empower, and educate African American women with PCOS to become involved in health education programs to promote healthier outcomes.

Summary

Chapter 1 discussed the problem statement, the background of the study, the purpose of the study, the nature of the study, the theoretical framework, and the gap in the literature as it relates to the lack of in- depth information on the knowledge and experiences of African American women with PCOS. The information gathered in this study hoped to uncover the barriers and lack of health education and support provided to African American women with PCOS to better manage their condition. Additionally, this chapter included the limitations, scope and delimitations, definitions, assumptions, and significance of the study. Chapter 2 includes the literature review, search strategies, and the data that provided an overview of other studies that included African American women with PCOS and the impact the disorder has on this ethnic group.

Chapter 2: Literature Review

Introduction

According to the CDC (2020), PCOS affects 6-12% of women of reproductive age (as many as 5 million). PCOS is an overly complex disorder with reproductive, metabolic, and psychological features. PCOS can lead to several complications and is an independent risk factor for cardiovascular disease, Type 2 diabetes, and obesity (CDC, 2020). The primary purpose of this research project was to explore the knowledge and experiences of African American women with PCOS. As the literature was reviewed, findings showed the prevalence of PCOS was investigated in several studies in different continents and the results concluded that Black women, the majority being African American, tended to have the highest risks of developing PCOS when compared to White females living in the United States and Europe and females residing in the Middle East (Ding et al., 2017). Women suffering with PCOS are at a higher long-term risk of developing multiple disorders so the management and treatment could vary based on changes in symptoms at various life stages (Rao et al., 2020). However, there is a paucity of research concerning African American women and PCOS, the knowledge and experiences of African American women with PCOS, and the education and support available to African American women with PCOS. Information was gathered from articles to review literature regarding the knowledge and experiences of women in general with PCOS and the themes that generated from those encounters.

Literature Strategy

The primary source of information used to search for scholarly and peer-reviewed articles was the Walden University Library, which allowed the use of multiple databases. The databases included in this search included SAGE, PubMed, EBSCO, ProQuest, CINAHL, and MEDLINE. Google Scholar was also used to identify scholarly and peer-reviewed articles. Using these databases, I reviewed approximately about 341 articles through November 2019 to identify articles that were 5 years old or less and relevant to the research. The following key phrases were searched: *polycystic ovary syndrome, signs and symptoms of PCOS, treatment of PCOS, prevalence of PCOS in women, health risks associated with PCOS, PCOS and perceived knowledge, polycystic ovar**, PCOS and African American women, PCOS and Black women, PCOS and lifestyle management, PCOS and self-help methods, education and support, understanding and experiences of African American or Black women with PCOS, cardiovascular disease,* and *metabolic syndrome and diabetes in African American or Black women with PCOS*.

Theoretical Foundation

The theory for this framework was based on HBM. The HBM was initially developed in the 1950s to describe why people fail to engage in programs to prevent and detect disease (Champion & Skinner, 2008). Kurt Lewin conceptualized those certain aspects of a person’s life space that have negative, positive, or neutral values (Rosenstock, 1974). Lewin believed that disease is a negative value and, as a result, exerts a force to move the person towards health behavior change (Rosenstock, 1974). The HBM is a commonly used theory that is used in health education and health promotion. The concept of the HBM is that health behavior is determined by personal beliefs or perceptions about a disease and how to decrease the occurrence (Glanz et al., 2008). Over the past decades, the HBM has expanded, been used with other frameworks, and supported interventions to change health behavior (Champion & Skinner, 2008). The understanding is that the person will take a health-related action if they feel that a negative health condition can be avoided, has a positive expectation of a healthier outcome, and believes that they can be successful at taking a healthy action (Glanz et al., 2008)

The HBM consists of six constructs which include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (Jones et al., 2015). The HBM can help individuals take action to prevent, screen, or control their conditions (Glanz et al., 2008). Motivation plays an important role in a person's desire to change a health behavior which could lead to developing individual perceptions, modifying behaviors, and likelihood of action (Hochbaum et al., 1952). The model applies to behaviors with the potential to reduce the risk of disease as well the effects of an existing disease (Champions & Skinner, 2008). The use of the HBM constructs has made this model popular to use in community-based interventions where there has been a lack of education or awareness of the specific disease. The HBM was used in a study to measure the health- related knowledge, beliefs, and self-efficacy in women with PCOS (Lin et al., 2018). The authors developed an online instrument using some of the HBM constructs to assess the participants beliefs about the severity of adverse outcomes and the perceived susceptibility to adverse health outcomes. The finding reported that most of the women with PCOS had misconceptions about diagnostic criteria and PCOS was associated with greater perceived susceptibility for disease and weight gain and poorer perceived control over these health outcomes (Lin et al., 2018). The study also supported the idea that behavioral interventions should use psychosocial considerations associated with PCOS to promote patient engagement in lifestyle interventions.

James et al. (2012) used the HBM to explore developing culturally appropriate weight- management programs for African American women. The literature discussed that losing weight is heavily dependent on one's perception of weight. Weight perceptions differ by culture and African American women tend to compare themselves to be more overweight or obese than their White counterparts (James et al., 2012). The participants reported believing that culture and genetics made them susceptible to obesity but reiterated the benefits of losing weight to help reduce the risk of diabetes and hypertension. Lack of time was a major barrier and feeling pressured to devote time to family and friends was a concern. James et al. suggested that developing a culturally tailored program can increase self-efficacy because it becomes more personalized. As a result, the authors explained that the HBM provided a good outline for data and helped to generate themes from each theoretical construct to develop weight-management materials for African American. Table 1 below summarizes the HBM constructs and how they were used in relation to my research study.

Table 1

The HBM Constructs

Concept	Definition	Application
Perceived susceptibility	Refers to a person’s chance of experiencing a risk or acquiring the disease	Understanding the education of Black women with PCOS and belief about risk associated with disease.
Perceived severity	Refers to a person’s belief of the seriousness of contacting the disease	Identifying risks associated with PCOS and Black women and consequences of those risks.
Perceived benefits	Refers to a person’s belief of the effectiveness of actions to reduce risk	Addressing the values that are placed on engaging in health-promoting behavior.
Perceived barriers	Refers to a person’s feelings on the challenges of performing such actions	Reducing barriers through education about PCOS in Black women
Cues to action	Strategies to trigger decision-making thoughts for readiness to change	Providing resources and education to help initiate change in the aid of managing the condition
Self-efficacy	Confidence in one’s ability to perform a behavior	Increasing awareness and education among Black women with PCOS to provide reinforcement in the ability to manage condition

Masoudiyekta et al. (2018) described using the HBM to determine the effect of education on the behavior of breast cancer screening in women. The findings reported a significant increase after educational intervention in knowledge of the theoretical constructs. The participants performance regarding breast cancer screening and mammography was higher after the educational intervention. The authors noted that the effectiveness of the intervention was due to designing the program based on the HBM. Using the theoretical constructs to specifically address breast cancer helped to increase knowledge and awareness (Masoudiyekta et al., 2018). Another study regarding assessing the level of knowledge of cancer warning signs showed that although knowledge was average in both groups, the intervention group showed increase after 1 month of education using the HBM constructs (Sharifikia et al., 2019).

Another study wanted to investigate health-promoting behaviors in participants with or at high risk for metabolic syndrome and if those behaviors were influenced by the HBM constructs (Lo et al., 2015). The authors reported that knowledge alone could not be a predictor of health behaviors but found the importance of self-efficacy and beliefs about barriers crucial to behavior change. The findings showed the success of using the HBM constructs to reduce perceived barriers and increase self-efficacy to increase health promoting behaviors. Participants with a lower level of perceived barriers had an increase in exercise and diet management (Lo et al., 2015). In contrast, those with a higher level of perceived barriers were associated with a lower frequency of health promoting behaviors.

Karimy et al. (2016) conducted a study addressing adherence to self-care behaviors among women with Type 2 diabetes using the HBM. The authors reported that the HBM constructs revealed a 59.9% variance in self-care behavior with self-efficacy, perceived barriers, benefits, and susceptibility as significant predictors of adherence to the self-care behaviors. There was also a positive correlation between patients who had more perceived severity of the disease being more adherent to self-care, yet self-efficacy was explained to be the strongest predictor of adherence of self-care behaviors (Karimy et al., 2016). Negative associations were found between increased perceived barriers and self-care behaviors. The authors suggested that putting emphasis on self- efficacy when developing educational programs would likely increase adherence to self-care behaviors.

Knowing the current knowledge and experiences of African American women with PCOS could help develop educational and intervention programs that will tailor to their specific needs. Kozica et al. (2013) explained that limited knowledge, frustration about the condition, and where to find high quality health information may lower self-engagement and reduce participation in self-help methods. They also found that reduced self-help in women with PCOS was correlated with lower self-efficacy and self-management. The HBM requires an individual to have positive health perceptions and have the capability to overcome any perceived barriers to develop lifestyle changes (Kozica et al., 2013). There is a lack of research using the HBM in women with PCOS and specifically centered around African American women with PCOS. Using the HBM will add to the literature to further incorporate health promoting behaviors through recognizing the awareness of susceptibility and severity, identifying barriers and benefits, and increasing self-efficacy to help develop positive change.

If African American women with PCOS understood their condition and became knowledgeable about the severity of it then that could produce a positive outcome and increase self-help methods (cues to action) that would decrease the associated risk of health diseases (i.e., cardiovascular disease, diabetes, stroke). Understanding and increasing PCOS education in Black women could decrease poor perceptions (perceived susceptibility) about developing adverse health outcomes. As well as increasing perceived control and beliefs caused by perceived barriers (ability to eat healthy, exercise, reduce weight, and control symptoms) to help manage and reduce symptoms of PCOS. In turn, this would increase their knowledge and understanding of their susceptibility to the condition. This could be done by assessing the value that is placed on engaging in health promoting behaviors (perceived benefits) among African American women with PCOS. Furthermore, the increase of PCOS education in Black women could improve the confidence and ability (self-efficacy) to change health behaviors that could result in a lifelong management of the condition. In addition, HBM constructs can be used to develop an instrument to assess PCOS related health knowledge, beliefs about health outcomes and confidence in lifestyle behaviors, and current self-evaluation of lifestyle.

Literature Review Related to Key Variables and Concepts

What is Polycystic Ovary Syndrome (PCOS)

PCOS, from a biomedicine perspective, is considered an endocrine disorder that impacts women of reproductive age. It is normally caused by a hormonal imbalance that is characterized by HA, ovulatory dysfunction, and PCOM (Azziz et al., 2016). PCOS is a complex disorder with reproductive, metabolic, and psychological features. PCOS can lead to several complications and is an independent risk factor for CVD, Type 2 diabetes, and obesity (Azziz et al., 2016). Since the etiology of PCOS is not completely understood, the known cause has not been found although genetic components have been identified (Wolf et al., 2018). PCOS was first defined in 1935 by Stern and Leventhal identifying women with obesity, hirsutism, and chronic OA (Goldrat & Delbaere, 2018). The clinical appearance is heterogenous and can be in several phenotype categories depending on the presence or absence of characteristic features such as infertility, hirsutism, acne, obesity, and menstrual dysfunction (Rao et al., 2020).

The diagnostic criteria and phenotypes of PCOS have been developed over years through different groups of experts and have been redefined but PCOS is still considered underdiagnosed due to the diversity of phenotypes manifested by this disorder (Dennett & Simon, 2015). The first attempt to classify PCOS was in 1990 by the NIH (Lizneva et al., 2016). These criteria included the presence of OA and HA but did not include ultrasound features. Later in 2003, The European Society of Human Reproduction and Embryology (ESHRE) and the American Society for Reproductive Medicine (ASRM) developed the ROT criteria consensus (Goldrat & Delbaere, 2018). Under this classification, women were diagnosed with PCOS if they showed two of the three following conditions: OA, PCOM, and/or HA. Years later in 2006, the Androgen Excess PCOS Society (AE-PCOS) published criteria that focused on HA as a mandatory or required diagnosis for PCOS (Wolf et al., 2018). In the most recent update, NIH recommended that the broad ROT criteria of 2003 be kept with the addition of four different phenotypes (Goldrat & Delbaere, 2018). All three of these criteria have different clinical, biological, and image-based findings that would determine the absence or presence of PCOS (Wolf et al., 2018).

The ROT criteria are the most widely used classification among scientific societies and health authorities even though the debate in 2012 never established which diagnostic criteria is most appropriate to use (Escobar- Morreale, 2018). Also, the recommendation to rename the condition was not adopted during the workshop in which experts stated that the term PCOS could be confusing to patients and primary health care physicians. This comes from the term polycystic which is the accumulation of ovarian follicles in different stages of maturation that appear in women with PCOS that is a single oocyte and are not cysts (Escobar- Morreale, 2018), which has led to the belief that the name PCOS could be considered a misnomer. The definition of PCOS has continued to bring disputes on whether women that have OA, PCOM, HA or who do not show signs have PCOS. The 2018 International Guidelines for PCOS were developed by the Center for Research Excellence in PCOS along with ESHRE and ASRM to provide evidence-based recommendations for PCOS diagnosis and management of health outcomes and quality of life (Goldrat & Delbaere, 2018). Due to the constant evolving diagnostic criteria, the prevalence of PCOS seems to continue to be difficult to determine with consistency and has been suggested that there are no criteria that could fully be sufficient for diagnosis (Wolf et al., 2018).

Although guidelines have been established to diagnosis women with PCOS there is still debate and controversy among experts and researchers on the definition of PCOS.

The etiology of PCOS remains unknown and is still poorly understood due to its heterogenous nature (Goldrat & Delbaere, 2018). Escobar- Morreale (2018) agreed and explained that the lack of interest from health authorities and the pharmaceutical industry is due to PCOS being poorly understood among scientists, patients, and even physicians. This has led to misunderstandings of the condition and its lifelong consequences for both the patient and their families which has resulted in limited research and resources in this area of study (Escobar- Morreale, 2018). The diagnosis, symptoms, and criteria for PCOS can be difficult to understand and medical professionals are still trying to gain full knowledge of the spectrum of reproductive disorders (Rao et al., 2020). Teede et al. (2018) further discussed how there is inconsistency in the management of PCOS, lack of the development of a rigorous best practice, and gaps in key evidence-based practices.

Misdiagnosis, missed diagnosis, overdiagnosis, and underdiagnosis has led to inaccurate diagnoses due to a lack of consensus and provider knowledge (Witchel et al., 2020). While all women with PCOS are not formally diagnosed, if they are showing signs or symptoms of PCOS it could take several doctors and years before being diagnosed (Rao et al., 2020). Researchers found over one-third of women with PCOS reported not being diagnosed until 2 years and three different health professionals later (Gibson-Helms et al., 2017). March et al. (2010) discussed that many women have no knowledge of having PCOS and up to 70% of women reported not being diagnosed. It was estimated that 75% or more women remain undiagnosed with PCOS when they visit their doctors (Wolf et al., 2018). Capturing more women with PCOS could lead to more screenings for comorbidities, linkage to proper care, and improvement of PCOS management (March et al., 2010).

Prevalence/Data of PCOS in Women

According to the CDC (2020) it has been estimated that the prevalence of PCOS in the United States (US) is between 6% and 12%. From previous studies the estimated global prevalence of PCOS is between 6% and 26% (Rao et al., 2020). Depending on the criteria used it can greatly affect the prevalence of PCOS (Wolf et al., 2018). Determining the prevalence of PCOS is made difficult due to the constant evolving of changes in the diagnostic criteria. The lowest prevalence rates were reported as being 1.8% and the highest being 18% in similar ethnic populations using the Rotterdam criteria (Wolf et al., 2018). Several factors can attribute to the variability in PCOS prevalence such as a heterogeneity in racial, ethnic, and age distribution in the sample population and the location of data collection (Rao et al., 2020). Wolf et al. (2018) explained why it is important to continue to encourage effectively using the diagnostic criteria because misdiagnosis only skews prevalence rates and could prevent women from getting the most accurate and appropriate care.

Some past studies have been conducted to access the prevalence of PCOS using different diagnostic criteria to define the syndrome. There have been a few systematic reviews and meta-analysis on published studies that have reported the prevalence of PCOS using at least one subset diagnostic criteria (Rao et al., 2018). The conclusion of all these studies have determined that the prevalence of PCOS differs on the Phenotypes that were defined and other factors that make diagnosing PCOS a complex multistep process (Lizneva et al., 2016). The prevalence of PCOS worldwide and in different geographical regions differ depending on the criterion used. According to the NIH 1990 criteria it ranges from 5% to 10%, 10% to 15% according to the AE-PCOS criteria, and from 6% to 21% using the ESHRE/ASRM 2003 criteria (Lizneva et al., 2016). It has been stated that the global and geographic prevalence of PCOS depends on the specific definition used to diagnose PCOS (Rao et al., 2020).

In one study assessing the prevalence of PCOS in 240 aged- matched women based on the diagnostic criteria found differences among each subset (Amato et al., 2008). The authors identified the prevalence of a PCOS in the population in Italy to be 83% in ROT criteria, 51% according to the NIH criteria, and 70.6% with the AE-PCOS criteria. These findings not only showed a difference in the prevalence but in an increase of the frequency in the severity of symptoms in the identified population (Amato et al., 2008). Yildiz et al (2012) conducted a study with 392 volunteers and found the prevalence to be greatly impacted by the diagnostic criteria. The participants were all female and mainly Caucasian aged between 18-45 living in Turkey. The results showed that the prevalence was lower in the NIH criteria at 6.1%, followed by 15.3% using the AE-PCOS criteria, and the highest using the ROT criteria at 19.9% (Yildiz et al., 2012). In a comparative study that sought to understand the prevalence among the three different diagnosis criteria it found few differences (Skiba et al., 2018). The results showed similar differences between NIH and AE-PCOS criteria and ROT and AE-PCOS criteria. This was mainly due to the added assessment of ovarian morphology and including women with PCOS who had ovarian cysts which is not all the time related to PCOS (Skiba et al., 2018). Wolf et al. (2018) further added that when clinician’s diagnose ovarian cysts as polycystic ovaries then misdiagnosis occurs and skews the prevalence rates as well. It was suggested that ovarian cysts should not be considered a symptom of PCOS. While there are specific universal guidelines that should be used, not all clinicians adhere to the recommended criteria.

Bozdag et al. (2016) conducted the first current report that presented a systematic review and meta-analysis evaluating the overall prevalence of PCOS using NIH, ROT, and AE-PCOS criteria in several different studies. NIH criteria had a 6% prevalence and the ROT and AE-PCOS had a 10% prevalence each. There were only 24 studies selected and only 2 were from the United States (Bozdag et al., 2016). The evaluated prevalence in these studies were categorized by geographical locations and estimated by continental specific prevalence. Skiba et al (2018) also found similar prevalence rates in the systematic review conducted on 21 studies between all three subsets of the diagnostic criteria. The findings indicated that based on the NIH criteria the prevalence was 12% and between 10-12% for both the ROT and the AE-PCOS criteria (Skiba et al., 2018). Both reviews concluded that the variation in diagnostic criteria used among populations and geographical areas could lead to under diagnosis of PCOS and skew prevalence rates significantly (Bozdag et al., 2016; Skiba et al., 2018).

