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Health Education Practices for Middle Eastern Women with Polycystic Ovary Syndrome

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2023

Abstract

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Walaa Daffaalla

MS, Logan University, 2018

BS, Texas Woman’s University, 2014

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Polycystic ovarian syndrome (PCOS) is a complex women's health condition that reduces women's quality of life, leading to health complications, such as menstruation issues, infertility, insulin resistance, risk of type 2 diabetes, depression, anxiety, emotional stress, being overweight or obese, and more. Research on PCOS has focused on the etiology and complications in women from different ethnicities. But limited research has explored the experiences and perspectives of Middle Eastern (ME) women in the United States with PCOS related to PCOS health education. The purpose of this qualitative study was to explore the perspectives and experiences of ME women of reproductive age (ages 18–45) with PCOS health education provided by their health care providers (HCPs). Three research questions aimed to explore ME women's perspectives and experiences, health beliefs, and cues to actions regarding PCOS health education provided by their HCPs. An interview questionnaire was used to interview seven ME women. This qualitative study was guided by the basic interpretive approach, and the health belief model six constructs were used to analyze participants' behavior related to PCOS. MAXQDA and Microsoft Word were used for data analysis. Findings indicated that ME women with PCOS experienced inadequate PCOS health education that emphasizes lifestyle changes and poor communication with HCPs. Recommendations are to improve between HCPs and ME women with PCOS and provide adequate PCOS health education. Positive social change implications include creating a comprehensive PCOS health education for HCPs to provide for ME women with PCOS that is culturally competent.

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Dedication

Thank you, Allah, for giving me the strength and power to start and complete this PhD journey. I dedicate this work to women struggling with PCOS in silence. I would like to thank my research participants for allowing me to interview them and for expressing their perspectives and experiences with PCOS. I am praying that I can use this knowledge to help others that are less fortunate in this life through increasing health education and awareness.

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I want to thank my family for their continued support and encouragement to continue my education journey.

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Chapter 1: Introduction to the Study

Background

Polycystic ovary syndrome (PCOS) is a hormonal disorder common among women of reproductive age (Mayo Foundation for Medical Education and Research, 2020). Women experiencing PCOS can have many complications with menstruation, fertility, mental problems, and metabolic functions. The prevalence of adolescents with PCOS is estimated at 9% to 15% based on the available evidence of PCOS complications like metabolic, inflammatory, oxidative, emotional, and psychological stress (Saei Ghare Naz et al., 2019). PCOS is a lifelong health condition that can progress to induce conditions like insulin resistance and increase the risk for type 2 diabetes (Centers for Disease Control and Prevention, 2020). PCOS is underdiagnosed or diagnosed late due to women's inability to report or understand the symptoms when it begins.

The onset of PCOS's signs and symptoms can start in any women's life stage, adolescence, reproductive age, or menopause (CDC, 2020). PCOS's main symptoms are menstrual irregularities, infertility, hirsutism, severe acne, weight gain or obesity, pelvic pain, oily skin, or acanthosis nigricans (U.S. Department of Health and Human Services, n.d.). Some PCOS symptoms can be identified immediately in women, such as having polycystic ovaries, a condition in which ovaries might be enlarged and contain follicles surrounding the eggs resulting in dysfunctions of the ovaries (Mayo Foundation for Medical Education and Research, 2020). Among the symptoms of PCOS, emotional problems, distress, depression, and anxiety are common and frequent psychological complications (Saei Ghare Naz et al., 2019).

All women may benefit from PCOS health education to understand and identify this complex condition. Women with PCOS from different ethnicity may benefit from PCOS health education that is culturally competent. The lack of proper health education provided for populations like Middle Eastern (ME) women with PCOS in health care settings regarding their condition is a concern. Health education for ME women with PCOS is necessary to improve treatment and management practices. Education programs can improve the mental health and well-being of women with PCOS (Mani et al., 2018).