There is limited research detailing the different geographical trends in the US (Wolf et al., 2018). One study known to be the largest prevalence study done on a geographically diverse population within the US was published in 2012 (Okoroh et al., 2012). The study compared regional prevalence and its phenotypes across the US being the first study to use all available criteria to estimate the prevalence. The study had access to medical charts that were previously completed, and a database was analyzed containing claim reports that were collected from 2003 to 2008 (Okoroh et al., 2012). The participants were women aged 18- 45 from geographically diverse states. The results showed a 47% higher prevalence of PCOS in the southern US than anywhere else in the US. The lowest prevalence was found in the North East with 10.3%. The West showed a prevalence of 18.7% and North Central with 23.0% (Okoroh et al., 2012). Only 1.6% of women reported meeting at least one of the diagnostic criteria for PCOS. Due to this study being a retrospective design the estimated prevalence could be relatively low.

Knochenhauer et al. (1998) conducted one of the first studies to estimate the prevalence of PCOS in unselected Black and White women in the Southeastern US. This article is relevant because there is limited research on geographical trends and prevalence among ethnic backgrounds (Rao et al., 2020). There were 396 consecutive women of reproductive– aged recruited to participate in the study. It was 174 White women and 195 Black women between the age 18-45 (Knochenhauer et al., 1998). The study consisted of obtaining body measures, body hair being quantified, completing a questionnaire, and having additional blood drawn. Trained nurses used the Ferriman- Gallwey (F-G) method to score the terminal hairs over nine areas of the body (Knochenhauer et al., 1998). The participants were group according to the score they received which was either 6, 8, or 10. The results showed there was no real significant racial difference with hirsutism prevalence's of 7.1% (scored 6), 6.1% (scored 8), and 2.1% (scored 10) in Blacks and 8.0% (scored 6), 2.8% (scored 8), and 1.6% (scored 10) in Whites. The presence of terminal hairs was examined over nine areas of the body (upper lip, chin, chest, upper and lower abdomen, thighs, upper and lower back, and upper arms) (Knochenhauer et al., 1998). The study reported no difference in the appearance of acne between Black and White women with Blacks with 5.2% and Whites 4.1%. Overall, despite the correlation between a higher prevalence in PCOS and a higher Black population there was no real significant difference between White and Black women in Alabama with a prevalence of 4.7% and 3.4%, respectfully (Knochenhauer et al., 1998). This study only used the NIH guidelines as diagnostic criteria therefore it did not include the PCOS definitions.

Another study that was similar and of importance in estimating the prevalence of PCOS was conducted using the same database and criteria from the previous study but with 400 reproductive aged women (Azziz et al., 2004). The participants included 223 Blacks. 166 Whites, and 11 of other races living in Alabama. The prevalence of hirsutism among Black and White women were 8.1% and 5.4%, respectfully. The prevalence rates of obesity and overweight was higher among Black than White women and the data compared to other studies suggest that there is significant ethnic difference in the prevalence of obesity and PCOS (Azziz et al., 2004). The authors suggested that there was no real significant difference among Black and White women with the prevalence of PCOS yielding 8.0% and 4.8%. Also, this study did not include the newer diagnostic criteria the ROT that was developed in 2003 and therefore did not include the additional phenotypes (Wolf et al., 2018).

In a more recent systematic review and meta-analysis on the prevalence of PCOS in different ethnic groups it was found that Black women had a higher prevalence of

7.4% compared to Chinese 5.6%, Whites 5.5%, and Middle Eastern 6.1%(Ding et al., 2017). The authors explained the need for ethnicity- specific guidelines of PCOS and the prevalence of PCOS in distinct ethnic groups had not been established. The study completed a comprehensive literature review of relevant studies retrieving 40 studies to evaluate the prevalence (Ding et al., 2017). The results of this study found that Black women, the majority African American, tend to have higher risks of developing PCOS. In comparison to White women there was a substantial difference in the potential of developing the syndrome. The study also revealed that more studies have been conducted on Caucasian women only than any other race (Ding et al., 2017). Wolf et al. (2018) agreed that there has been an ample number of studies assessed on Caucasian women in the US, Spain, and Australia determining the prevalence in different countries in this population. It was noted that again due to certain diagnostic criteria being used the variance in prevalence should be taken into consideration based on phenotype definitions (Ding et al., 2017).

Rao et al. (2020) conducted a more recent cross-sectional study to examine the prevalence of PCOS at a multiethnic university. The researchers conducted an online survey from students, faculty, and staff at Texas Woman's University (TWU) at three different campus locations. A survey was completed by 722 females and among those 60.8% were Caucasian, 15.2% Hispanic, and 10.5% African American (Rao et al., 2020). In addition, 12.2% of African American women reported not being sure if they had been formally diagnosed with PCOS and 40% (almost half) of the women reported symptoms consistent with the ROT diagnostic criteria yet not formally diagnosed. The authors argued that the prevalence according to the CDC 2020 (6% and 12% of all women) is one fourth to one half of the prevalence recorded in their (28.5%). It was explained that although TWU has a high diverse population it does not count for the higher prevalence of PCOS reported due to the population being mainly Caucasian (Rao et al., 2020). It was suggested that either there is a higher prevalence in Texas compared to the US or the CDC numbers are underestimates that may need updated. The study reported that due to various information missing only limited conclusions can be drawn from the results, but it does show that ethnic differences should be taken in account.

It should be noted that there is still limited research and epidemiological studies to determine the prevalence of PCOS more accurately among racial and ethnic groups (Wolf et al., 2018). Although, there have been studies that suggested there are no racial and ethnic difference among populations there is not enough existing data conclusive enough to establish whether significant differences exist. Azziz (2021) explained that there is still little understanding on the impact ethnicity, diet, and lifestyle have on the development of PCOS and the phenotypes. The need for greater numbers of epidemiological studies would help in identifying those answers. Wolf et al. (2018) further explained that many factors suggest further research is needed to evaluate the prevalence such as the lack of comparability studies, biased group selections, and small sample sizes. Also, improving the diagnostic criteria to help reduce the many women that go undiagnosed will help develop a more accurate prevalence which could be used to assess according to sub-populations. Azziz (2021) mentioned how research has been limited due to the lack of governmental investment which led to minimal support to the economic burden of the disorder.

Brakta et al. (2017) conducted a study evaluating if PCOS research was underfunded. The study examined grants awarded by the NIH for PCOS and three other disorders similar in degrees of morbidity or in prevalence. It compared funding for research from 2006 to 2015 for all four disorders. The results showed that PCOS was less funded than the other three disorders and more individual research grants were awarded to the other disorders (Brakta et al., 2017). The NIH is the largest single biomedical sponsor and invests nearly $30.0 billion annually in medical research. Of that $30.0 billion the study reported that over the ten years PCOS was awarded $215.12 million compared to $454.39 (rheumatoid arthritis), $609.52 (tuberculosis), and $773.77 (systematic lupus) million to the others. It was mentioned that during the study period that the PCOS research fund tended to decline (Brakta et al., 2017). Azziz (2020) suggested that this lack of support from governmental funders has made a negative impact on gaining more knowledge about the pathophysiology of this disorder to develop new therapies to help manage and treat the condition. Some of the factors stated that might be the cause of lack of funding for PCOS included diseases of women tend to be underfunded, limited research of PCOS in various institutes/centers, and PCOS being funded by only one institute of the NIH (Brakta et al., 2017). The National Institutes of Child Health and Development (NICHD) provided 68.4% of the funding for PCOS while the other disorders had at least two NIH institutes funding their research.

Brakta et al. (2017) explained that the NICHD is one of the lowest funded institutes within the NIH. Therefore, this could be the reason for the lack of funding of PCOS research and due to the discordance between the NICHD's mission and the pathophysiology of the disorder. Part of the NICHD mission stated that women should not suffer any harmful effects from reproductive processes focusing more on the reproductive consequences of a disorder (Brakta et al., 2017). PCOS on the other hand is also a metabolic disorder and includes origin of cardiovascular morbidity. Which receives little funding from the two institute centers that these disorders fall under and they are the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD). Less funding for PCOS research was also noted to be from the small pool of applicants and it seems to be a 50% decline in the number of applicants over the past decade (Brakta et al., 2017). Azziz (2021) stated that this could be a result from the difficulty in obtaining research support. There is currently no organization or institute that is tracking the prevalence or number of women being diagnosed with PCOS. In fact, the NICHD does not even mention PCOS in their current strategic plan (NICHD, 2020).

Signs/Symptoms/ Health Risks of PCOS

According to the Centers for Disease Control and Prevention (CDC, 2020) PCOS affects women of reproductive age at a rate of 6% to 12% (as many as 5 million) but a lot more than that. It has been reported that women with PCOS seem to produce higher amounts of male hormones which leads to a disruption in menstrual cycles, so women experience fewer periods (American College of Obstetricians and Gynecologists

(ACOG), 2020) PCOS is a syndrome where the group of symptoms affects the ovaries and ovulation. Common symptoms of PCOS include the following: severe acne on the face, chest, and back, weight gain, darkening of the skin, obesity, thinning hair, oily skin, infertility, multiple sacs in the ovaries, irregular menstrual cycles, skin tags, and excess hair (ACOG, 2020). The NIH (2017) explained that since oily skin, acne, and excess hair is not considered a serious problem to many women so most of the time the symptoms are rarely mentioned during health care visits.

Azziz et al. (2016) discussed how clinical studies found that acne affects 15%-25% of women with PCOS and varies with ethnicity. In addition, 65%- 75% of Black and White women with PCOS were found to have hirsutism. PCOS symptoms can lead to other long-term health risks and increased risks for other complications (Azziz et al., 2016). In one study conducted women reported PCOS symptoms that included negative emotional and mental health associated with being overweight and reproductive disorders (Arentz et al., 2021). It is important that women draw attention about their symptoms to their primary care physician so a detailed history can be obtained (Rao et al., 2020). Obtaining this information could lead to a thorough examination and used to gain a proper diagnosis.

PCOS signs and symptoms could vary in women due to its heterogenous nature making it difficult to visibly know if a woman has PCOS. Diagnostic criteria and symptoms could overlap in adolescent girls with PCOS due to physiological changes that occur during puberty (Mohammad & Seghinsara, 2017). Since most of the symptoms are evident in women of reproductive age it is only recent that risks and symptoms have been identified in prepuberty and postmenopausal women (Azziz et al., 2016). Early diagnosis in the adolescent group could allow for earlier prevention and treatment. While there is no cure for PCOS, medical professionals and researchers are continuously trying to increase their knowledge about the condition and best practices for treatment and management (Rao et al., 2020).

Escobar- Morreale (2018) explained that the focus and thinking should be less about the patient only having the disorder and more about the exposure of associated health risks that derives from the different phenotypes of PCOS. The author further discussed that many women will not all be vulnerable to the same health risks nor display all the manifestations of the disorder. Depending on the individual criterion defined in the diagnosis will determine the increased associated health risks (Escobar- Morreale, 2018). In essence, the more criteria met means the more severe characteristics of the phenotypes. All areas of the body can be affected by PCOS and increases the risks of long-term consequences caused by serious conditions (ACOG, 2020).

There are several health risks associated with PCOS. Some of the health problems associated with PCOS include heart disease, stroke, high blood pressure, diabetes, gestational diabetes, sleep apnea, and cholesterol (CDC, 2020). Women who are overweight are especially susceptible to these health problems. Dermatologic, oncologic, reproductive, metabolic, and psychological abnormalities have been detected in women with PCOS (Rao et al., 2020). Some women develop endometrial hyperplasia which increases the risk for endometrial cancer (ACOG, 2020). Women with PCOS have higher rates of cardiovascular disease (CVD) and the occurrence of PCOS increases the risk of type 2 diabetes (Williams et al., 2016).

One study reviewed patients with PCOS in the United Kingdom database and discovered that women with PCOS have twice as many health physicians' visits and higher systolic blood pressure and BMI (Morgan et al., 2012). The risks for developing diabetes were higher in those women with PCOS and endometrial cancer was increased. Metabolic syndrome (MetSyn) has also been found to be in twice as many women with PCOS than the general population due to one-half of women being obese (Williams et al., 2016). Mood disorders and depression seem to be another increased risk in women with PCOS. Screening for all associated health risks has been suggested for women with PCOS.

Screening women with PCOS can help with early detection and prevention of all associated health risks. Lua et al. (2018) discussed screening for type 2 diabetes, fasting lipid and glucose should be measured, and blood pressure should be taken at each visit. Screening could be dependent on ethnicity and race and should be evaluated and determined on an individual level. Associated health risks of PCOS have been shown to differentiate in different ethnic groups and populations so it's important to take that in consideration while screening (Morgan et al., 2012). Screening for CVD and sleep apnea should be considered especially those that are at high risk (Lua et al., 2018). PCOS has many implications that has effects in the short term and in the long term for the risks of chronic conditions; healthcare resources need to be available to reduce those risks (Hart & Doherty, 2015).

Treatment/Financial Cost for PCOS

There is no universal treatment for PCOS, and it is usually symptom- oriented (Escobar- Morreale, 2018). Women that display mild symptoms might not require much intervention other than lifestyle modifications. Escobar- Morreale (2018) discussed how there are no drugs that are officially approved specifically for PCOS but pharmacological treatment targets oligo- ovulation, androgen excess, and insulin resistance. Lifestyle modifications are usually the first line of treatment for PCOS, and these changes could improve infertility, metabolic dysfunction, ovulation, and mood swings (Azziz et al., 2016). Even with treatment, women could suffer from a lower quality of life due to PCOS (Bazarganipour et al., 2015). Treatment should be individualized to the actual personal needs and expectations of the patient (Escobar- Morreale, 2018). PCOS may not be treated or diagnosed until women experience troublesome issues and problems (Rao et al., 2020).

Women suffering with PCOS are at a higher long-term risk of developing multiple disorders so the management and treatment could vary based on changes in symptoms at various life stages (Rao et al., 2020). The Office of Women's Health (2019) listed different types of medicines to treat PCOS that include hormonal birth control (e.g., the pill, patch, shot, vaginal ring, or the intrauterine device), which can make menstrual cycles more regular, reduce extra hair on the face and body, and lower the risk of endometrial cancer. There are anti- androgen medicines that are intended to block the effect of androgens to help reduce acne and scalp and facial hair loss. But these medicines have not been approved by the Food and Drug Administration (FDA) to treat

PCOS symptoms and they might affect pregnancy (Office of Women's Health, 2019). The prescription drug Metformin, which is used to control blood sugar in people with type 2 diabetes, is used to treat women with PCOS symptoms due to improving insulin's ability to lower blood sugar and androgen levels. Researched findings showed that lower body mass and improved cholesterol levels in women with PCOS may be due to taking Metformin (Office of Women's Health, 2019).

Williams et al. (2016) explained that participating in a team approach by primary care physicians and specialist could be beneficial in tackling the manifold phenotypes of the disorder. In 2004 it was reported that the economic effect of PCOS surpassed $4 billion in the United States alone without incorporating the cost of the heightened risk of type 2 diabetes, obstetrical complications, and other disorders (Azziz et al., 2016). The cost of treatment and diagnosis may be an added barrier to women with PCOS (Rao et al., 2020). One study explored the inhibiting factors of adherence to treatment in women with PCOS and the results revealed that financial and insurance status prevented women from following up with treatment (Bazarganipour et al., 2017). Some participants even reported that the drugs were expensive, and it was a burden trying to get repeated prescriptions. The lack of adequate health insurance could delay the transition from pediatricians to adult care providers and prevent continuous quality service for women with PCOS (Rao et al., 2020).

PCOS in African American/Black Women

PCOS affects women of all race and ethnicities but it has different affects in each ethnic group. Black women, compared with White women, with PCOS have shown to have lower pregnancy rates due to less success with in vitro fertilization; Black women have, higher rates of obesity, increased rates of hirsutism, and higher risk of CVD and MetSyn compared to White women (Black Women's Health Imperative [BWHI], 2017). PCOS is associated with MetSyn that can create health concerns and issues such as obesity, diabetes, insulin, high blood pressure, and high cholesterol. Research has found that women of color suffer from PCOS more often than white women and since Black people have a higher rate of morbidity and mortality due to CVD and diabetes it's important to understand racial and ethnic differences among women with PCOS (Basile, 2020). There is still little to no statistical data among Black women with PCOS and there is little to no research found on PCOS and African American women specifically. However, there are a few studies that have included African American women in the sample, but the sample sizes are small therefore, true results might not be sufficient to draw accurate conclusions. Some research has been conducted on racial and ethnic differences in the prevalence of MetSyn and CVD risks in women with PCOS.

According to the CDC (2020) women are more likely to develop PCOS if their mother or sister has PCOS or type 2 diabetes. Yilmaz et al. (2018) conducted a systematic meta-analysis review examining cholesterol, hypertension, and MetSyn in mothers, fathers, sisters, and brothers of women with PCOS. The review examined 14 comparative studies providing significant evidence of increased prevalence of metabolic abnormalities in first degree relatives of women with PCOS compared to those who did not. Results showed an increase prevalence of MetSyn and cholesterol in PCOS mothers, hypertension and MetSyn in sisters, hypertension, cholesterol and MetSyn in fathers, and hypertension in PCOS brothers (Yilmaz et al., 2018). However, there were several limitations that included the sample being a selected population, PCOS mothers and fathers were significantly older than the control population, differences in diagnostic criteria might have caused inaccurate estimation of prevalence, and the small sample size of the studies. Also, there was less than a small percentage of Black women being represented in the sample which did not provide with sufficient data on that specific population. Maya et al. (2019) mentioned that conducting larger epidemiological studies in the ancestral women in the African American population could provide better insight to the origin of PCOS. `

A case control study examined racial disparities in the PCOS phenotype among Black and White women (Ladson et al., 2011). Participants were recruited from both Pennsylvania State College and Meharry Medical College (Nashville, TN). White women were recruited mainly from Pennsylvania State and Black women from Meharry College. It was reported that race has some influence on the PCOS phenotype (Ladson et al., 2011). According to their results it showed that there were no significant differences between Black and White women with PCOS that influences phenotype. Specifically, it was noted that the phenotype of PCOS seemed similar in Black and White women and may be more favorable in Black women. Ladson et al. (2011) discussed how there were higher- high density protein cholesterol levels (HDL), lower triglyceride levels, and lower serum creatinine levels in Black women with PCOS, compared to White women. Hillman et al. (2014) explained that those results were not clear enough to translate if there was a decreased risk for MetSyn or CVD. However, it was noted that there was a higher systolic blood pressure and increased BMI in Black women compared to White women with PCOS. This study concluded that their results showed little difference which might be due to not using the broader ROT criteria that could have shown more disparities among both races (Ladson et al., 2011). It was suggested that more research on racial disparities among races using a strict criterion could identify reproductive variances in women of difference races.

Hillman et al. (2014) conducted a retrospective cohort study to examine the prevalence of MetSYn and CVD in Black and White adolescents and young adult women with PCOS. Participants included 621 adolescents and adult women, which were made up of 106 Black subjects and 413 White subjects who were evaluated at PENN PCOS Center from January 2010 to January 2013. This was the first study to expansively demonstrate racial differences in both MetSYn and CVD in adolescents and adult women with PCOS. The results showed that both Black adolescents and adult women had significantly more cardiometabolic risk factors and a higher risk of MetSyn compared to White women with PCOS (Hillman et al., 2014). Specifically, Black older women compared to White older women had the following percentages represented below. Table 2 below shows the prevalence of MetSyn and its components compared to Black and White women with PCOS.

Table 2

Prevalence of Metabolic Syndrome and its components in Black and White women with PCOS

Variable	Black women	White women
	%	%
Age 20- 34 y		
MetSYn	40	22.6
BMI >30	72.7	51.7
Triglycerides >150	10.6	24.6
HDL <50	76.6	35.6
Blood pressure >130/85	45.5	31.9
Glucose >100	18.8	4.9

Although lower TG levels were shown in adult Black women compared to White women, metabolic abnormalities in Black women with PCOS were obesity, hypertension, and high glucose levels. Using the 10-year general CVD risk score it was noted that Black women with PCOS had a higher score (2.23%) than their White counterparts (1.42%). From the findings, it was suggested that early intervention and therapeutic lifestyle changes should be implemented in this high-risk population (Hillman et al., 2014).

PCOS being defined as a syndrome is often related mimicking disorders after the exclusion and inclusion of signs and symptoms (Maya et al., 2018). Research has made it clear that women of reproductive age with PCOS are at an increased risk of metabolic syndrome, diabetes, and CVD. MetSyn is a cluster of biological factors that are characterized by cholesterol, high blood pressure, type 2 diabetes, and obesity (Moore et al., 2017). There is a link between metabolic syndrome and increased chronic diseases such CVD and other conditions. According to the BWHI (2017), African American women with PCOS have higher risk of developing CVD and MetSyn. Although according to one study it was reported that Hispanic women have a higher risk of MetSyn than Black women (Engmann et al., 2017). The authors explained that since MetSyn is a progression for CVD and the prevalence of the syndrome by race and ethnic group in women with PCOS should be examined for early treatment. The study included 702 women including 476 White women (WW), 98 Black women (BW), and 128 Hispanic women (HW) all reported having PCOS (Engmann et al., 2017). The results of the study concluded that Hispanic women had a significantly higher prevalence of MetSyn compared to Black women (42.2% vs. 24.5%, respectfully). But the difference between Hispanic women and White women was insignificant (42.2% vs. 33.8%, respectfully). However, there was not a significant difference among BMI between the groups (HW 36.4%, WW 35.1%, and BW 35.7%). The results showed a difference among fasting glucose levels (WW 6.5%, BW 7.1%, and HW 14.8%) (Engmann et al., 2017). But Hispanic women and Black women showed a higher prevalence of systolic blood pressure compared to White women. The small sample size of Black women could have contributed to the higher prevalence of MetSyn in Hispanic women.

In another study data was examined from the National Health and Nutrition Examination Survey (NHANES) from over 3 periods starting from 1988 to 2012 (Moore et al., 2017). The data analyzed was looking at the prevalence of MetSyn by race and sex. Participants included were US adults aged 18 years and older and the results showed that the prevalence of MetSyn increased from 1988 to 2012. From 2007-2012 it increased from 25.3% to 34.2% overall. Black men and women, White men and women, and

Mexican men and women were the ethnic groups included in the study. Specifically, for Black women it was reported that Black women were more likely than White women to have MetSyn (Moore et al., 2017). For Black women, the prevalence of MetSyn increased from 30.6% to 36.5% and the major increase was attributed to obesity and hypertension. Many factors could have contributed to the increase in MetSyn in African American women and it is important to understand the trends of MetSyn and its components in African American women (Gaillard, 2018).

Studies and statistics have shown that African American women also have higher rates of obesity, high blood pressure, and blood glucose than their ethnic counterparts (Gaillard, 2018). Lower triglycerides and higher HDL have been reported among African American compared to White women (Kazemi et al., 2020). For this reason, the focus in this discussion will only be on obesity, high blood pressure, and type 2 diabetes in African American women. According to the Office of Minority Health (OMH, 2020) African American women have the highest rates of being overweight or obesity compared to other groups in the US, with about 4 out of 5 African American women are overweight or obese. African American women were 50% more likely to be obese than non-Hispanic White women in 2018. Between 2013- 2016 it was reported that 80.6% of African American women were overweight or obese with a BMI 25 or greater compared to 64.8 White women (CDC, 2019). Individuals that are overweight or obese are more likely to suffer from diabetes, high blood pressure, and LDL cholesterol (OMH, 2020).

According to Chan et al. (2017) Black women with PCOS had a higher BMI (37.5) compared to their White counterparts (30.6). Overall Black women with PCOS had the highest prevalence of MetSyn compared to the US White group. This was mainly contributed to the elevated BMI among African American women (Chan et al., 2017). Waist circumference (WC) plays an important role in the development of MetSyn. Abdominal obesity is defined as a WC greater than 88cm in women and varying among racial and ethnic groups (Gaillard, 2018). Using the NHANES III data it was reported that the percentage of abdominal obesity was 44.6% in African American women and 37.2% in White women. There was also an increase in WC trends for African American women in the NHANES data ranging from 38.25% to 68.8% from 1988- 2012 (Moore et al., 2017). Higher BMI and WC in African American women has been linked to an increased risk of PCOS in African American women and further research has been suggested in ethnic groups to determine the best treatment to manage the condition. Stockton et al. (2020) conducted a study that analyzed data from the University of Mississippi Medical Center (UMMC) and found that Black women with PCOS in Mississippi (MS) had a higher BMI than White women (39.3 vs. 36.0). It was reported that Morbid obesity was highly prevalent in women with PCOS in MS using the UMMC data. Marinos et al. (2017) agreed that Black women who are obese have a greater detrimental impact on their health than any other racial group.

According to Marinos et al. (2017) Black women have one of the highest prevalence rates of obesity and hypertension. In fact, African Americans are shown to have one of the highest prevalence of hypertension in the world (Gaillard, 2018). OMH (2020) reported that African American women are 60% more likely to have hypertension as compared to non-Hispanic White women. The AHA (2015) reported that African

American women suffer from higher rates of high blood pressure and CVD mortality compared to White women. Gaillard (2018) mentioned that the exact causes for hypertension in African American women are unknown. It has been suggested that hypertension tends to develop at a younger age in Black women which is often associated with a 5-fold increase in coronary heart disease (Marinos et al., 2017). CVD has been estimated to cause about 54,000 deaths each year in Black women (Marinos et al., 2017). PCOS is associated with a higher prevalence of CVD risk factors and the role of race/ethnicity could be a factor in determining the impact (Chang et al., 2016). In one study the impact of race/ethnicity on the prevalence of CV risk factors was evaluated on women with PCOS. The results showed that Black women with PCOS had a significantly higher difference in systolic and diastolic blood pressure than White women (Chang et al., 2016). Black women with PCOS reported having a hypertension prevalence of 37.1% and White women with 18.8%. Findings also suggested that there was a higher significance of hypertension in women with PCOS compared to the controls. The data suggested that PCOS increases the prevalence of hypertension among all racial and ethnic groups and should be considered in the management of PCOS (Chang et al., 2016).

In another study examining the metabolic components among different racial/ethnic groups of women with PCOS, the results showed that Black women with PCOS had a significantly higher elevated risk of hypertension compared to White women (Chan et al., 2017). Findings also showed that Black women with a BMI had a higher percentage of elevated blood pressure. Marinos et al. (2017) also found the high prevalence of hypertension could be due to 80% of their population of Black women being overweight/obese. Also, US Black women with PCOS had a higher risk for the 10-year general CVD compared to White women. Kazemi et al. (2020) conducted a systematic meta-analysis evaluating 11 studies documenting cardiometabolic health disparities in Black and White women with PCOS. The results concluded that Black women with PCOS had an increased systolic blood pressure higher than their White counterparts. In the study evaluating the cardiometabolic risk factors among African American women and White women with PCOS in MS, the results showed that African American women with PCOS had a higher mean arterial blood pressure than White women (Stockton et al., 2020). Future studies have been suggested to examine the racial differences in CVD in women with PCOS.

PCOS is also associated with insulin resistance and in earlier studies in the US showed that fasting insulin or insulin resistance was higher in Black women with PCOS than White women (Chang et al., 2016). However, it has been stated that more research needs to be done on racial differences among insulin resistance in women with PCOS. It has been reported that African American women are twice as likely to be diagnosed with type 2 diabetes compared to White women (Gaillard, 2018). Since type 2 diabetes is an outcome of MetSyn it is important to address the condition because those with type 2 diabetes have a higher prevalence of MetSyn. In 2018 the OMH reported that 12.7% Black women were diagnosed with diabetes while only 7.5% White women were diagnosed. According to the CDC (2020) women with PCOS are more likely to be insulin resistant which could lead to developing type 2 diabetes.

Chang et al. (2016) reported seeing a significant difference in fasting insulin among Black and White women with PCOS. The percentage was 15.6% in Black women and 10.5% in White women with PCOS. The fasting glucose numbers among the groups were 92 in Black women with PCOS and 89 in White women with PCOS (Chang et al., 2016). In another study evaluating MetSyn components, the results of a fasting glucose among Black women and White women in the US with PCOS was significantly different, 28.6% and24.3%, respectfully (Chan et al., 2017). In the systematic meta-analysis, it was concluded that overall Black women with PCOS had an increased insulin of 59.0% compared to White women with PCOS (Kazemi et al., 2020). Stockton et al. (2020) examined MetSyn components in Black and White women with PCOS in MS and found that Black women with PCOS had a higher hemoglobin A1C of 6.03 compared to 5.63 in White women with PCOS. PCOS is a risk factor for developing type 2 diabetes and insulin resistance is seen in about 50%- 80% of women with PCOS (Orio et al., 2016). Chang et al. (2017) recommended that more attention needed to be given in the screening of Black women with PCOS for hypertension and type 2 diabetes. More research has been suggested to examine racial/ethnic differences in women with PCOS to determine genetic and environmental factors that could increase prevalence of type 2 diabetes.

According to Orio et al. (2016) women with PCOS have a higher prevalence of overweight and obese than the general female population. CVD risk factors has been shown to be increased in women with PCOS and early screening is recommended to prevent or implement treatment. Specifically, for African American women with PCOS there is a tendency to have a greater cardiometabolic risk profile (Kazemi et al., 2020).

These observations should guide future recommendations for diagnostic, monitoring, and management practices in African American women with PCOS. Maya et al. (2019) explained the need to conduct epidemiological studies of PCOS in Africa due to the complex prehistoric genetic trait. Looking into the insight of the origins of PCOS through an epidemiologic study of different groups around the globe could reveal more ancestral characteristics that leads to the prevalence of the disorder. It was noted that there is not much significant data from Africa, South America, or Northern Asia with the few exceptions of the paucity of studies among Black women in other countries (Maya et al., 2019). The need for more large-scale epidemiological studies highlights the lack of research among Black women in Sub-Saharan Africa despite the need to address women's health regionally and globally. Conducting further research among Black women with PCOS could show more association with additional or more severe morbidities (Maya et al., 2019). The current data suggest that more epidemiological studies are needed among unselected populations to address the gaps of this highly prevalent disorder. Chang et al. (2017) recommended that more attention needed to be given in the screening of Black women with PCOS for hypertension and type 2 diabetes.

Diagnosis Experiences/Knowledge of PCOS in Women

There is little to no research on the diagnosis experiences and knowledge of PCOS in African American or Black women specifically. It has been suggested that additional research should be conducted on the racial/ethnic differences in women with PCOS and the experiences and knowledge that is available to them in the management of the condition (Gibson- Helm et al., 2017). There have been studies conducted examining the knowledge and experiences of women in different countries and in the US. Very few studies have addressed the diagnostic experience of women with PCOS and the knowledge given by their health care provider. Rao et al. (2020) expressed the need to explore the different aspects of women's awareness and understanding of PCOS and identify their sources for information. Exploring the knowledge and experiences in different ethnicities of women with PCOS could better help develop education materials and resources that tailors to their specific needs.

Gibson- Helm et al. (2014) examined the perceived diagnosis experience of women with PCOS that lived in Australia through a cross-sectional study. This study included 210 women from a community-based sample with a previous medical diagnosis of PCOS. The results showed that 24% of women reported not even knowing about their diagnosis until after seeing about two to three health care professionals over a span of two years. Some women reported the process being prolonged and frustrating and they received inadequate PCOS information (Gibson- Helm et al., 2014). In addition, 62% of the women felt the information given about PCOS was dissatisfying and left for unmet informational needs. In another similar study, the diagnostic experience was examined using online questionnaires with 1385 women who reported a diagnosis of PCOS living in North America, Europe, and other regions (Gibson- Helm et al., 2017). The results resembled the previous study, showing reports of delayed diagnosis and lack of information provided from health care professionals. Only 17% of the participants were from Africa and the study does not provide racial data from the US. The participants also discussed their experiences and concerns of irregular cycles, increased facial hair, and difficulty losing weight (Gibson- Helm et al., 2017). Other known experiences noted were increased metabolic risk factors, type 2 diabetes, and cardiovascular risk factors. Over half of the women were dissatisfied with the delayed diagnosis and poor diagnosis experience. The authors explained that due to variations of PCOS features in ethnic origins, genetic factors, and environmental factors leads to delayed diagnosis. This is one of the reasons why specifically tailoring research towards different cultures and ethnicities could provide better health outcomes for women with PCOS (Gibson- Helms et al., 2017).

Dokras et al. (2017) conducted an online survey through the American College of Obstetrics and Gynecology of gynecologist (ObGyn) and American Society of Reproductive Medicine of Reproductive Endocrinologist (REI- ObGyn) to identify gaps in PCOS knowledge among physicians in North America. There were 630 responding participants living in North America with 70% being ObGyn and 29.8% REI-ObGyn. The REI-ObGyn reported seeing about 50-200 women with PCOS per year and the ObGyn reported seeing fewer than 50 women with PCOS per year (Dokras et al., 2017). More than half of the physicians were over the age of 45 and 64.4% were women physicians. Of those physicians, 27.2% reported not knowing which diagnostic criteria they used to make the diagnosis of PCOS or listed criteria not on the guidelines by the ROT and NIH. The prevalence of PCOS was reported to be between 11%- 20% and most of the physicians recognized the clinical features associated with PCOS and identified type 2 diabetes, body weight issues, and cardiovascular disease as potential risks. Overall, the results showed that a large number of physicians were still not sure of the currently recommended criteria for the diagnosis of PCOS and it highlighted the opportunity for the improved training of education in physicians to increase better diagnosis of PCOS (Dokras et al., 2017).

Many women with PCOS experience different symptoms and have co-morbidities that may have a negative impact on their quality of life. Living with PCOS can be very different for women of different ethnic backgrounds and culture and addressing those concerns would be beneficial in determining the best management practices for PCOS (Williams et al., 2015). In a study conducted using skype interviews, women with PCOS discussed their experience of living with PCOS. There were 10 women from the UK with their age ranging from 20- 41 years old who were suffering from symptoms of PCOS (Williams et al., 2015). The interviews were completed by skype voice call only and lasted between 40-90 minutes. Nine of the participants reported suffering from co-morbidities such as depression and hyperthyroidism. Themes that emerged from the study included identity (feminine identity), change (life plans and changing nature of condition), co-morbidities (living with other health conditions), and support (healthcare professionals and education). Tomlinson et al. (2017) conducted a study exploring the lived experience of women with PCOS in the UK and similar themes emerged such as support, delays and barriers to diagnosis, and risk of other medical conditions such as diabetes and depression. More themes developed from this study such as lack of empathy by healthcare professionals, inconsistent and unsatisfactory experience with medications, and lack of information from professionals (Tomlinson et al., 2017).

Both studies reported lack of support from healthcare professionals and having to seek several different physicians before getting a formal diagnosis of PCOS. Due to the lack of straightforwardness that the diagnosis of PCOS provides a lot of women are left uncertain about their condition (Tomlinson et al., 2017). There are a lot of emotional and social consequences of living with PCOS. Addressing the specific needs of women with PCOS individually and culturally could improve the experiences of women with PCOS. Ee et al. (2020) also found significant concern through a study exploring the experiences of Australian women who were overweight/obese with PCOS through focus groups and semi-structured interviews. There were 10 women aged 27- 46 who self-reported being diagnosed with PCOS and meeting the ROT criteria through social media and paid advertisements (Ee et al., 2020). The themes that emerged from the study were referred as “the whole package deal” because of the complex nature of PCOS and the multiple manifestations of the condition. Similar concerns that were discussed in previous studies were also found in this study such as delayed diagnosis, the need for support, and implications from other health conditions. Future research on the varied aspects of the disorder and the dynamic and diverse nature of PCOS in women of different ethnic background could improve the guidelines to a multidisciplinary approach (Ee et al., 2020).

Most women have a basic understanding about PCOS, and the associated symptoms and health risk related to the condition (Lin et al., 2018). However, there is little to no research on the perceived knowledge about PCOS among African American women with PCOS. Lin et al. (2018) expressed that there is limited understanding about the actual health- related knowledge and beliefs among women with PCOS and conducted a study addressing the knowledge gap between women with PCOS and a comparison group. The participants were 475 US residents between the age 18-38 years old and were predominately white. Although the study did include 18 Black women with PCOS and 14 Black women without PCOS, findings related to racial/ethnic backgrounds were not reported (Lin et al., 2018). Overall, the results showed that there was a lot of misconceptions about the diagnostic criteria for PCOS and women with PCOS relatively had a lower health related belief than the comparison group. Women with PCOS also believed that they were more vulnerable to adverse health outcomes and weight issues. The PCOS group also revealed knowing basic government dietary guidelines but not specifically targeting management of PCOS. Suggestions for more studies to be performed in order to examine the knowledge among different geographical, racial, and ethnic groups to help identify beliefs and barriers were mentioned (Lin et al., 2018).

In a study trying to identify the knowledge of PCOS through surveying a multiethnic cohort of students, faculty, and staff at a university school in the US, 769 participants over the age of 18 responded to the survey from different ethnic backgrounds (Rao et al, 2020). Of the 769 participants 47 of them were males and 89 of them were African American. The study did not detail if the 89 African American were all women or if those included men. The results showed that the perceived knowledge about PCOS from women revealed that 21.7% of women knew nothing about PCOS, 66.3% of women knew some information about PCOS, and only 4% reported knowing everything about PCOS (Rao et al., 2020). In contrast, a study conducted in Perak, Malaysia evaluating the knowledge, attitude, and perception of PCOS among young students in higher educational institutions (Hussin & Abd Kadir, 2020). The participants included 163 females and 56 males from several different public and private institutions in Perak. Compared to the US study, this study reported that the level of knowledge regarding PCOS among the students were a high level with a 92.2% having adequate knowledge. However, the study did reveal that many of them, although having a good knowledge of PCOS, still were unaware of what their signs and symptoms of PCOS looked like because many were present in them (Hussin & Abd Kadir, 2020).

Omagbemi et al. (2020) examined the current knowledge and perceptions about PCOS in 387 women in Nigeria. The sample was recruited from a tertiary institution at the undergraduate and post graduate levels including students who were staff with ages ranging from 15- 50 years old. According to the results, 56.8% of the respondents indicated that they had never heard of PCOS, 67.2% responded that PCOS is not a curable disease, 52.5% indicated that hormonal imbalance is not a key feature of PCOS, and 76.0% were not aware that PCOS was treatable (Omagbemi et al., 2020). Most women perceived that their genetic makeup increased their risk of having PCOS and associated PCOS with a poorer quality of life and additional health problems. These findings suggest that the etiology is still unknown in women and health practitioners even in Nigeria and addressing the knowledge is essential for creating educational opportunities. These studies could give insight on the need for more education and awareness about PCOS in different geographical areas that lack the understanding of the disorder.