Treatment recommendations for PCOS include making lifestyle changes such as losing weight if you are overweight/obese or increasing physical activity suggested to lower the risk of developing type 2 diabetes and prevent or delay other health problems (CDC, 2020). Depending on the PCOS symptoms and associated health disorders, HCPs can provide treatment options. Special conditions like PCOS related infertility need to be addressed differently as some treatment options may prevent pregnancy or harm the fetus during pregnancy (U.S. Department of Health and Human Services, n.d.). Non-pharmaceutical treatment methods that rely on health education and lifestyle changes regime provided for women with PCOS need to be at the frontline of the treatment options to improve women’s health. The recommendation for a safe PCOS treatment strategy is self-management plus lifestyle changes, such as weight loss, increasing activity level, and eating healthy (Hajivandi et al., 2020). Though pharmaceutical treatments for PCOS like oral contraceptives, insulin-sensitizing medications, anti-androgens, clomiphene, metformin, letrozole, ovarian drilling, and gonadotrophin can pose serious health risks (U.S. Department of Health and Human Services, n.d.), PCOS associated health risks can weaken women's health and reduce quality of life.

This qualitative research aimed to understand the perspectives and experiences of ME women with PCOS health education provided by their healthcare providers' (HCPs). I used the health belief model (HBM) six constructs to guide this research to specify the susceptibility, severity, barriers, benefits, self-efficacy, and cues to action needed to identify PCOS health education needs for ME women. This research will help HCPs provide appropriate PCOS health education and intervention for the ME women population.

Statement of the Problem

This research addressed the perspectives and experiences of ME women regarding PCOS health education provided by HCPs. The current research on PCOS has focused on identifying the disease etiology among women of all races and the treatment methods. There was limited research on women with PCOS understanding of PCOS as a complex disorder and how HCPs educate women about PCOS post diagnoses. There is also a lack of culturally competent PCOS health education provided to women with PCOS specifically in the ME women community. This may have led to ME women having decreased awareness of PCOS and increased prevalence of PCOS complications. It is unknown how much PCOS health education is provided for ME women with PCOS from HCPs as part of the PCOS intervention program and whether it is culturally competent health education. Health education interventions that are culturally competent should be part of the HCPs' tools to increase PCOS awareness among ME women. This will increase awareness and understanding of PCOS complexity and its associated health risks among ME women diagnosed with PCOS.

Purpose Statement

The purpose was to explore the perspectives and experiences of ME women of reproductive age (ages 18–45) with PCOS health education provided by their HCPs. I also wanted to determine their health beliefs that influence their understanding of PCOS health education. Finally, I wanted to identify factors that influence ME women with PCOS to adopt lifestyle modifications to improve their PCOS condition. This research can increase awareness about PCOS and its associated health risks in the ME women community through exploring the perspectives and experiences of ME women with PCOS. It will guide HCPs about the importance of providing proper PCOS health education to ME women struggling with PCOS. This research can be a guide for the future development of PCOS interventions programs to help ME women recognize PCOS signs and symptoms early on and seek treatment. Social implication of this research would be developing a culturally competent PCOS health education guide to for ME women with PCOS, including lifestyle intervention practices to treat or manage their condition.

Research Questions

RQ 1: What are the perspectives and experiences with PCOS health education in healthcare settings for ME women ages 18–45 (reproductive age)?

RQ 2: How do the health beliefs of ME women of reproductive age (ages 18–45) affect their perception of health education practices provided by their HCPs for PCOS?

RQ 3: What are the cues to actions influencing ME women of reproductive age (ages 18-45) diagnosed with PCOS to adopt healthy lifestyle changes as a treatment for PCOS?