Self- Management/Education and Programs for PCOS

Self- management has been defined as the individual’s ability to manage the symptoms, treatment, and physical and psychological outcomes, and lifestyle changes implicit to living with a chronic condition (Dwarswaard et al., 2015). Lin et al. (2018) explained that there could be an association between the high attrition rates in intervention studies and less engagement in self-help methods due to the complex nature of PCOS. According to Kozica et al. (2013) there is limited research available exploring self-help in women with PCOS and it is crucial to explore self-help behaviors in PCOS to guide future interventions. In addition, more research found that there is a lack of structured education programs for women with PCOS which could increase understanding of the condition and promote self-management strategies for a lifestyle change (Mani et al., 2015). There is little to no research and information on education and support specifically tailored for African American women with PCOS.

The purpose of self- management interventions is to allow the individual to gain empowerment and increase confidence to handle long term health conditions (Mani et al., 2015). From previous research and studies, it has been clearly stated that women with PCOS feel like they are not being taken seriously. The themes that have emerged from their lived experience are feelings of frustration, loss of control, confusion, lack of information, or searching for adequate information. In order to successfully self-manage the signs and symptoms of PCOS women will need to have sufficient and accurate information about the condition available to them (Mani et al., 2015). Offering more information and educating women with PCOS will help improve their understanding of causes and treatment choices which could increase the quality of life in women with PCOS. The lack of information, education, and support provided to women with PCOS has been associated with poor health quality of life, and less motivation to engage in managing the condition (Hadjiconstantiou et al., 2017). Specifically, there has been no research conducted exploring the education and support on African American or Black women with PCOS alone.

Rao et al. (2020) conducted a study that included a small sample of African American women that included men regarding the sources of information about PCOS obtained. It was reported that African American women and men were less likely to use social media to gain information compared to Caucasians and less likely to see information from health care professionals, family, or friends. The results also suggested that there are ethnic and educational differences that exist and should be considered when developing education materials for women with PCOS (Rao et al., 2020). Gibosn- Helm et al. (2017) also observed the symptom differences in different cultures and ethnicities; the lack of awareness, accessibility, and suitability of resources may all be contributors to the information needs not being met. It is important to increase the awareness about PCOS and its associated health risks among ethnicities because early development could reduce risks of other health conditions.

Women with PCOS also expressed lack of education and support from health care professionals' feelings of being pushed to the side because their condition was not considered serious (Williams et al., 2015). This resulted in many women seeking information from other sources like the internet and trying to educate themselves about the condition. Some women expressed feeling exhausted and overwhelmed with information and understanding it was sometimes confusing. Tomlinson et al. (2017) reported women feeling a lack of empathy from their doctors and not being given an adequate amount of information to begin managing their condition. Consistent with previous research, in another study women reported seeing their doctor and was just given medication to treat their symptoms and received no education about the condition (Ee et al., 2020). Hadjiconstantiou et al. (2017) discussed how women wanted to see more education materials in hospitals, doctor's offices, and clinics so they would not feel embarrassed to ask for help or advice. Some women felt like the it was too "hush, hush" and even the doctors seemed uneducated on the condition.

There is little to no research of structured education programs that offer education and support for women with PCOS. Mani et al. (2015) expressed how there is a lack of evidence for structured education programs for women with PCOS. The need to understand the condition and interaction with peers to increase knowledge are the main elements of a basic group structured education program. Some women have found support and education through online support groups claiming they have more knowledge and reduces the feeling of loneliness and isolation (Williams et al., 2015). It allowed them to feel empowered and connected to other women with PCOS that can offer information and advice. Sometimes online forums could offer women the ability to find other women with the same symptoms and struggles and it is easier to relate to them (Ee et al., 2020). Mani et al. (2015) expressed that although online support groups may be beneficial it also lacks a direct interaction with others and the level of peer support. It was suggested that there is a positive association with peer support groups among women with PCOS.

Hadjiconstantiou et al. (2017) reported women with PCOS being supportive of education sessions with other women with the same condition to provide encouragement and being able to share their experiences. However, some of the women felt that group sessions might not be suitable for them due to privacy concerns and not knowing the other women personally. One participant offered the suggestion of grouping women with similarity in age and cultural background (Hadjiconstantiou et al., 2017). Mani et al. (2018) conducted a single randomized control trial study evaluating a single exposure to a group based, face -to -face, structured education program with an intervention and non-intervention group. The study included 161 women with PCOS with the majority being White (69%) and 10% being Black women. The program consisted of 7 hours of interactive discussions over various topics related to PCOS symptoms, balancing life with PCOS, and a self-management plan. Each session was taught by a trained educator and participants received resource packets summarizing every session and at the end of the day participants were able to reflect on what they had learned (Mani et al., 2018). The results showed improved feelings of living with PCOS, sense of relief after being diagnosed, increased understanding of their condition, and improved illness perception or quality of life. However, the researchers did not specifically address if the education materials were tailored to cultural backgrounds. The findings also suggested more funding applications to design web-based interventions in addition to group-based interventions.

Summary

The primary goal of this research was to explore the knowledge and experiences among African American women with PCOS. The literature that was reviewed in this study highlights the known and unknown regarding the various aspects of PCOS among women with PCOS. PCOS is an overly complex disorder with reproductive, metabolic, and psychological features (Escobar-Morreale, 2018). PCOS can lead to several complications and is an independent risk factor for cardiovascular disease, type 2 diabetes, and obesity (Azziz et al., 2016). African American women with PCOS have a higher risk of developing cardiovascular disease and metabolic syndrome (BWHI, 2017). It is still unknown the exact prevalence or percentage of African American who reports a diagnosis of PCOS or those that are managing other health conditions. There is still little to no statistical data among Black women with PCOS and there is little to no research found on PCOS and African American women specifically. There is no national organization tracking the prevalence or percentage of African American women diagnosed with PCOS and there is limited funding and research from NICHD and other national institutes to provide additional studies regarding PCOS in geographical areas or among different ethnic groups.

There is no cure for PCOS and improving awareness, education, and support for women with PCOS is vital in the management of the condition. Concerns about PCOS among women vary across world regions and individualizing resources and information to fit the needs culturally, could help improve the understanding of PCOS among different ethnic groups. Research that has been conducted only included small samples of

African American women with PCOS and there was no information or education specifically tailored for this ethnic group specifically. The need for structured education programs that provide education and support for women with PCOS has been recognized and little to no research provided specific education for African American women. Therefore, this research endeavors to uncover factors that will add value to future development of educational materials for African American women with PCOS. The principal factors cited in the literature as affecting the lack of education in African American women with PCOS are an inaccurate prevalence of African American women diagnosed with PCOS; lack of studies tailored towards African American women with PCOS, specifically; lack of information; delayed diagnosis; general education materials, rather than tailored specifically for African American women with PCOS; small samples of African American women with PCOS in the research; and lack of structured educational programs available for African American women with PCOS. A major limitation is paucity of information on the knowledge and experiences of African American women with PCOS to help manage the condition. The discovery for the need to conduct a qualitative research study and uncover the experiences and current knowledge could lead to the improvement of education awareness and self- management of the condition. The information from this research can be shared with other sectors, researchers, and health educators to design more effective health promotion programs for African American women with PCOS.

In chapter three, the research design is introduced, including the role of the researcher, the participants, the instrument, procedures, and data analysis. The interview protocol is discussed which consists of the institutional review board’s (IRB) compliance statement, the interview guide, and ethical procedures. The coding method is outlined to help find descriptive themes, concepts, and patterns of codes from the data. Trustworthiness criteria is discussed to ensure the rigor of qualitative findings. The methodology and sampling strategy is described to help identify the participants and the selection criteria.

Chapter 3: Research Method

Introduction

In this chapter, I reviewed the qualitative method and basic qualitative research design that was used to collect data on the knowledge and experiences of African American women with PCOS. Merriam (2009) stated that the basic qualitative research approach attempts to uncover the participants' experiences, the meaning the participant ascribes to those experiences, or a process. Qualitative research allows for the collection of data to be analyzed for themes and perspectives of the participants (Creswell, 2013). Due to this, the basic qualitative research approach was used for the study. This chapter discussed the research design, the role of the researcher, process and procedures, data collection and analysis, issues of trustworthiness, and ethical procedures.

Research Design and Rationale

Qualitative research was the best method for this study because it grants the permission for the collection of data to be analyzed for themes and perspectives of participants, an idea posed by Creswell (2013) as a key component of qualitative studies. The chosen approach was the basic qualitative research design. This approach aligned with the research questions because in basic qualitative research design the researchers are interested in how people interpret their experiences and what meaning they attribute to that experience (see Merriam, 2009). The focus of the basic qualitative research design was to seek how the experience can be described or explored. A basic qualitative study can be used to uncover strategies, techniques, and practices (Worthington, n.d.).

I used a basic qualitative research design to guide the research to obtain broader understanding of the knowledge and experiences of the barriers, issues, and culture behaviors associated among this ethnic group with PCOS. During the interview process, I used interview questions designed for qualitative research to gain significant information and evaluate the responses of the participants. The overarching purpose of this research study was to explore the knowledge and experiences of African American women with PCOS. The three research questions were as follows:

RQ1: What is the current health-related knowledge of PCOS in African American women with PCOS?

RQ2: What are the symptoms/experiences of African American women with PCOS both before and after diagnosis?

RQ3: After diagnosis, how have African American women managed PCOS symptoms in terms of self-help?

Role of the Researcher

As the principal investigator in this research study, my role of the researcher as a data collection instrument was especially important because I was learning the process of collecting data and coding qualitative data. It was a journey learning how researchers are shaped by the research process which, accordingly Palaganas et al. (2017), can be an empowering process. Data is mediated through a human instrument and there are different aspects that are included to conduct this research (Greenbank, 2003). The role of the researcher as an instrument should include keeping a journal of personal reactions and reflections (Greenbank, 2003). I kept a journal throughout the interview process.

Researchers are changed in many ways due to conducting research, specifically fieldwork. My role as the researcher consisted of designing the study, developing the protocol, developing the instrument, recruiting, and screening the participants, conducting interviews, collecting data, transcribing the data, and coding and analyzing the findings.

The research was conducted in a manner to make every effort to reduce any harm to the participants (see Creswell, 2013). I contacted each participant individually and personally to increase the chances of the study being successful. I protected the confidentiality of the participants and all their responses with every ethical consideration possible to reduce conflict of interest. In efforts to remain confidentiality of each participant, informed consents were given to each participant, any identifiers obtained remained anonymous and was removed from the data set ensuring the privacy of the participant during the interview (see Petrova et al., 2014). I created a master list using Microsoft Word to connect each participant that conducted an in person interview to their informed consent using pseudonyms. The master list was password protected and the informed consents were locked away in a cabinet with a secure padlock. The recordings were deleted once fully transcribed. Discussing confidentiality with the participants at the beginning of the research study was important and I also explained explaining the nature of the study and for the purpose of the collected information (see Kaiser, 2009).

I have a personal experience with the topic, and I am compassionate about researching more about the topic to help educate and support not only African American women but all women that suffer from PCOS. I may share a similar experience with

PCOS, which led to the interest in the topic and could bias the interactions and results. It was easy for me to empathize with the potential participants and understand what they are going through and how they felt when they first got diagnosed. This could have led to some researchers bias due to the personal experience and sharing the same feelings of the participants. Interview bias can be minimized by remaining neutral in facial expressions, body language, and tone of voice (Shah, 2019). Refraining from offering opinions and recording all interviews and keeping notes or a journal of the interview process are other ways to minimize the potential for bias (Shah, 2019). I chose to minimize by not offering opinions, remaining neutral in facial expressions, body language, and tone of voice. Another bias that could occur is confirmation bias, which is when a researcher interprets the data to support their own research question or omit data that does not favor their research question (Shah, 2019). I considered all data collected and analyzed it with an unbiased mind. A researcher should not have any preexisting assumptions and continue to evaluate impressions and responses (Shah, 2019).

Methodology

Participation Selection Logic

Purposeful sampling was done to select African American women with PCOS who live in and around the Northern Region of Mississippi. The reason a purposeful sample was drawn was because it yielded for a more in depth of insight and understanding rather than just generalization (see Patton, 2002). Studying information rich cases allows a researcher to learn more about the central importance of issues to the purpose of inquiry (Patton, 2002). Identifying and selecting this group of individuals are usually knowledgeable or experienced with the research study at hand (see Creswell & Plano Clark, 2011). The following criteria were required for participation:

- African American or Black women
- Target ages ranging from 21- 45 but young or older may be considered depending on the participants who agree to study. Participants will not be younger than 18.
- Diagnosed with PCOS not less than 3 years
- Currently living in or around the Northern Region of Mississippi

Women interested in the study completed a screening survey to determine eligibility. Women having a clear diagnosis of PCOS based on the ROT was asked to participate in an interview. The number of participants recruited for the study was 12. Qualitative study samples are generally much smaller than quantitative samples (see Mason, 2010). In one study, the author's sample size was 15 participants using purposive sampling and continued until data saturation was reached (Naz et al., 2019). It is the researcher's role to determine saturation in this study. Naz et al. (2019) also used in-depth semistructured interviews to collect data and thematic analysis was used to analyze the data, which is like my study.

Bazarganipour et al. (2017) conducted a study with a purposive sample of 20 women with a confirmed diagnosis of PCOS between the ages 21-34. The study used in-depth, semistructured interviews to collect data. Saturation point was reached after analysis with participant 18 (Bazarganipour et al., 2017). Saturation cannot be determined before research and data collection; it will be dependent upon at what point there is no new information emerging (Guest et al., 2006). I determined saturation was reached by reading the transcriptions 3 times. Tomlinson et al. (2017) stated that after three members of the research team read the transcriptions independently, it was clear that saturation had been reached.

The participants were mainly identified from social media, local churches, and the church health clinic. Flyers were posted in all locations. I also contacted the clinics and asked for support in approaching their patients. There was a QR code on the flyer for potential participants to scan and obtain my contact information. Respondents were screened and if they met the study criteria, I asked them to continue with the study. I emailed all selected participants an invitation to participate in the study and once accepted the participants were sent a consent form to read over. If the participant agreed to an interview via an online platform (Zoom) they were asked to reply to my email with the words “I consent”. Participants who preferred to be interviewed face-to-face signed the consent form before the interview. I used the consent form to gain permission from the participant to interview them and use all data collected.

Instrumentation

I created the interview questions used for data collection. The questions were developed based on the research questions and the research purpose. I used information from the literature and similar questions from previous studies to create the interview questions. The questions were guided to answer the research questions. The interview guide was used to help create the interview questions. Some specific examples from the interview guide included using open-ended questions, asking probing questions, using an introduction to the interview, and using questions to close the interview. I also developed questions to help participants explain personal experiences and the meaning of those experiences. I used constructs from the theoretical framework HBM to create the semistructured interview questions. My process was like Lin et al. (2018), who developed an online instrument using some of the HBM constructs to assess the participants beliefs about the severity of adverse outcomes and the perceived susceptibility to adverse health outcomes. Lin et al. (2018) reported that most of the women with PCOS had misconceptions about diagnostic criteria and PCOS was associated with greater perceived susceptibility for disease and weight gain and poorer perceived control over these health outcomes. I created notes to help them stay on task with the interview questions. The interview questions I asked during data collection interviews are located in Appendix E.

The interview protocol consisted of the IRB compliance statement, the interview guide, and ethical procedures. I used the interview guide to lead me through the interview process. Ideally, I hoped to conduct all interviews face-to-face but using Zoom technology was also an option provided to participants. I completed nine interviews via online Zoom and three interviews face-to-face. Zoom technology is a video conferencing software available free online. All zoom interviews were recorded via Zoom. The Zoom meeting was passcode protected so that only I and the participant were able to enter the meeting. Within the interview guide, I used an invitation to participate in the study, introductory statement, interview questions, and a closing statement. The instruments used to collect data and guide this research included the recruitment flyer, the screening questionnaire, invitation to participate in study, demographic questions, and interview questions. Data will be kept for 5 years in case needed for related other research opportunities.

The first instrument used was the recruitment flyer which was posted on social media, at the local churches, and at the Church Health clinic. Permission was obtained to put flyers in health clinics. The flyers had a QR code for potential participants to scan to obtain the researchers contact information. Once interested participants contacted the researcher, then the invitation to participate in the study and the screening questionnaire was emailed prospective participants. Participants either replied with the words “I consent” or signed a consent form before the study depending on location of interview. The opened- ended interview questions was asked to generate qualitative data.

An audio recorder app called voice recorder on a cell phone was used to capture the data verbatim from each person that conducted a face-to-face interview. All interviews conducted via the online platform (Zoom) was recorded through Zoom. The data was then transferred to my computer to be stored and password protected. To prepare for the success of each face-to-face interview the audio recorder was checked prior to each meeting to ensure that it was in good working condition. The Zoom recording was also checked prior to each Zoom interview. I kept an extra cell phone with the same audio recorder app available as a backup to collect data. Although the responsibility of all instruments relied on the researcher, reviewing of the literature helped to mirror similar instruments and questions used in previous studies.

Procedures

After approval was obtained from Walden's Institutional Review Board (10-19-21-0752709), approval to advertise the study was requested from doctor offices, health clinics, churches, community centers and organizations in the Northern Region of Mississippi. African American women with PCOS was recruited mainly from social media, local churches, and the Church Health clinic. I created and developed the flyer (See Appendix A), the consent form, the invitation to participate in the study (See Appendix B), the prescreening interview questionnaire (See Appendix C), the demographic questions (See Appendix D), and the open- ended interview questions (See Appendix E). I conducted both face-to-face and an online platform (Zoom) semistructured interviews. The scheduling of the interviews was dependent on the days and times that work for both the researcher and interviewee. To ensure that the interview process was smooth, I arranged the interviews during times of privacy, quietness, and to limit interruptions. The interviews were conducted in a neutral private location. A local church (Spirit of Excellence) meeting room and one of the Church Health clinic's meeting rooms was provided for the participants to ensure comfortability and seclusion. Verbal permission was granted to use both facilities. Interviews that were conducted via Zoom was conducted in a private location or area of the researchers and participants choice. An audio recorder app on a cell phone was used to record the face-to-face interviews and Zoom interviews was recorded on Zoom. I used a privacy focused transcription to speech software called Transcribe by Wreally to transcribe all interviews. I collected and transcribed all data.

I conducted on average two to three interviews a week and the interviews lasted between 25- 90 minutes. Prior to the interview, each participant received notification of time and location if conducting a face-to-face interview or received a Zoom link to join the meeting if interview was conducted via Zoom. Participants that conducted interviews via Zoom had already read the consent form and replied with the words “I consent” and those that conducted the interview face-to-face signed the consent form before the interview began. All interviews began with an introductory statement. The data was collected through semistructured interviews via face-to-face or online using Zoom. At the end of each interview, I asked each participant to add or share any other thoughts or experiences regarding PCOS. I then provided a closing statement regarding words of thanks and instructions about how data will be analyzed and transcribed and if there are any additional follow up questions or clarification needed that each participant would be contacted directly. After all interviews were completed, I analyzed the data to depict the themes and the data that arose from the interviews. I categorized all data to protect anonymity of each participant.

Data Analysis

The data collected from the screening interview, transcribed interviews, in-depth face-to-face interviews, field notes, including observation notes, and the transcripts of the participant experiences was coded using a Qualitative Data Analysis (QDA) software (https://atlasti.com/). I purchased the Atlas.ti software to analyze and code all data. Atlas.ti was used to code all the data and group them into categories. I also categorized the data so it could be easily retrieved for information and analysis. A coding system such as P1, P2, etcetera. was developed to identify each person and provide information systematically for easy retrieval. I used coding terms to mark identifiers in the transcripts and used those to go back and deidentify by using pseudonyms. I developed themes from the categories to help provide an explanation of the research study.

Issues of Trustworthiness

Credibility

Anney (2014) stated that qualitative researchers consider dependability, credibility, transferability, and confirmability as trustworthiness criteria that ensure the rigor of qualitative findings. Credibility is one of the trustworthiness criteria for quality research and it simply wants to know about the confidence that can be placed in the truth about the research findings (Korstjens & Moser, 2018). It was important that ample amount of time was spent with each participant to ensure all details of the research received adequate consideration to answer the research question. I determined point of saturation after reviewing the data, as new themes unfold it would add rigor to the research. I was careful not to interject any biases due to personal experiences with PCOS.

Transferability

Transferability is when the researcher provides a thick description of the participants and the research process (Korstiens & Moser, 2018). Korstjens and Moser (2018) stated that providing a rich account of descriptive data including the setting, interview procedure and topics, excerpts from the interview guide, and how the research was carried out, gives a detailed account of the experience during data collection. Although the small purposeful sample size of 12 participants might not be generalizable to larger populations, they do open up new variables like the knowledge and experiences of African American women with PCOS to be examined in a subsequent larger scale study.

Dependability and Conformability

Dependability and conformability deal with the aspects of consistency and stability of the findings over time and making sure that all information is strictly derived from the data (Anney, 2014). Providing the appropriate amount of time for each participant, using the same procedures and techniques, and using the same interview questions helped establish dependability. Providing personal reflections as a role of the researcher and interviewer could help with conformability. Also keeping an audit trail of the process of data collection, data analysis, and the interpretation of the data established conformability (see Anney, 2014). I also ensured trustworthiness by allowing each participant the opportunity to review the written interview in order to validate and strengthen the credibility of their story.

Ethical Procedures

Possible ethical considerations in research are obtaining informed consent, confidentiality, and respect for privacy for all participants (Fouka & Mantzorou, 2011). The informed consent included information on confidentiality as well as reasons the researcher will break confidentiality, such as talking about suicide, harm to self or others, including children, elderly, and individuals living with a disability. I would notify the local authorities and the National Suicide Prevention Hotline. All participants were informed of the list of excluded items that are no longer confidential if they are disclosed and explain before any interview process begins (see Patton, 2012). To ensure the privacy of the participants the researcher provided in detail about the study and how all information would be kept confidential. Obtaining informed consent, preserving the confidentiality of the data, and giving the participants the right to leave the study whenever they desired (see Naz et al., 2019).

All data obtained was password protected and locked away in a secure location or file on the computer. This included audio files, transcripts, location of interviews, coding software, and notes. The data was uploaded to a Cloud, saved to a jump drive, and password protected in each location. Once all audio files were fully transcribed and de-identified they were deleted but all typed transcripts will be encrypted, and password protected. Data will be kept for 5 years in case needed for related other research opportunities.

The research started with Walden's IRB approval to conduct the research study. I provided each participant a copy of the IRB's compliance statement in the interview's protocol. The participants were emailed a copy of the informed consent and either signed the informed consent form or replied with the words "I consent" before the interview began. I explained to each participant that participation was voluntary, and they could excuse themselves at any point during the interview process without any repercussions. Any information collected such as name, date of birth and gender was deleted from all transcripts. To further protect the identity, pseudonyms were used during the coding process so I would be privy to this information. Clarifying the nature of the study, the participant's role, the objective of the study, and how the results will be used; helped establish trust between the interviewer and participants to help reduce ethical concerns (see Sanjari et al., 2014). The respect for privacy and the establishment of open and honest conversations helped to avoid any misrepresentations of participants’ views (see Sanjari et al., 2014). Also making sure there was confidentiality of all participants and any information obtained was kept confidential.

Summary

This chapter discussed the methodology approach, research design, and the process and procedures that will be followed for collecting and analyzing data to answer the research questions. This included the procedures for recruitment, the eligibility for participation, the data collection process, data analysis plan, and how trustworthiness was ensured. Ethical procedures were also addressed which included the protection of each participant and the confidentiality of all data collected. In chapter 4, the results of the research findings are presented, including a description of the research setting, the demographics of the participants and a summary of the themes identified.

Chapter 4: Research Findings

Introduction

I designed this basic qualitative research study to explore the knowledge and experiences of African American women with PCOS aiming at helping to increase education, reduce barriers, and promote self-help methods among African American women with PCOS that will aid in lifelong management. I obtained data needed for this study through semistructured interviews which allowed the participants to share their points of view more openly rather than in generalizations. This setting allowed me to investigate deeper with probing questions during the interview.

The overarching research question in this study was “What are the knowledge and experiences among African American women suffering from PCOS?”

There are three research questions as follows:

RQ1: What is the current health-related knowledge of PCOS in African American women with PCOS?

RQ2: What are the symptoms/experiences of African American women with PCOS both before and after diagnosis?

RQ3: After diagnosis, how have African American women managed PCOS symptoms in terms of self-help?

During the interviews all the questions were asked in the same manner to each person so that the information provided would be consistent. Prior to starting the official interviews, the instrument was tested on two individuals (a family member and a friend) to ensure that the questions were clear, understandable, and appropriate. No results were analyzed during those tests. After these sessions, the instrument was finalized.

In Chapter 4, I presented the perspectives of African American women with PCOS and the results of this research. The chapter included the demographics and characteristics of the research participants and the recurring themes extracted from the data to answer the research questions. I also described the process used for data collection and data analysis.

Setting

Most of the data collected was done using the online platform Zoom. Two of the in person interviews were conducted at Spirit of Excellence Church located in Oxford, MS. One in person interview was conducted at Church Health located in Memphis, TN. Verbal permission was granted from both facilities to conduct interviews. All interviews were conducted in a setting that was conducive to safety and comfort for each participant. All interviews were conducted in a private setting with no distractions or loud noise. All participants made scheduled interview appointments with no cancellations or rescheduling. Participants were asked if they were comfortable and ready to begin before the interview. The setting allowed for an open and honest dialogue for each participant to answer the interview questions.

Demographics

A purposeful sample of 14 African American women were recruited and 12 participated. These participants lived in or around the Northern region of Mississippi. Two of the participants were in the age group of 45 and up. All the participants had been diagnosed with PCOS for over 3 years. Most of the participants (*n*=10) had the same characteristics pertaining to the symptoms of PCOS. All the participants had consulted a doctor in the past about symptoms. Eleven participants reported having hair and/or dark spots on their chin and only one participant reported not experiencing any dark patches or course hair on any area of the body. Other demographic and personal characteristics of the sample is shown in Figure 1 and Table 3. Characteristics of dark spots and hair growth is shown in Table 4.

Figure 1

Demographic Characteristics of Participants

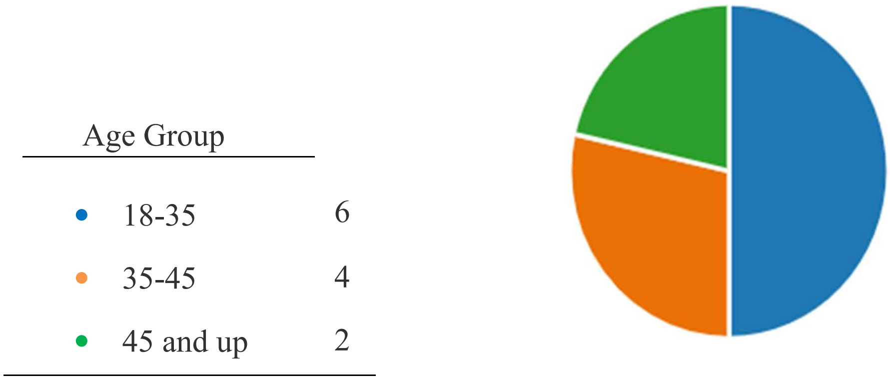

Figure 1 shows the age group of the participants. The participants' ages ranged from 31-47 years. The demographic data revealed that the participants in all age groups are suffering from PCOS. Most participants were in the 18-35 group.

Table 3

Age, Height, Weight, and Body Mass Index of Participants

Participants	Age	Height	Weight	BMI	Obese/Overweight
P10	31	5’0	170	33.2	Obese
P11	35	5’0	182	35.5	Obese
P6	30	5’3	171	30.3	Obese
P7	40	5’3	322	57.0	Obese
P1	36	5’5	174	29.0	Overweight
P8	31	5’5	250	41.6	Obese
P12	47	5’5	327	54.4	Obese
P9	47	5’6	250	40.3	Obese
P5	27	5’7	220	34.5	Obese
P2	34	5’8	300	45.6	Obese
P3	31	5’8	315	47.9	Obese
P4	39	5’9	227	33.5	Obese

Table 3 shows the data reported by the participants on height, weight and obesity status, and the calculated body mass index (BMI; see CDC, 2021). The calculated BMI for most of these participants was high and therefore suggested a health risk, according to the CDC’s BMI guideline. Eleven participants were obese and one was overweight.

Table 4

Characteristics of Dark Patches and Course Hair Growth on the following areas among the Participants

Areas of the Body	Frequency (%)
Upper lips	7
Chin	11
Breasts	2
Chest between breasts	6
Back	2
Belly	5
Upper arms	3
Upper thighs	4
Neck	7
None	1

Table 4 shows the variety of areas that the participants reported having dark patches or course hair growth and the frequency in that area. The chin area was most reported, then the upper lips, neck, and followed by the chest between breasts. Only one participant reported having none of the following characteristics.

Data Collection

I conducted all interviews one-on-one via an online platform (Zoom) or face-to-face. Data was collected from 12 participants. To ensure that all data was collected accurately, I recorded on Zoom, used an audio recorder app on my phone, and took notes for each question. I had an extra personal phone available to avert any technical issues with interviews conducted face-to-face. The interviews were conducted in a neutral private location. The Spirit of Excellence Church's meeting room and one of the Church Health clinic's meeting rooms was provided for the participants to ensure comfortability and seclusion. Verbal permission was granted from both facilities to conduct interviews. I conducted on average two to three interviews a week over a 5-week period and the interviews lasted between 25- 90 minutes. Participants were emailed a copy of their transcript to verify the validity and credibility of their interview. The participants were asked to reply with "no changes" or "see changes below" to verify receipt of transcript. There were no adjustments needed to be made during the data collection process and there was no variation in the data collection plan presented in Chapter 3.

Data Analysis

The participants provided detailed information concerning their knowledge and experiences with PCOS. I reviewed notes, tapes, and each participant answer to the same questions and searched for similar and different responses from the participants. I also used the qualitative data software Atlas.ti and uploaded all the interview transcripts and begin using free codes (noted below in next paragraph) which I created to look for similar quotations from the participants. Once I made up the free codes, the software searched for all quotations that contained those codes. The software allowed me to categorize the codes and group them in themes to help find the quotations for each theme. The process of coding using the software was fairly easy and I was able to use color coded bullets to separate the themes. From this review, I was able to identify the statements categorically; words and phrases provided recurrent and emerging themes. The overall goal of this analysis was to make the association between the data gathered and the research questions.

As a result of the data analysis, some of the following free codes were generated: PCOS as a hormonal imbalance, symptoms of PCOS, prior knowledge about PCOS, experience of having PCOS, discussing PCOS with the doctor, and lifestyle changes to manage PCOS. From these codes some of the following themes were identified: (a) PCOS is a hormonal imbalance but very difficult to understand, (b) PCOS symptoms are similar in African American women, and (c) Managing PCOS through lifestyle changes.

Evidence of Trustworthiness

Credibility

I spent enough time with each participant to obtain the necessary information needed to answer the research questions. I was careful not to interject any bias due to personal experiences with managing PCOS. The point of saturation was met after interviewing nine participants. According to Saunders et al (2018), data saturation can be related to the measure of when new data replicates what was conveyed in previous data. To add more rigor to the study, I continued to conduct research and interviewed three more participants. The results reported include both positive and negative facts concerning their knowledge and experiences overall with PCOS.

Transferability

The data collected in this small purposeful study can possibly be transferable to a larger study with similar circumstances and in other geographical areas to compare the findings with a similar framework and methodological approach. The participants shared their knowledge and lived experiences individually of what they believed to be true concerning their encounter with PCOS. The exact quotes from the participants helped to ensure transferability.

Dependability and Conformability

I allotted the appropriate amount of time for each participant to answer each interview question to ensure dependability. I used the same prescreening interview questionnaire (See Appendix C) and semistructured open interview questions (See Appendix E), along with the same procedures and techniques during the interview process. I kept a notebook journal with all the participants deidentified and listed as P1, P2, etcetera. and kept track of all the activities, details, and sequences throughout the entire study to help monitor the process of the research study to better draw a conclusion of the study, through these steps conformability was established. Upon completion of the interview, the participants had the opportunity to review their transcript, which validated and strengthened the credibility of their responses, so that trustworthiness could be realized.

Results

Interview Data

The participants were asked about their knowledge and experiences suffering from PCOS. Their experiences or attitudes were similar. Most of them (*n*=11) had a basic knowledge of PCOS and knew some of the symptoms and treatments available. Only a couple (*n*=2) participants had an in-depth knowledge about PCOS due to their own research over the years. None of the participants (*n*=0) had any prior knowledge about PCOS before they were diagnosed and many still did not fully understand the condition once they were diagnosed. Most of the participants (*n*=9) experienced shock, confusion, being overwhelmed, and aggravation as they learned about their diagnosis. Many of the participants (*n*=9) felt that they received little to no advice or health education from their doctor. Most participants (*n*=11) adapted to lifestyle changes once diagnosed and for some it has been helpful but for others not so much. Many participants (*n*=11) still feel like they do not have enough sufficient information and resources to help them manage their condition. The answers shared by these participants provided a wealth of information that have given insight to the barriers to managing the condition and factors that have influenced their experiences and the importance of social support.

RQ1: What is the Current Health-Related Knowledge of PCOS in African American Women with PCOS?

The participants cited their own definitions of PCOS and some of what they have learned has been from talking with other women that were diagnosed with the condition. Their understanding of PCOS is still vague and many of the participants are still learning about the many symptoms associated with PCOS. Using the internet is the most common way these participants learned about PCOS

Theme 1: PCOS is a Hormonal Imbalance but Very Difficult to Understand.

Most of the participants (*n*=8) understood PCOS as a hormonal imbalance. The participants stated that they knew their symptoms had something to do with the hormonal issues going on in their body. Although they have been given explanations, it was stated that it is still difficult to understand, for example:

> It is a very difficult process, and a lot of people are not familiar with it so you don't have a whole lot of people to talk to and get information from. I just feel like it's a lot of hormonal imbalances processes going on and pretty much all the stories I've heard were pretty much dealing with hormonal issues. (P8)

P3 stated,

> It's more of a hormonal imbalance than anything else that just has a lot of severe conditions with it. And that most women do suffer from it, but a lot of times is not diagnosed until something is to happen with the body where it shows that she has evidence of it."

P7 responded that PCOS was

> Difficult to understand. It was difficult to understand because now there is so much about PCOS, but I don't think there's a lot of education that we are giving once we are diagnosed with it or prior to because I had no clue what PCOS was until I was told that I had it. So, it was definitely difficult.

P11 stated,

> I believe it is a hormonal imbalance of sorts that can you know make you more susceptible to diabetes like syndromes, weight gain, hair growth, some skin abnormalities, and other things and that it really requires me to have a good diet and a good exercise routine to deal with the symptoms of PCOS.

P9 answered,

> Okay, my understanding as of now is basically it deals with your hormones having hormone issues and from my testing that I had done back in 2010. My doctor informed me that I had very high male hormones. My hormones were very off balance, and he also said that was what attributed to my weight gain and with my issue with not being able to lose weight.

Theme 2: No Prior Knowledge of PCOS Before Diagnosis.

None of the participants had any prior knowledge of PCOS before they were diagnosed. Many participants explained that they had never heard of PCOS before though two of the participants knew of the condition because someone they knew had it. Below are some of their responses:

> I didn't know anything about it because I was in college maybe like my freshman year and like I said, all I knew was what the doctor said. I didn't really go into in depth research or anything on it, then, but as I got older I kind of learned about it from other places. (P1)

P4 stated,

> I knew absolutely nothing, and in 2009 after I got married, we immediately tried to start having a baby. I knew something was not right, when several months went

> by and nothing. So, actually, I went to my first gynecologist and they diagnosed me with endometriosis and said, oh, you have a cyst on your ovary sent me home that was it.

P10 answered,

> Before I had no prior knowledge of PCOS I never heard of it before. Actually, when I was younger, I think maybe about 15 the doctor had mentioned that I had imbalance hormones but I never, I never took any consideration like I never asked any other questions like what causes this you know what is the medical terminology for this?

P7 responded,

> So, before I was told that I had PCOS I had heard just in conversations with people who have PCOS but mostly it was just people saying that they had it because they were diagnosed with it due to not being able to have a child the infertility and once I found out about PCOS it was way more than just that, like that is one of the things but there's way more about PCOS that I did not know.

P11 was one of the participants who had heard of PCOS prior to their own diagnosis: “So, I only had heard of the term because my cousin who's three years older than me was diagnosed. I didn't know anything outside of that.” P5 indicated she did her own research after she was diagnosed:

> I had no prior knowledge of PCOS before being diagnosed, after I was diagnosed my mother and I took the time to research as much as we possibly could at that time. Some things that I had been dealing with for years had an explanation at that

> point that I didn't even take into consideration that it was associated with some type of illness or disorder.

Theme 3: Google was the Primary Source for Information about PCOS.

For most of the participants (n=10) Google was the main source to research information about PCOS. The participants stated that the internet and medical websites were helpful when looking for information. Although some of the participants (n=5) felt it was a lot of information to obtain. Two of the participants also stated that they read books and were given information from their doctor. Several comments follow:

P2 answered saying,

> I started to read books. And of course, the internet was evolving. So, I started to do a lot of research online on what was going on from a medical perspective. If that included reading case studies that were limited but we're still out there.

P6 stated,

> So, I went to Google and just Googled PCOS and just read like the symptoms to see if I had any other symptoms. And of course, I did but it still wasn't making sense to me because it would say that doctors were still learning about this and I could tell from just talking to my doctor that he didn't know what to do because he would suggest birth control.

P3 was one of the participants that used Google: “At first, I did Google and I was very overwhelmed because of most of the tagline under the headline was not viable research and not enough research.” P4 indicated

> I was given a lot of pamphlet information from my OBGYN. That was a lot of information. Now, let me say Google. I love Google, but Google has so much stuff. So, WebMD on Google was what worked for me. I did a lot of research on there also with the information that he gave me.

P9 was one of the participants that mentioned her doctor giving information: “The first thing was the doctor that diagnosed me he gave me some information and some handouts. So, I read over those and then after that I researched on YouTube and Google and that was very helpful.” P10 also indicated reading articles: “So, like I said the doctor had given me some articles to read about PCOS. Basically, it gave me the understanding of it. So, it was helpful because I had an idea of it. But those was the only two places like I said Googling.