Theoretical Framework

Theories are helpful to explain, predict, and understand social phenomena that are otherwise difficult to clarify (Abend, 2008). The theoretical framework grounding this study was the HBM. The HBM is one of the first theories of health behavior, developed in the 1950s by a group of U.S. Public Health service social psychologists who wanted to explain why few people were participating in programs to prevent and detect disease (National Cancer Institute, 2005). The HBM is used as a theory to explain a particular social phenomenon (Abend, 2008), which in this study was PCOS in the ME women population. The lack of proper PCOS health education and intervention programs for PCOS patients requires understanding problem behaviors that arouse health concerns for PCOS patients (National Cancer Institute, 2005). The HBM is appropriate to predict and explain the association of health risks such as obesity, insulin resistance, and type 2 diabetes with PCOS in the ME population (CDC, 2020). In this research, the HBM helped understand PCOS patients' beliefs about the condition, which predict individual health-related behaviors (Rural Health Information Hub, n.d.).

The HBM has six main constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Rural Health Information Hub, n.d.). The HBM main constructs were used to guide research questions to investigate ME, women, with PCOS response to the lack of proper health education for PCOS by their HCPs. The constructs applied to the study in the following way:

- Perceived susceptibility: Identify signs/symptoms of the condition PCOS.
- Perceived severity: Identify PCOS health consequences and health conditions associated with having PCOS.
- Perceived benefits: Explain the positive results of treating PCOS through lifestyle modification.
- Perceived barriers: Identify obstacles to take action to treat PCOS and how to overcome them.
- Cues to action: Provide a health education program that helps treat the condition and maintain health.
- Self-efficacy: Encourage women to track disease signs/symptoms and set a goal to maintain a healthy lifestyle.

The application of HBM to address the individual's perceptions of the threat posed by a health problem (susceptibility, severity) and the benefits of avoiding the threat will guide the development of research questions (National Cancer Institute, 2005). In this research, the HBM may assist HCPs and health educators in understanding factors that influence ME women with PCOS behaviors as well as identifying culturally competent health education practices needed to promote behavioral changes in this population.

Nature of the Study

This qualitative study followed a basic interpretive (generic) approach (BIA) to explore the perspectives and experiences of ME women with PCOS with health education practices provided by their HCPs. Qualitative research requires a broader and less restrictive concept of “design” than the traditional ones (Maxwell, 2008). A generic qualitative approach is used to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved (Cooper & Endacott, 2007). This research approach enabled research participants struggling with PCOS to express their opinions of their HCPs’ treatment of PCOS and its associated health risks. The ME women population is a conservative community regarding gynecological diseases (Mousa et al., 2021). The BIA allowed ME women with PCOS to describe their struggle with understanding PCOS complications and the lack of proper PCOS health education from HCPs. Interviewing ME women with PCOS provided the opportunity to reflect on their progress with PCOS health education practices. Interviews provided the most data from participants’ experiences and understanding of the PCOS condition. Besides dialogue and understanding, a qualitative study may lead to an understanding or assess an issue with an understudied group or population (Creswell, 2016). ME women with PCOS represent an understudied population and require more exploration to determine the reason for limited research and underdiagnoses of PCOS in this unique women population.

Limitations & Delimitations

As an academic scholar conducting this research and the main instrument, plus a ME woman diagnosed with PCOS, I may have introduced researcher bias in the research process or influenced participants’ responses to interview’s questions. I avoided researcher bias by holding blind audio call interviews with participants to limit participants’ influence by my reaction to answers from visual cues. I also recruited participants from different ME countries and those unaware of my diagnosis with PCOS. In addition, I avoided sharing personal experiences with PCOS with research participants before the interviews.

This research recruited participants from online platforms such as Facebook, Instagram, and Twitter. The challenge was finding participants from different ME countries on social media platforms that are interested in participating in a research study. PCOS is a sensitive topic to share and discuss with others or in studies. Providing an introduction about the study's aim and its significance in this population of ME women may have encouraged participation. I also ensured participants that identities will be masked and anonymous in the research.

Another limitation of recruiting ME women with PCOS to participate in the research could have been language barriers. The ME region is a broad region with different nations and languages including South Asian, Arabs, Sub Saharan Africa, and North Africa, who speak Arabic, Urdu, Pashto, and Persian. Recruiting participants with different languages may require using translators or translation applications for research consent and interview questions.