P7 stated,

> The resources I use was with a girl I worked with that told me she had PCOS and I was like I've been hearing about this like just random. What is it? And she was explaining it to me and she was like that's where I get the facial hair from and this is why I have to wax my face and I was like so is it some sort of a hormonal imbalance? and she was like yes it's more than that.

P6 mentioned listening to a doctor on Tic Toc: “So, I can't think of what this black doctor name that was on Tic Toc but she was the one that really broke it down for me to understand a lot about it.”

RQ2: What are the Symptoms/Experiences of African American Women with PCOS both Before and After diagnosis?

The participants in this sample shared many of the same emotions and feelings once they were diagnosed with PCOS. Many of the participants (n=9) felt overwhelmed and feelings of anxiety and depression, scared, didn't understand how they got the condition. Two of the participants stated that they were relieved to know that there was a medical term for what they were experiencing. Some of the women (n=6) were very devastated to hear the possibility of not being able to have children. Being able to bare children was one of the concerns from all of the participants. Also, many of the participants (n=9) felt like their doctor or OBGYN did not give enough information or education about PCOS at their doctor visit.

Theme 4: African American Women Shared Similar Responses to PCOS Diagnosis.

Many of the participants' (n=10) responses to their diagnosis was the same which included having feelings of emotional distress and anxiety because they didn't know what to expect of the outcome. Majority of the participants (n=11) cited being very emotional and concerned about not having children and trying to figure out how to treat the condition. One participant stated that "I didn't really have a response to it because I didn't know what it was. And once I found out through the information my doctor gave me, I was like wow there's a whole community of people of women out here with this." (P9) P11 mentioned "My initial reaction was a little concerned because my mother died of a uterine cancer and so concern of just anything in a gynecological area was always going to be top of mind." P5 stated: "I was confused because I didn't understand where it came from. I didn't understand how I got it or how I ended up with it. The part about the cysts on my ovary I think scared me."

P6 responded with,

> I was relieved because I kept going to the doctors and they didn't have any answers so, it was relief and once I heard the diagnose like it was like I was ready to make a change but I'm still working on that change.

P4 answered saying,

> My response was emotional because I felt like at that moment, I had failed my husband because I was not going to be able to give him any children because that was the main thing for me was not being able to have children.

P7 stated,

> When I got diagnosed, I cried. I cried. I was very emotional. I'm sorry, I get emotional talking about anyway I was emotional because I love children and when they told me that I may or may not be able to have a child it crushed me it crushed my heart.

P12 responded,

> I mean I think like the shock and the laughter in the room was just like I can't believe this is happening, but it was really heartbreaking, life-changing having to adjust. For me PCOS is that thing that robbed me of some what I thought it meant to be a woman because one of the things I always wanted to do was have children biologically and it robbed me of that.

P3 was one of the participants that indicated: “I was shocked and heartbroken then angry because of a major reason of why I was told that I had PCOS was because of a certain birth control I was put on.”

P2 stated,

> I was relieved to know that there was a name for it because where I come from and in my sort of family background the way that my family was taking too, you started your period and now you not having it, so, to be able to have a diagnosis that prove to my family that I was not sexually active.

Theme 5: PCOS Symptoms and Experiences are Similar in African American Women. As many of the participants began to describe and explain their symptoms and experiences, it was noted that most of them were comparable. Many participants (n=11) discussed having missed periods, dealing with issues of weight gain, and experiencing unusual hair growth on their face and neck, and mood swings. Most of the participants (n=9) were dealing with infertility but some of the participants (n=5) were able to have children. P5 explained

> I've had people reach out to me and asked me Hey, you know, I'm suffering from PCOS, I'm trying to have a baby what did you do? What did you do? And I feel bad at times because I can't really give them a for sure answer because I can't say what I did differently than what they already do or why you know that I have two children just on my own without any additional support or things like that.

P9 stated she does not experience mental health issues and this was her response “I haven't experienced any of that the mood swings, depression, and things like that, that come along with the hormone imbalance. I didn't and I currently do not experience any of those things." Below is what other participants had to say:

P12 answered with,

> I was already having problems conceiving and I knew that whatever this was did not mean it would be easier to do. I was depressed I think for a while. I won't say that PCOS ended my engagement, but we had two miscarriages trying to conceive and that was just a lot to deal with.

P1 responded saying,

> I feel like I experienced all of them now, the weight gain in my stomach area. Definitely the facial hair. I deal with, still irregular periods, depression, mood swings. I deal with that. I think those are the main things.

P7 indicated,

> So, my initial experience was pretty hard for me because I had to go through some tests and everything like that to even be diagnosed with it. I have hot flashes, acne, and the irregular cycles and excessive hair on my face sometimes.

P2 mentioned,

> I still have the missed period, the irregular menstrual cycle. I have higher, I don't have my panel with me, but I do have the misalignment or the hormone variances with more testosterone, still elevated estrogen, I do have a diagnosed anxiety disorder. I do suffer from migraines. I do have weight gain that goes up and down and right now is up.

P11 also discussed their symptoms: “Initial experience was a period lasting over 20 days at a very heavy flow, facial hair growth, weight or the inability to effectively maintain weight loss.”

P5 stated,

> I feel like right now I'm kind of starting from square one because I initially had the irregular cycles, the hair growth, the unexplainable weight gain, and the acne. Well then about four months ago I made an executive decision that I wanted to give my body a break just for a little while just to see if my PCOS symptoms were still there, and so, I did and ever since I did that my acne has come back. It's basically back 24/7. My cycles are irregular again. My hair growth happens extremely fast continuously.

Theme 6: Doctors and Medical Professionals did not Provide Sufficient Advice or Education about PCOS.

The participants in this sample expressed that for many of them (n=9) their experience discussing PCOS with their doctor was not a pleasant process. Most of the participants (n=9) stated that their doctor or OBGYN did not provide much information or education about PCOS after diagnosis. Three participants explained that they had to go to numerous doctors before given a diagnosis and received little to no information. A few participants (n=3) experienced doctors providing a lot of information and education about PCOS after diagnosis. One participant stated: “I was given a lot of pamphlet information from my OBGYN. The day that he diagnosed me, I guess he knew to look at my face, and he, he actually, he gave me a lot of statistics of African American women and PCOS." (P4)

Two participants expressed how the doctors made them feel shamed because of their body size and was told that they just needed to lose weight. P2 mentioned, "The doctors was negative and it was discouraging and it was all so humiliating because I did not expect the sort of body shaming that I would get at the doctor's office around being a bigger body person who might need help." Other participant's comments in regard to receiving advice and education from doctors follows: P5 stated "At my original diagnosis I received a lot of information, and they did offer me like a treatment plan with the exception of the birth control because that wasn't something that they could prescribe to me there." P8 also indicated "The doctors that I've personally seen has always been Passover about it and really didn't take much time to explain the process."

P7 responded,

> My doctor basically was educating me on it and actually giving me tools like for me and she definitely wants me to of course lose the weight. So, she set up my dietician, I started seeing a dietitian, she sent me to a fertility doctor. My doctor is amazing, and she wanted to ease my mind about everything else as well, so she put those people in place for me without me asking her to do those things.

P3 answered,

> It was aggravating with the first doctor who initially diagnosed this and there was no information given. It wasn't until I met with my current OBGYN when we were having trouble getting pregnant and asked for an ultrasound, that he started

> to develop a I don't know the word you would call it, but a helpful plan or a medical health plan where you know trying to do everything we could that when I got pregnant was able to keep you know the pregnancy full term until I was able to deliver.

P12 stated,

> Outside of my gynecologist on like the initial diagnosis, we have not really talked about PCOS. I mentioned it to my GP when we were going over like a list of medications and her only response was like would you like me to refill the metformin for you and I was like nope. I haven't really had any discussions.

P6 responded,

> Well, my doctor like I said he diagnosed me and he drew a picture telling me, let's see something about a hair follicle not falling I mean he tried to explain it to me but it really wasn't making sense. And all he was offering me was birth control or something to get me pregnant.

P8 mentioned,

> The only time I really discussed this with two different doctors when I was trying to get pregnant and one of them she indeed said yes you have it but she wouldn't put me on the metformin to treat it. So, my second doctor that I came in contact with she was like you indeed have it and then that's when she started me on the metformin but as far as them trying to really educate me and as far as the dieting part they didn't really go into details about none of that.

Below are other comments from participants in regard to if the information given from the doctors about PCOS was helpful or not:

> "No, I don't really, I don't really think so, and I don't know if it's because I was just young. But she didn't really expound upon what it can do and all that, and then things that I can do. I'm not sure, but I don't think she gave me enough information as a doctor." (P1)

P7 stated,

> I do. I do think she was because she did sit me down and talk to me and explained to me what it was, so I think she did her best and she definitely made the process a little bit better because she was so consoling and because she's been my doctor for a little while now, so she definitely was consoling.

P8 answered,

> No, that was just like I was just saying that there was no help or support telling me how to treat this or really explaining to me what it is or what's the effects of it, like I said anything that I pretty much know about it I've learned from other people or googling it myself.

P10 indicated,

> I'm going to say yes and no. He was very knowledgeable about the PCOS just telling me about it and explaining it to me. Um, I feel like there he did a great job with that. But when it came down to me getting off of birth control pills and what can I do to control my weight? What can I do to control the other issues besides

> the irregular period? I feel like he wasn't. It wasn't beneficial the information that he was giving me.

RQ3: After Diagnosis, How have African American Women Managed PCOS Symptoms in Terms of Self-Help?

Many of the participants (n=11) discussed changing lifestyle behaviors after they were diagnosed with PCOS. Some participants (n=9) started limiting fried foods, foods high in carbs, process foods, and sugar intake. Most participants (n=8) tried to increase their exercise and drink more water. Several participants (n=7) reported seeing positive changes as a result of lifestyle changes and a couple women discussed not really seeing any drastic changes. Some participants (n=8) discussed feeling better when they were eating better, exercising, and limiting sugar intake. One participant discussed her road to weight loss surgery to help with lifestyle changes.

Theme 7: Managing PCOS through Lifestyle Changes and Behaviors.

Many participants (n=11) in this sample discussed changing their eating habits, increasing their exercise, and drinking more water to help manage their PCOS. All participants explained how difficult it was to remain consistent and how they easily would get off track. When the participants would modify behaviors, they talked about how much better their body felt and overall had more energy. The participant that is on the road to weight loss surgery stated, “I'm not saying that is going to reverse it but it would definitely help in a lot of my problems that I have going on. So definitely on the road to eating better eating healthier and just watching my caffeine intake, exercising, and not to indulge in so much wine that I love but those are a couple of things that I have started putting in place to help with my diagnosis with PCOS." (P7) Other participants specifically discussed some of their changes like:

> "Started having a lower carb diet started really trying to understand what a good workout regimen for me is. A lot of what I'm doing is through food intake and exercise and just well-being." (P11)

P5 stated,

So, I cut out red meat for about six to eight months and I did feel a lot better. I was not able to continue the intermittent fasting the way that I wanted to simply because I think my fasting window that I was trying to do was entirely too long for me.

P3 responded,

> I stopped drinking alcohol well like completely no alcohol, no wine, no liquor, no beer, anything like that. I've cut out pork unless it's like bacon is just that's the only exception and I don't have a very fatty diet, but my problem is remembering to eat.

P12 answered,

> So, it's mainly more to manage the weight which I believe is related to PCOS. And that's like the way I eat. I'm not the best eater but I'm not a bad eater either but I'll do like no meat days and focus heavily on vegetables and proteins at least two days a week. I limit the number of sweets. I still crave sweets and salty stuff, but I do try and limit those items. I try to get the water in and I just cut sugar and watch sugar where I can.

P9 indicated,

> So only like within the last year have I made changes to my diet so I try to do less dairy and I try to do less sugars that I can. And then with exercise I try to instead of doing 30 minutes do an hour and when time allows me to I do two hours to try to help with that.

P2 stated,

> So, yes, I did make Lifestyle Changes. I would say, one of the biggest ones was limiting my excess to like, processed foods and fried foods. I'm not vegan, I'm not vegetarian, I'm not pescatarian and I still will go to Popeyes every now and then, but I do keep a lower intake of processed foods as much as possible. I think covid sort of shifted this, but I was very active going to the gym more, going outside more, walking more, doing yoga, doing Zumba and those things have always helped.

P11 reiterated,

> Yeah, I think when I'm on a very strict diet and workout routine regimen I can see a lot of results. But um, so like intermittent fasting, very low carb diet work for me along with like low intensity exercise, those things work, but I have to be very, very strict.

P2 responded,

> I can tell overall that when I eat better and that better, for me means consuming a higher level of green vegetables, berries, water, when I'm doing those things and continue with my lean chicken. I noticed that my body just also overall feels better. My mood is better. I rest better.

P10 answered,

> When my weight is between 150 and 165 I'm fine. My periods are regular its easier for me to work out. I don't see any excessive hair growth. My hair don't grow as fast now versus like it's the holiday season I'm at 170 and now I noticed my periods are irregular I'm feeling fatigue.

P4 stated,

> I work out every day at least 30 minutes a day, If I don't get it in every day I'm getting it in every other day or I might do five out of seven days of the week. The main number one thing for me is I have to; I have to move my body. I have to do some type of exercises. I drink more water now, which helps a lot and the way that I eat. My goal is not to look skinny, but to be healthy. So, when I do work out, my mood is so much better. It's those happy healthy endorphins when I do work out. I do notice the weight loss.

Theme 8: African American Women found Online Social Media Groups Helpful and Supportive.

Online social media groups were mentioned as one of the most supportive groups the participants in this sample found to be helpful. Many participants (n=11) found that listening and reading other women's experiences helped them a lot. The participants would ask questions and receive answers from these online support groups. Many of the participants (n=10) felt encouraged and inspired from stories of other women that were able to still have children and they also didn't feel alone in dealing with this condition. P9 participant did not seek an online support group, and this is what she said "No, I did not seek support group. Like I said the friend that told me about that had it and told me about it of course you know I talk with her and then later found out that another friend had it as well and then my sister had it and then my aunt." P7 participant also stated "I did not seek a support group like I said I am an open book and sometimes I think I'm too open. But after telling some people in my circle what was going on with me they were like me too." This is what P8 stated about support groups: "The support groups on Facebook were a great support and it was absolutely helpful because it was relatable. Other participants commented as follows:

> Yes I actually join a support group on Facebook I didn't know anybody personally that had PCOS, no PCOS doesn't run in my family so when I found out it was a support group on Facebook I wanted to see how other ladies was feeling about PCOS and what they were doing to control their PCOS." (P10)

P6 responded,

> Yes, so on Facebook I joined a PCOS group and it's a lot of women just talking about PCOS and what they got to get pregnant and like what medicines they are taking. So, their information was very helpful because I knew that birth control was not the route to go. So, it was very helpful.

P3 stated,

> So, I ended up turning to Facebook where I got into some groups with women who had it themselves and just kind of talking about life experiences and what they did to kind of help ease what was going on or just to be able to tolerate. It

> does get a little discouraging but your encouraged that you got so many other women who are dealing with this same thing and who is just trying to get help.

P1 indicated,

> “Well, I know I'm in one of the Facebook support groups, and a lot of the women that are in that group, you know, they share a lot of the different things and a lot of research that they may have had and did. They share their symptoms and things that they deal with.

P4 answered,

> I did online, it was in one of the, I think Facebook groups, and I think it was just African American women with PCOS after I was diagnosed and it was helpful, especially when I was going through trying to get pregnant very, very supportive.

P2 indicated,

> As social media evolved joining and following some Instagram pages and joining some Facebook groups to learn more about other people's experiences so that I could ask better informed questions when I went to the doctor, even thinking about the things that I was reading from other people in these Facebook groups and on these Instagram posts, I developed a journal so that I could track my symptoms. They were absolutely helpful; I don't think I would be in the place I'm in right now without them.

Theme 9: More Tools and Resources should be Available for African American Women with PCOS.

Many of the participants (n=10) in this study expressed their concerns of the lack of education materials and resources available to help manage their condition, specifically tailored to their ethnic group. Some participants (n=5) also felt like if the right tools were available maybe they would have been diagnosed sooner than later. Four participants discussed how PCOS should be talked more about like breast and ovarian cancer. One participant mentioned “We talk about those things, check your breasts, you know, go get your pap smear, but we don't talk about PCOS and like what to look for and what causes it like we don't give that type of information out like we do for the other two in my opinion.” (P7) It was also discussed how more pamphlets and brochures about PCOS should be in doctor offices like OBGYN clinics. Below are some of the responses about what tools and resources should be available:

> I would love more forums where doctors and women who have these issues and conditions can come together and really have good in-depth discussions with doctors in that sense of you know medical doctors, OBGYN, General Practitioners, nutritionist, dieticians, and whoever. (P3)

P7 stated,

> I wish there were you know maybe a pamphlet in the room because there are pamphlets about everything else but there's none about PCOS in the room at least not at the doctor's office I went to. I think it's something that all women should be educated on.

P5 responded,

> I would love for our local community to have a support group just within the community for women who struggle with PCOS and just talk about what that looks like and how we cope and work together and build up on each other. I know a lot of the times it's been difficult for me in regard to relationships explaining what PCOS looks like to my partner and explaining why I have to do some of the things I have to do.

P12 indicated,

> I think support groups would probably be the best way to help or even at the point of diagnosis and if it was like some information that a provider could give you like here is this brochure with these things and these items you can go to for help or just more information.

P4 answered,

> Hands-On workshops, I think the main thing though before we can get to those workshops, were its just raw this is what it is, this is what's going on is that we as black people have to go to the doctor. We need to know it's okay to go have these exams.

P11 mentioned,

> Some kind of tool kit and maybe a broader understanding of what works and what doesn't like some do's and don'ts that don't force you to go down like a Google rabbit hole and I think doctors being more confident about the treatment of it. I found that a lot of doctors are not confident in the best way to treat PCOS.

P2 stated,

> If there were doctors who specialized in PCOS, who had like a helpline, whether it was a physical phone number is not really where I'm going at, but more of sort of a consortium of information in a space to ask questions and get them, those who want it. I just want it to be a community of people who actually care from the medical profession whether it's because this is their specialty in their degree program or something that they have experienced that they have lots of patience, I don't really care how, but I just wish that there was a space for us to be able to ask questions to get varying degrees of support from the medical profession.

P10 participant suggested: “Basically, I feel like it should be a support group in the different communities in different churches because I feel like it affects the people that have it more than they know.

P9 responded,

> I would like to see more in depth or in-depth study per woman's body of course you’re going to find some similarities with other women you know and like break it down and say like if you have this blood type with your PCOS this is some of the things that you may need to refrain from.

Summary

The participants in this study were all African American women living in or around the Northern Region of Mississippi. These participants have had a diagnosis of PCOS for over 3 years. I met with each participant either through an online platform (Zoom) or in a private setting to conduct a one-on-one interview to obtain their perspective on the knowledge and experiences suffering from PCOS. Participants in this study had various perceptions about their experience and most of them were similar in many ways. Most of the participants (n=11) had a basic understanding of PCOS as a hormonal imbalance and affected their body in many ways. One participant went in greater details about the physiology of PCOS and the increase risks it as for other disease conditions. Two participants knew very little about PCOS and only learned about the term once they were diagnosed. Even after diagnosis, some participants (n=8) explained that the understanding of PCOS is still complex and difficult to comprehend.

All participants in this sample concluded that they had no prior knowledge about PCOS before they were diagnosis. Two participants were diagnosed at an early age but most of the participants (n=10) didn't find out their diagnosis until after their 20s and 30s. Three participants learned about PCOS from other family members, friends, or other women that shared their experience with them. They noted that learning about PCOS from others prompted them to go to their doctor and inquire about the symptoms they were having because it was similar. Some of the participants (n=5) discussed how they were having symptoms for years and had seen several doctors before they could even get a diagnosis.

Most participants (n=10) talked about using Google as the main source for information about PCOS. Three participants discussed how other websites such as WebMD was a good tool for information about PCOS. Two participants read medical books and researched articles to increase their knowledge about the condition. Most participants (n=10) agreed that more tools and resources should be available about PCOS in doctor offices and OBGYN clinics. One participant stated that she has never seen a pamphlet or brochure in her doctor’s office.

The participants in this study all shared similar responses to their initial diagnosis of PCOS and some of the experiences they encountered. Most of the participants (n=10) expressed feelings of anxiety, being overwhelmed, scared, and very emotional. One participant discussed the shock and heartbreak after being diagnosis and feeling robbed of being able to get pregnant. The PCOS symptoms were similar in the participants. Some of the symptoms noted from all participants included irregular periods, weight gain, excessive hair growth, and infertility. Despite infertility, there were five participants that were able to get pregnant and give birth to children. One participant stated that she doesn’t know how she got pregnant because she really didn’t do anything different in trying to conceive.

The majority of the participants (n=9) discussed how they received little to no advice or education from their doctor or medical professional. Some of the participants (n=4) explained how their doctor basically gave them the diagnosis and told them to eat healthy and exercise. Two participants that stated after seeing numerous doctors, they finally found one that actually gave them more information about PCOS. Majority of the participants (n=11) stated that they were offered a form of treatment like birth control or Metformin to help control their symptoms. Three participants described having a wonderful doctor that was very informing and gave them an ample amount of education materials about PCOS. One participant described their doctor as very consoling and supportive throughout the entire process of trying to get pregnant.

Many of the participants (n=11) made lifestyle changes to try to help manage their condition. Some of those lifestyle changes were cutting out red meat, drinking more water, exercising more, decreasing sugar intake, and intermittent fasting. Some participants (n=8) thought that they lifestyle changes made their body feel better, they were in a better mood, and overall had more energy. Two participants weren't sure if the lifestyle changes were making a difference but admitted to not staying consistent enough to see positive results. Most of the participants (n=10) agreed that online support groups through Facebook and Instagram have been very helpful and supportive with managing PCOS. One participant admitted that if she wasn't in the online social media support groups for PCOS, she wouldn't have made it without them.

In conclusion, this research finding posits that the experiences shared among these participants with PCOS have similarity and comparability that could be strongly influenced by their cultural and ethnic background. While these participants might have faced many obstacles and challenges suffering from PCOS, they are confident and inspired to continue learning in hopes to effectively manage this lifelong condition.

In Chapter 5 the following will be discussed: interpretation and findings, limitations of the findings, recommendations for future research, implications for positive social change and conclusions.

Chapter 5: Discussions, Conclusions, and Recommendations

Introduction

The purpose of this basic qualitative study was to explore the knowledge and experiences of African American women with PCOS. Overall, my primary goal for this study was to gain a deeper insight of these African American women's perceptions as they try to manage through the symptoms and lifelong battle with this condition. I also wanted to determine how health program interventions and support from other resources would be beneficial in reducing barriers and increasing better self-help methods for African American women with PCOS.

The African American women in this study all struggled with symptoms of PCOS ,especially being overweight, excessive hair growth, and difficulty getting pregnant. Black women, compared with White women, with PCOS have shown to have lower pregnancy rates due to less success with in vitro fertilization (BWHI, 2017). Black women have higher rates of obesity, increased rates of hirsutism, and higher risk of CVD and MetSyn compared to White women (BWHI, 2017). Research has found that women of color suffer from PCOS more often than White women. Since Black people have a higher rate of morbidity and mortality due to CVD and diabetes is important to understand racial and ethnic differences among women with PCOS (Basile, 2020).

The 12 African American women in this study all live in or around the Northern Region of Mississippi. These women all have been diagnosed with PCOS for over 3 years. All these women have and still are experiencing symptoms with PCOS and are continually trying to find the best way to manage their symptoms and condition. All the women concluded that more resources such as health education materials in doctor offices and forums and workshops discussing PCOS with experts specialized in the area would help provide better management of the condition.

There is still little to no statistical data among Black women with PCOS and there is little to no research found on PCOS and African American women specifically. However, there are a few studies that have included African American women in the sample, but the sample sizes are small therefore, true results might not be sufficient to draw accurate conclusions. In the previous chapter, the main findings were summarized into nine themes. The first three themes fell under the category of current health-related knowledge of PCOS in African American women with PCOS:

1. PCOS is a hormonal imbalance.
2. No prior knowledge of PCOS before diagnosis.
3. Google was the primary source for information about PCOS.

Themes 4-6 were related to symptoms/experiences of African American women with PCOS both before and after diagnosis while Themes 7-9 connected to African American women managing PCOS symptoms in terms of self-help:

4. African American women shared similar responses to PCOS diagnosis
5. PCOS symptoms and experiences are similar in African American women
6. Doctors and medical professionals did not provide sufficient advice or education about PCOS
7. Managing PCOS through lifestyle changes
8. African American women found social medial support groups helpful.

9. More tools and resources should be available for African American women with PCOS

These findings revealed that these African American women all shared the same basic knowledge of PCOS and encountered similar experiences with suffering from PCOS. Most of the women still feel like they do not have sufficient information to better manage PCOS because of the lack of awareness about the condition which led to late diagnoses, their doctor not being educated about PCOS to provide an adequate amount of information, the lack of support from their doctor or medical provider, not enough health education materials available about PCOS in doctor offices, and the lack of importance that PCOS seems to have globally.

In this chapter, I interpreted the findings from the interviews and provided more detailed information on the major themes that helped to answer the overall purpose of this study.

Interpretation of the Findings

In this research, I used a thematic analysis approach to extrapolate the themes for this study. The primary purpose of this research was to explore the knowledge and experiences of African American women with PCOS. Of interest was the discovery of facts from the cultural, social, and environmental perspectives that may influence future approaches to the awareness and education of PCOS. I examined the experiences of African American women with PCOS as they expressed their personal encounters with the condition. During the data analysis process, I recognized major themes aligned with those in the literature review as noted in Chapter 2. There were commonalities that resonated throughout the review and some of the same factors that were prevalent in those studies were reiterated during the interviews. Both the previous literature and this study found that PCOS is still difficult to understand due to the lack of support and education from their doctor or medical provider. There are also similar symptoms and experiences between African American women with PCOS and women from other ethnic backgrounds that suffer from PCOS.

The following research questions were asked to each participant concerning their knowledge and experiences suffering from PCOS. The discussion is organized by research questions.

The Current Health-Related Knowledge of PCOS in African American Women with PCOS

The research revealed that some of the basic knowledge known by the 12 African American women about PCOS was also cited in the literature (e.g., Azziz et al., 2016; Goldrat & Delbaere, 2018; Wolf et al., 2018), such as being a hormonal imbalance, ovulatory dysfunction, and PCOM. Most of the women considered PCOS to be very difficult to understand and a complex issue to explain. According to Wolf et al. (2018), the etiology of PCOS is not completely understood and the cause has not been found although genetic components have been identified. The diagnosis, symptoms, and criteria for PCOS can be difficult to understand and medical professionals are still trying to gain full knowledge of the spectrum of reproductive disorders (Rao et al., 2020). One participant described PCOS as “ever-changing, fluctuating, unknown, and stigmatized.” Add summary to conclude the paragraph. Overall, the research findings revealed that

PCOS is still considered a disorder difficult to understand and more education would help increase knowledge about the condition.

Most of the women knew PCOS was related to some kind of hormonal imbalance or dealings with hormonal issues. As noted in Chapter 4, several participants alluded to PCOS as a hormonal imbalance of some sort where the body is not responding the way it should. One participant stated that “it's more of a hormonal imbalance than anything else that just has a lot of severe conditions with it.” Although in the study by Omagbemi et al. (2020), it was reported that 52.5% of Nigeria women stated that hormonal imbalance was not a key feature of PCOS but on the other hand 76% were unaware that PCOS was treatable. Lin et al. (2018) explained that most women had a basic understanding of PCOS and the associated symptoms. Most women in this study knew most of the symptoms related to PCOS even if they did not experience all of them. However, Hussin and Abd Kadir (2020) noted that although many of the women had a good knowledge about PCOS they were still unaware of what their signs and symptoms of PCOS looked like because many were present in them. Also, most of the women in this study did not know the associated health risks related to PCOS. Lin et al further stated that there is limited understanding about the actual health-related knowledge and beliefs among women with PCOS. One participant felt like it was “the most unresearched syndrome when it came to the female body.”

No prior knowledge of PCOS was reported among all the African American women in this study. It was evident in this research that the women did not learn details about PCOS until they were diagnosed. A few of the women learned about PCOS from a friend or family member who has been diagnosed with it. One participant stated that she learned about PCOS “from a friend describing the symptoms she was having”. Rao et al. (2020) reported in their study that 21% of women knew nothing about PCOS. In the literature, it also discussed that many women have no knowledge of having PCOS and up to 70% of women reported not being diagnosed (March et al., 2010). One participant in this research explained that she had several doctors for years before she was properly diagnosed. Another participant discussed how one doctor talked to her about having PCOS but never diagnosed her or gave her any treatment plan. Researchers found from the literature that over one-third of women with PCOS reported not being diagnosed until 2 years and three different health professionals later (Gibson-Helms et al., 2017). Rao et al further explained that while all women with PCOS are not formally diagnosed, if they are showing signs or symptoms of PCOS it could take several doctors and years before being diagnosed.

Most of the research participants mentioned using the internet and Google as their primary source for information about PCOS. A couple of women mentioned reading books and medical books to help get a better understanding of PCOS. A few of the women received an ample amount of information from their doctor but most of the women received little to no information from their doctor. In one study by Williams et al. (2015) it was reported that many women were seeking information from other sources like the internet and trying to educate themselves about the condition.

Overall, the research participants were aware of the basic knowledge and understanding of PCOS but most agreed that it was still very difficult to understand and realized there is still more information unknown. Nevertheless, most of these women understood the need for more resources and that there will be a continuous learning curve to help better understand the condition. Some of the women expressed feeling overwhelmed at the information and having to only digest small amounts at a time. One woman admitted that she “doesn’t know that much about PCOS and she needs to really take it more seriously and try to learn as much information as she can”. Rao et al (2020) reported that African American women in this study were less likely to receive information from health care professionals. It also should be noted that there is no comparable study in the literature or previous research conducted on the health-related knowledge of PCOS in African American women specifically but it is evident from the literature that women in general still have a basic understanding of PCOS and many women have no prior knowledge of PCOS. Suggestions for more studies to be performed to examine the knowledge among different geographical, racial, and ethnic groups to help identify beliefs and barriers were mentioned (Lin et al., 2018).

Symptoms/Experiences of African American Women with PCOS Both Before and After Diagnosis

The African American women in this sample shared similar responses to PCOS diagnosis. Some of their feelings were very emotional, shocked, overwhelmed, angry, and confused. A few women expressed how they cried after they received their diagnosis. Although past research has little to no studies on the responses to PCOS diagnosis among African American women specifically, the literature does suggest that women in general and from other ethnic backgrounds had similar encounters. Gibson- Helm et al. (2014)

conducted a study and found that women reported the process being prolonged and frustrating and they received inadequate PCOS information. Most of the women in my research study expressed their concern about the ability to get pregnant and have children once they were diagnosed. One participant even stated that she felt like she had failed her husband because she did not think she would be able to give him a child. According to Tomlinson et al. (2017), due to the lack of straightforwardness that the diagnosis of PCOS provides a lot of women are left uncertain about their condition.

Another participant discussed how she felt less of a woman once she learned of the diagnosis. One of the themes that emerged from a study by Williams et al. (2015) was feminine identity and some of the women were questioning their femininity. Other African American women in my study stated that they did not know what to expect of the health outcomes associated with PCOS. It was reported in the literature from one study that women with PCOS also believed that they were more vulnerable to adverse health outcomes and weight issues (Lin et al., 2018). Most of the research participants from my study shared the feeling of being very emotional and some were relieved to know their condition had a medical term. One participant stated that she did not know how to respond because she was not sure what it meant. From the literature it was noted that there are a lot of emotional and social consequences of living with PCOS and addressing the specific needs of women with PCOS individually and culturally could improve the experiences of women with PCOS (Tomlinson et al., 2017).

The research findings in this study also revealed that PCOS symptoms and experiences were similar among African American women. Again, the literature or past research does not provide a study that discusses PCOS symptoms in African American women specifically but the literature does recognize the need to address this need. It has been suggested that additional research should be conducted on the racial/ethnic differences in women with PCOS and the experiences and knowledge that is available to them in the management of the condition (Gibson- Helm et al., 2017).

From the literature review, most of the common symptoms stated were also seen in the research participants such as severe acne on the face, chest, and back, weight gain, darkening of the skin, obesity, thinning hair, oily skin, infertility, multiple sacs in the ovaries, irregular menstrual cycles, skin tags, mood swings and excess hair (ACOG, 2020; CDC, 2020; NIH 2017). The main symptoms that were reported from these women in my study were excessive hair growth, weight gain, infertility, irregular cycles, and mood swings. Majority of the women discussed still experiencing irregular cycles even after childbirth. Some of the women explained how they were offered treatment like birth control and Metformin to help with those symptoms. One participant stated that the Metformin made her so sick each time she took it, so she eventually stopped taking it. In one study conducted by Bazarganipour et al. (2017) it was revealed that adherence to treatment was an inhibiting factor due to side effects.

All the research participants expressed their issue with weight gain. Most of the women were actively trying to reduce their weight because it is a never ending matter. One participant discussed how she is in the process of having weight loss surgery in hopes to jump start the process. According to BWHI (2017), Black women have higher rates of obesity, increased rates of hirsutism, and higher risk of CVD and MetSYn compared to White women. The women in this study were all categorized according to their BMI as either overweight or obese. Research has found that women with PCOS have an increased with of MetSyn and one of the factors associated with that is obesity (Moore et al., 2017). According to the OMH (2020), African American women have the highest rates of being overweight or obesity compared to other groups in the United States, where about four out of five African American women are overweight or obese. One study in the literature review found that Black women with PCOS had a higher BMI (37.5) compared to their White counterparts (30.6; Chan et al., 2017).

Many of the African American women also discussed experiencing mood swings and periods of depression. Some of the women did not understood why they were experiencing these symptoms because they were unaware it was linked to PCOS. The literature also suggested that mood disorders and depression seem to be another increased risk in women with PCOS (Williams et al., 2016). However, one participant explained that she has not experienced any mood swings or depression at all.

Several of the women in this study experienced the same symptoms and issues with treatment and unsatisfying experiences with medication. Many of them also dealt with delayed diagnosis and feeling uncertain about the condition. Although most of the women did not have any other health issues, a couple of the women did identify having high blood pressure and diabetes which occurred after being diagnosed. This is one of many reasons why some of the women in this sample felt like there was a lack of support from their doctor and did not receive the appropriate amount of information about PCOS.

Most of the research participants discussed how their doctor or medical professional did not provide sufficient amount of advice or education about PCOS. Some of the women explained how their doctor gave them the diagnosis and that was it and others stated that their doctor only offered them treatment and told them to diet and exercise. This statement is consistent with the literature that discussed a study detailing women reporting seeing their doctor and was just given medication to treat their symptoms and received no education about the condition (Tomlinson et al., 2017). One participant from my study said that their doctor told her she had PCOS and tried to draw an ovary on a sheet of paper and that was the end of the conversation. A few of the women felt like their doctor wasn’t very knowledgeable about PCOS and therefore couldn’t really explain to them what it was or give a true understanding. One participant explained that their doctor was very knowledgeable about the condition but wasn’t able to give appropriate education on how to control the symptoms. However, there was a couple of women that discussed having doctors that were very good about giving an ample amount of advice about PCOS and they were very supportive and concerned about helping them better manage their condition. One of the women described her doctor as being very consoling and reassuring.

As noted in Chapter 2, the literature review seems to coincide with some of the statements from the research participants in regard to support from their doctor. Williams et al. (2015) conducted a study and found that women with PCOS also expressed lack of education and support from health care professionals’ feelings of being pushed to the side because their condition was not considered serious. Another study reported women feeling a lack of empathy from their doctors and not being given an adequate amount of information to begin managing their condition (Tomlinson et al., 2017). One of the research participant’s from my study recalled their doctor making her feel shamed because of her weight and stating that she “just needed to push away from the table”. Overall, all of the participants expressed their concern that doctors and medical professionals are not being educated and trained enough about PCOS to help support and increase knowledge to women with this condition. Dokras et al. (2017) also found through an online survey study identifying gaps in PCOS knowledge among physicians that a large number of physicians were still not sure of the currently recommended criteria for the diagnosis of PCOS and it highlighted the opportunity for the improved training of education in physicians to increase better diagnosis of PCOS.

African American Women Managing PCOS Symptoms in Terms of Self-Help

The research findings from this study also revealed that most of the women in this study have been managing their PCOS symptoms through lifestyle and behavior changes. Most of the women discussed changing their eating habits by reducing their sugar intake, cutting out red meat, drinking more water, and eating more green vegetables. They also reported increasing their exercise with some of the women exercising about four to five times a week and others every day for about 30minutes. One participant explained that she has to work out every day or every other day because she has to move her body because it’s so easily for her to gain weight. There is little to no research that has discussed African American women with PCOS using self-help methods that included lifestyle changes specifically but the literature does mention lifestyle modifications as treatment for PCOS. Escobar- Morreale (2018) explained that lifestyle modifications are usually the first line of treatment for PCOS and women that display mild symptoms might not require much intervention other than simple behavior changes.

Many of the women expressed their frustration with making lifestyle changes because it is hard being consistent in eating healthy and exercising. For many of the women they would start out doing good and then eventually get off track and have to start over again. They did convey the idea of feeling better, being more energized, and an improved mood when they were eating healthy and exercising. One woman discussed how she could tell a change in her body when she was eating healthy and exercising versus when she was not doing those things. Another participant stated that she experienced increased bloating in her stomach and rapid hair growth when she was eating unhealthily. Overall, the participants felt like they needed more specific information and education about the management of their symptoms based on their individual need.

The African American women in this sample also found online forums and social media groups very supportive and helpful. The majority of the women were in a PCOS support group on Facebook, Instagram, or both. One of the participant’s stated that she found the support and information from her online group very instrumental in getting her to where she was today. The women discussed how listening to other women talk about their experience and share their thoughts were inspiring and beneficial in learning more about PCOS and finding best ways to manage the symptoms. Another participant discussed how she didn’t feel alone and felt better knowing there were others dealing with the same issue. Specifically, there has been no research conducted exploring the education and support on African American or Black women with PCOS alone. However, the literature offered a few studies with similar findings.