Another delimitation in this study was finding a location to conduct the interviews and ensure participants' privacy. To ensure privacy interviews were conducted via phone call using a recording app to allow participants to select the appropriate and comfortable location. The research interviews via phone calls allowed research participants flexibility in the time and place to participate in this research. Participants were able to stop and proceed with the interview as needed. Interviews lasted 30 to 35 minutes duration. All of this will encourage participants to engage in the research knowing it will be confidential and suitable for their needs.

Significance of the Study

Through interviews with ME women with PCOS, this research was able to obtain ME women’s perspectives related to PCOS diagnosis. The outcomes of this research might assist in developing a culturally competent health education program targeting ME women with PCOS. Social change implications include a culturally competent PCOS health education for ME women, which can lead to quality-of-life improvement for women with this complex condition. Awareness of PCOS signs and symptoms through health education provided by HCPs will ensure women recognize this condition and seek treatment or self-management through lifestyle changes to prevent complications like developing type 2 diabetes. This research can also be a guide for the future exploration of the evaluation of HCPs’ delivery of PCOS diagnoses and intervention strategies from the perspective of ME women with PCOS evaluation. This research may also encourage further studies to investigate the reliability and validity of creating/delivering culturally competent intervention programs for different women ethnicity in health care settings.

Summary

This research goal was to explore ME women’s perspectives and experiences with their HCPs’ PCOS health education practices. This introductory chapter provided an overview of the condition PCOS and its complexity, plus the need for a multidisciplinary approach to treatment. The qualitative method with a BIA was used to explore the problem of limited culturally competent PCOS health education for ME women in health care settings. This research was also guided by the HBM used to explain PCOS in ME women and behavior related to this condition.

The next chapter of this qualitative research is the literature review on PCOS in ME women. This comprehensive literature review provided an overview of the present research, similar research, and research findings on ME women with PCOS. It supported the purpose, planning, and conducting of this research exploring ME women with PCOS and providing sound and original data that represent this population's needs related to PCOS and to develop future research.

Chapter 2: Literature Review

This chapter includes a literature review of the available research on ME women with PCOS. This literature review was completed to understand the perspectives and experiences of PCOS health education practices related to PCOS in the ME women population. I investigated the available data on PCOS among the ME women population. This literature review aided in understanding the current and relevant research article that examined ME prevalence and HCPs efforts to diagnose and increase awareness about PCOS. It also helped to identify the gap in research that explored ME women's understanding of PCOS.

Literature Search Strategy

The literature was collected from databases such as the CINAHL & MEDLINE Combined Search, PubMed, Google Scholar, and Walden library. This review focused on finding studies on ME women and PCOS. This research review focused on exploring factors leading to the development of PCOS, such as genetics, lifestyle, ethnicity, health conditions, health literacy, psychological effects, and infertility. This literature review was meant to look for the most relevant research on the issue of PCOS in the ME women population. There were limited data on ME women and this literature review covered as much as was available. Otherwise, this literature review concluded a good amount of data to clarify the complications and impact of PCOS among ME women. Reviewing research on the condition PCOS in ME women revealed limited research on this health issue among this specific population. Women suffering from this condition from the ME background may lack understanding of this condition because of the limited studies on PCOS condition in the ME region.

Theoretical Framework

The HBM is a theoretical model used to explain and predict individual changes in health behaviors, which was the most appropriate theory to use in my study with women from ME backgrounds with PCOS (Rural Health Information Hub, n.d.). The HBM was suitable for explaining the connection between the health risks associated with PCOS, such as obesity, insulin resistance, type 2 diabetes, and the condition (CDC, 2020). The HBM's six main components are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Rural Health Information Hub, n.d.). These six components guided the research in addressing whether ME women understand the presence and severity of PCOS and its associated health risks. The main advantage of using HBM to assess ME women and population understanding of PCOS is creating a guide to further focus on this health issue for health providers to provide in-depth health education for women with PCOS to improve treatment and management practices.