Williams et al. (2015) reported from their study that some women found support and education through online support groups claiming they have more knowledge and reduced feelings of loneliness and isolation. One of the women in the research study expressed how being able to relate to other women that share the same symptoms and experiences is comforting and reduced anxiety. Sometimes online forums could offer women the ability to find other women with the same symptoms and struggles and it is easier to relate to them (Ee et al., 2020). Although most of the women were very encouraged by the online forums and support groups the literature also suggested that online support groups could also lack a direct interaction with others and the level of peer support (Mani et al., 2015). It was suggested that there is a positive association with peer support groups among women with PCOS.

The research participants also discussed their concerns about not having any local support groups in their area. Many of the women stated that they had not found a local support group for women that suffer from PCOS. Most of the women were opened to attending a peer support group to gain more knowledge and education about the condition. One participant stated that she was not in an online support group but she has talked with her friends, sister, and aunt about PCOS. This could be supportive to the study that reported that some women felt that group sessions might not be suitable for them due to privacy concerns and not knowing the other women personally

(Hadjiconstantiou et al., 2017). One participant offered the suggestion of grouping women with similarity in age and cultural background (Hadjiconstantiou et al., 2017).

In addition to support, the research participants in this study wanted to see more educational tools and resources available for African American women that suffer with PCOS. Many of the women mentioned having more educational forums with doctors and other experts and being able to ask questions. One participant stated that she would love to see a toolkit that provided management for each symptom and tailored specifically for African American women. Some of the women thought that conferences and hands-on workshops with other women with PCOS could offer education by culture and ethnic background. Again, the literature doesn't provide any research on tools and resources tailored specifically for African American women with PCOS. Yet, research found that there is a lack of structured education programs for women with PCOS which could increase understanding of the condition and promote self-management strategies for a lifestyle change (Mani et al., 2015). From one study the results suggested that there are ethnic and educational differences that exist and should be considered when developing education materials for women with PCOS (Rao et al., 2020). Mani et al. (2015) also added that in order to successfully self-manage the signs and symptoms of PCOS women will need to have sufficient and accurate information about the condition available to them.

A few of the women in this study discussed how they would like to see more pamphlets and brochures in doctor offices and OBGYN clinics. Some of the participants suggested offering educational classes at the initial diagnosis to help women gain a better understanding. Hadjiconstantiou et al. (2017) also discussed how women wanted to see more education materials in hospitals, doctor’s offices, and clinics so they would not feel embarrassed to ask for help or advice. Some women felt like the it was too “hush, hush” and even the doctors seemed uneducated on the condition. Overall, African American women in my study were adamant about being provided the right tools and education resources to better manage their PCOS. A woman from the study explained how she wished she had known earlier instead of suffering the first year not knowing what to expect. This was also emphasized by Mani et al. (2018) in a study where women participated in a face-to-face structured education program taught by a trained educator and received resource packets summarizing every session and at the end of the day participants were able to reflect on what they had learned. The results showed improved feelings of living with PCOS, sense of relief after being diagnosed, increased understanding of their condition, and improved illness perception or quality of life.

This research is grounded in the Health Belief Model (HBM) framework. As fore stated, this framework consists of six constructs which include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (Jones et al., 2015). The HBM seeks to help individuals take action to prevent, screen, or control their conditions. As noted in this research the participants felt strongly that if more educational programs and resources were available then they could better manage and control their symptoms and condition. According to Kozica et al. (2013) limited knowledge, frustration about the condition, and where to find high quality health information may lower self-engagement and reduce participation in self-help methods.

Since the lack of education and program interventions seems to serve as the buffer against the ability to increase knowledge and awareness, the framework of the HBM in PCOS is expected to be beneficial in reducing perceived barriers and increasing self-efficacy to improve health promoting behaviors. The HBM requires an individual to have positive health perceptions and have the capability to overcome any perceived barriers to develop lifestyle changes (Kozica et al., 2013).

By framing this research with the HBM model the results from the study showed that the participants had misconceptions about PCOS after their diagnosis due to the inability to completely understand the information. The participants expressed their unawareness of the severity of PCOS and all the associated health risks that could be linked to the condition. The participants had a greater perceived susceptibility about PCOS being associated with weight gain, excessive hair growth, mood swings, and infertility. The lack of education and support from their doctors and medical providers decreased their perceived control of the symptoms and health outcomes. The participants felt like if they weren’t very knowledgeable about PCOS then they couldn’t manage their symptoms effectively. The findings also showed that participants that had a lower level of perceived barriers (ability to eat healthy, exercise, reduce weight) were more consistent with self-help methods and making lifestyle changes. Those participants who showed a higher level of perceived barriers were less consistent in making those lifestyle changes. The research also revealed that participants agreed that if there was more education and support available then it would increase self-efficacy to better promote self-help methods to manage the condition. The results suggested that creating a culturally tailored education program for African American women with PCOS could reduce barriers and increase self-efficacy because it would be more personalized.

Limitations of the Study

Some limitations did exist in this study. First of all, this was a purposeful and homogenous study with a sample of women from the same geographic area all diagnosed with PCOS. This limits the generalization of the overall results because of the various characteristics of each individual that could have affected their overall health status. Secondly, the sample size was small with only 12 participants, but it was large enough to reach a point of saturation. On the contrary, in a qualitative study this number is valid once a point of saturation has been reached (see Marshall et al., 2013).

Another limitation was the self-development of the interview instrument, which could have affected the validity and accuracy of the data (see Creswell, 2013). Researcher bias was a potential limitation due to the personal experience with PCOS (see Ross & Zaidi, 2019). I minimized interview bias by refraining from offering opinions, keeping a neutral facial expression and tone of voice.

Recommendations

During this research, I discovered that these African American women who struggled with PCOS were open and willing to discuss their experiences and feelings and offer recommendations on how their knowledge and experiences can be enhanced through the development of educational programs, more education from doctors and physicians, and possibly hands-on workshops to increase their ability to better manage their condition. The participants recommended that doctor offices offer pamphlets and brochures about PCOS, a toolkit be developed to outline specific management for PCOS, conferences be available to gather women with PCOS and educate specifically by ethnic background, and more education and training should be required for doctors and physicians to better communicate and educate about PCOS. While this study was limited to this small sample size, some of the findings may be applicable to other programs developed for African American women in similar geographic areas.

The literature review revealed that the majority of the studies that included African American women did not provide enough data to conclude accurate results. There is still little to no research in regard to PCOS and African American women alone. Specifically, there is no research on the education and support for African American women with PCOS. However, this basic qualitative study will be beneficial in adding scientific knowledge and rigor to the research field about PCOS among African American women. Research from the literature continually reiterated the need for more studies to be conducted geographically and culturally among race and ethnic groups to develop and design intervention programs targeted specifically for their needs. It should also be noted from the literature that PCOS was found to be underfunded by the government which could be cause for the limited research of PCOS (Brakta et al., 2017). PCOS was the only disorder out of two other disorders that received less funding which was provided by only one of the NIH institutes while the other two disorders received funds from multiple NIH institutes. In order to address this issue and increase funds for PCOS, it is recommended that other NIH institutes provide funding for PCOS and public health advocates and leaders become more invested into the advancement in research for

PCOS. Also, there is currently no organization or institute that is tracking the prevalence or number of women being diagnosed with PCOS.

Implications

The findings in this study have potential to promote positive social change once the results are revealed to other researchers, public health advocates, and practitioners. It has been concluded that PCOS is a complex disorder and very difficult to understand and these women have struggled with trying to manage their symptoms for long periods of time. The results of this study can help provide health education, awareness, and improve the knowledge gap concerning their culture and beliefs in regard to PCOS. The data collected can help improve and culturally organize the development of educational resources and programs to promote the success for participants to progress towards goals of reducing barriers and better managing their condition.

This study is limited in generalization due to the small sample size of African American women but can have some implications for women across socio-demographic backgrounds. Research shows that African American women and women of racial differences share some of the same experiences from PCOS such as lack of support from doctors, feelings of uncertainty, and lack of adequate information (Tomlinson et al., 2017). Some of the same attitudes and beliefs exist among racial groups. Research has found that women of color suffer from PCOS more often than White women but it’s still important to design culturally sensitive programs for all women with PCOS (Basile, 2020).

It is concluded that as participants continue to gain more knowledge concerning PCOS and find ways to better manage the condition, this can help to reduce barriers, reduce associated health risks, and improve self-help methods to promote a better quality of life within the African American community. Overall, this study could have a significant impact on the health of future generations.

Conclusions

This study described the knowledge and experiences of African American women as they continue to combat the task of managing PCOS. It is evident that education on PCOS and support from doctors and medical professionals is imperative, with both short- and long- term management strategies. Despite these women barriers to manage their symptoms, the majority of them continually try to improve symptoms through lifestyle and behavior changes. The themes that resonated throughout the discussions were: (1) no prior knowledge of PCOS before diagnosis, (2) PCOS symptoms and experiences are similar in African American women, (3) doctors and medical professionals did not provide sufficient advice and education about PCOS, and (4) more tools and resources should be available for African American women with PCOS. It is observed that if these components are introduced to a health promotion it can help bring some resolve to contending PCOS and help to promote positive social change on a higher scale.

As a result of this study, it is suggested that more additional research should be conducted among African American women with PCOS to better develop education programs and resources that specifically tailor to their needs. First, this research study should influence more studies to be conducted geographically and on a larger scale among African American women with PCOS. A larger database could help better understand the needs of this population. This could promote the development of better education programs and resources for PCOS among this culture group. Secondly, to improve the health education of PCOS it should be recommended that doctors and medical professionals are educated and trained specifically about PCOS. There should be educational training specifically targeted towards African American women with PCOS. This could lead to the development of a PCOS toolkit that outlines symptoms that are shown in African American women, education on controlling those symptoms, and resources to support lifelong management of the condition precisely for African American women. From this, pamphlets and brochures could be developed and disbursed in doctor offices and clinics that offer information about PCOS. Providing these tools could result in an earlier detection or diagnosis due to an increase of discussions with doctors about symptoms.

In addition to that, workshops and conferences should be available with experts specialized in PCOS that are available to answer questions and offer information geared towards different ethnic backgrounds. Lastly, this study supports the need for local peer support groups that provide education and support for African American women with PCOS. The participants in this study discussed joining a local support group to have the ability to listen and share their experiences with other African American women that suffer from PCOS. This extra amenity would offer additional support and reduce the feeling of loneliness. The overall need from this study proposes that there should be an increase in knowledge about PCOS among African American women and without the proper education and training from doctors and medical providers, the lack of these components will continue to be barriers for improvement in the management of this condition.

It is concluded that doctors, OBGYNs, medical professionals, health experts, educational resources, workshops, intervention programs, and the overall public health sector should be a major conduit to help contribute to increasing knowledge and improving self-help methods to better manage and control PCOS. The overall findings confirm that the African American women in this study have strong interests in self-help management to gain a better quality of life living with PCOS. The key findings in this study was revealed in relationship to knowledge of PCOS, sources for information, similarities in symptoms and experiences, and identifying needed support and better educational programs. The information derived from this study can provide evidence-based information that can help improve the knowledge and experiences of PCOS culturally and develop better educational resources tailored specifically for African American women with PCOS.

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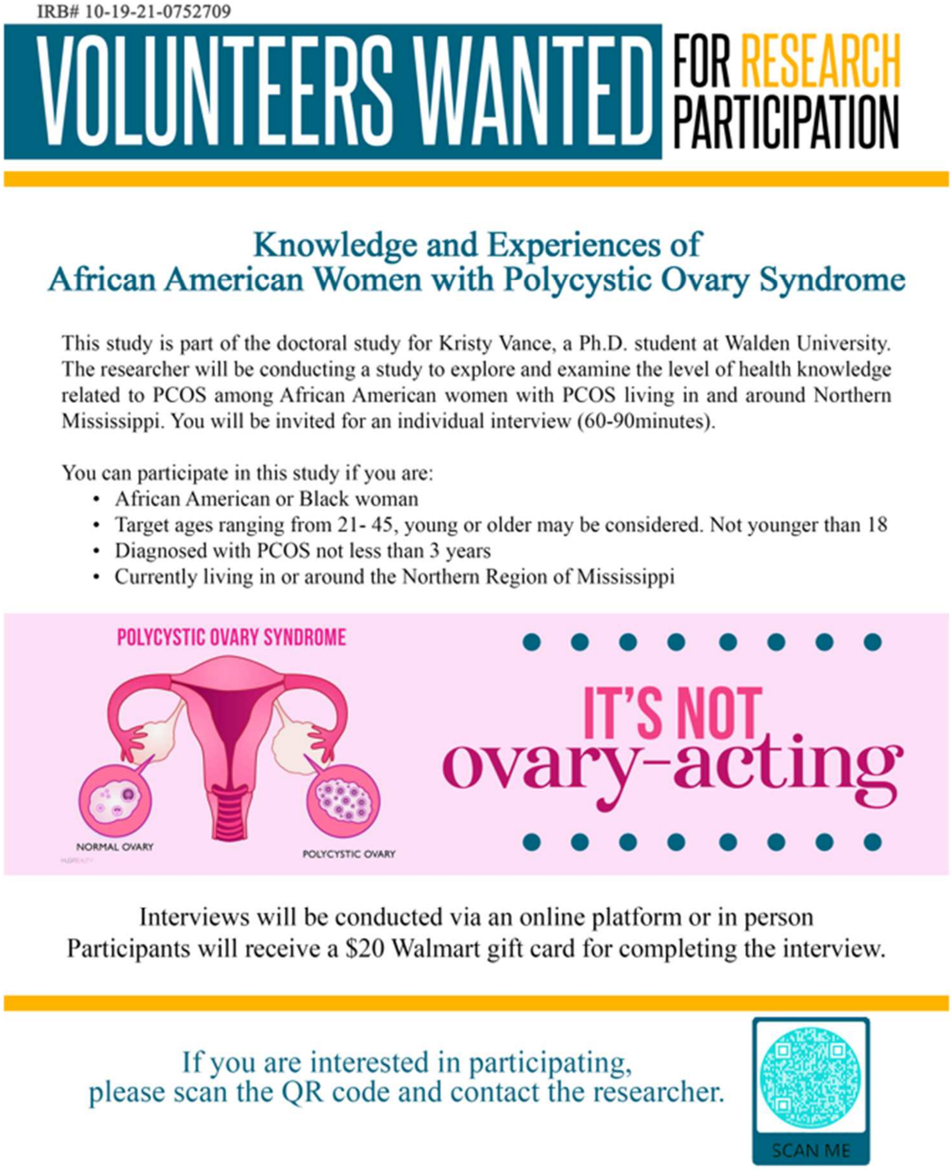
Appendix A: Recruitment Flyer



IRB# 10-19-21-0752709

VOLUNTEERS WANTED FOR RESEARCH PARTICIPATION

Knowledge and Experiences of African American Women with Polycystic Ovary Syndrome

This study is part of the doctoral study for Kristy Vance, a Ph.D. student at Walden University. The researcher will be conducting a study to explore and examine the level of health knowledge related to PCOS among African American women with PCOS living in and around Northern Mississippi. You will be invited for an individual interview (60-90minutes).

You can participate in this study if you are:

- African American or Black woman
- Target ages ranging from 21- 45, young or older may be considered. Not younger than 18
- Diagnosed with PCOS not less than 3 years
- Currently living in or around the Northern Region of Mississippi

Interviews will be conducted via an online platform or in person
Participants will receive a $20 Walmart gift card for completing the interview.

If you are interested in participating,
please scan the QR code and contact the researcher.

SCAN ME

Appendix B: Invitation to Participate in Study

Thank you for your interest in this research study. As part of my doctoral study, I am conducting a study to explore and examine the level of health knowledge related to PCOS among African American women. As part of the interview process, you will be given a consent form, which provides further details on what to expect as a participant in this study. If you agree, you will be asked to sign it and schedule an interview. Please beware that this interview will be recorded and transcribed for the formal study; however, your personal information will remain confidential (as will be explained in the consent form). The whole process should take between 95- 160 minutes of your time.

Appendix C: Prescreening Interview Questionnaire

Screening Questionnaire for Polycystic Ovary Syndrome (PCOS)

Research study examining the knowledge and experiences of African American women with PCOS

Required

1.What is your name?

2.What is your age group?

☐ 18-35

☐ 35-45

☐ 45 and up

3.What is your height and weight?

4.What is your race/ethnicity?

5.Do you live in or around the Northern Region of Mississippi?

☐ Yes

☐ No

6.Do you have irregular periods?

☐ Yes: My periods come about every 2-3 months or less often

☐ Yes: I get my period every 2-3 weeks.

☐ No: My periods are regular.

☐

7.Do you have trouble maintaining a healthy weight?

☐ Yes, It seems like I suddenly put on a lot of weight.

☐ Yes, No matter what I try, I have a hard time getting down to a normal weight.

☐ No, I don't have difficulty with my weight.

8.Do you have acne or skin problems?

○ Yes

○ No

9.Do you have a tendency to grow dark patches or course hair on any of the following areas? Check All that apply.

☐ upper lips

☐ chin

☐ breasts

☐ chest between breasts

☐ back

☐ belly

☐ upper arms

☐ upper thighs

☐ neck

☐ None

10.Do you have a family history of PCOS or Diabetes?

○ Yes, both.

○ Yes, PCOS.

○ Yes, Diabetes

○ No: Nobody in my family has PCOS or Diabetes

11.Have you ever consulted any doctor for the above problems?

○ Yes

○ No

12.Were you diagnosed with having PCOS? If so, how long has it been since you've been diagnosed?

Appendix D: Demographic Questions

Demographic questions

1. What is your age?
2. What is your height?
3. What is your weight?
4. What is your race/ethnicity?

Appendix E: Interview Questions

Interview Questions

RQ1: What is the current health-related knowledge of PCOS in African American women with PCOS?

1. In your own words, how would you define PCOS?
2. What have you heard about PCOS? v
3. Please share your understanding of PCOS?
4. Please share your knowledge of the symptoms? Risk factors? Treatments?
5. What did you know about PCOS before you were diagnosed? If no prior knowledge, how did you learn about PCOS?
6. Where did you look for information about PCOS? What resources did you use? Was it helpful? Why or why not?

RQ2: What are the symptoms/experiences of African American women with PCOS both before and after diagnosis?

7. How did you respond to the diagnosis?
8. What was your initial experience of having PCOS?
9. What symptoms do you (or did you) associate with PCOS?
10. What symptoms have you (or do you) experience with PCOS?
11. Describe your experience discussing PCOS with your doctor?
12. What type of advice or health education did the doctor offer?
13. Did you feel like the doctor was helpful in providing sufficient information regarding PCOS? Why or why not?

RQ3: After diagnosis, how have African American women managed POS symptoms in terms of self-help?

14. Since being diagnosed with PCOS, have you made any lifestyle changes to help manage PCOS? If so, what lifestyle changes did you make to help manage PCOS?
15. When did you start making the change(s)? Will ask specifically about each change.
16. Thinking about this lifestyle change, what, if any, results have you noticed?
17. If you've noticed results, how have these results made you feel? If you have not noticed results, how does that make you feel?
18. Do you currently have any other health issues? If so, were they present before or after diagnosis?
19. Can you describe if the health issues worsen, got better, or stayed the same with the lifestyle changes? Please explain in detail.
20. At this point in your life, do you feel like you have found sufficient information and resources to help manage PCOS? Explain in detail
21. Did you seek a support group or advice from others? Why or why not?
22. What tools would you like to see available to better educate and bring awareness about PCOS?
23. Is there anything else you would like to add about your experience or share any thoughts about PCOS?