Literature Review Related to Key Concepts

PCOS Research Related to Ethnicity

There is diversity in ethnicity in the females residing in the ME, generating a huge variation in the prevalence of PCOS based on different diagnostic criteria (Ding et al., 2017). Research that has evaluated the risks of developing PCOS indicated that Black women had the highest prevalence of developing PCOS, followed by Middle Eastern women, Caucasian women, and Chinese women with the lowest risk of developing PCOS (Ding et al., 2017). Women with different ethnic backgrounds also have variations in responses to screening and diagnosis, management priorities, and treatment, specifically when considering developing management guidelines for PCOS (Ding et al., 2017). HCPs can benefit from understanding PCOS prevalence based on women’s ethnic background combined with the signs and symptoms of PCOS pre-diagnosis. A health education tool that uses ethnicity-specific guidelines can help HCPs prevent under- or over-diagnosis of the condition PCOS to prevent metabolic disorders when underdiagnosing and negative psychological effects when over-diagnosing PCOS patients (Ding et al., 2017). This can be used to estimate PCOS patients from different ethnic backgrounds’ responses to the ethnicity-specific guidelines.

Ethnicity and demographics are factors that could influence the ME women population suffering from PCOS. Diversity in the ME region plays a role in developing a different degree of genetic admixture in the ME populations (Mousa et al., 2021). The result of the consanguineous marriages and intercontinental migration in the ME leads to a higher prevalence of globally rare genetic variations with a highly conserved gene pool (Mousa et al., 2021). This diversity in genetics made ME populations rich in culture and practices, along with exposing them to an increased risk of developing health problems. For example, obesity is a health problem with high rates in the ME population, specifically for ME females; obesity risk is twice as high as that for men. Obesity is associated with causing gynecological diseases and menstrual disorders (Mousa et al., 2021).

Other regional factors and genetic variations influence ME women's health. Exposure to war plus environmental toxins might alter circulating hormone levels and the immune system of ME women, therefore increasing gynecological diseases (Mousa et al., 2021). Based on research on Iranian ME women with PCOS, factors related to environment and culture can be associated with developing PCOS (Jalilian et al., 2015). Other research has found that ME Qatari females' prevalence of PCOS is distinctly higher compared to other females from other continents and ethnicities, based on the review by the National Institutes of Health (NIH) guidelines at 12.1% and the Rotterdam or Androgen Excess Society criteria at 20% (Lawrenz et al., 2019). This supports the assumption that other ME women may have the highest prevalence of PCOS due to similarities in culture, environment, and lifestyle factors like their corresponding ME Qatari females.

PCOS Research Related to Health Problems

A few studies addressed the abundance of health problems in the ME women population. Obesity has high rates in the ME women population and is the root of many of the health problems for this population (Al-Jefout et al., 2017; Dallel et al., 2021; Dutkowska et al., 2019; Mousa et al., 2021; Sulaiman et al., 2018). Obesity is a consistent feature of PCOS seen in 40–50% of patients and has an increasing and synergistic effect on the emergence of PCOS and exacerbates existing endocrine disorders (Jalilian et al., 2015). The presence of PCOS or obesity for women puts them at greater risk of heart diseases as well as type 2 diabetes mellitus, dyslipidemia, and nonalcoholic fatty liver disease (Shousha et al., 2018). PCOS comorbidity with obesity, type II diabetes, alopecia, hormonal disorders, hirsutism, infertility, or menstrual disorders may lead to other complications such as cardiovascular disease and infertility (Butler et al., 2020; Jalilian et al., 2015). PCOS and insulin resistance also have a unique linkage. Women with the type I PCOS phenotype were found to have more insulin resistance and higher values of free testosterone and the follicle stimulating hormone ratio, indicating that insulin resistance plays a role in developing PCOS (Al-Jefout et al., 2017). Insulin has a gonadotrophic function, with an increase in insulin availability within ovarian tissue may enhance excess androgen synthesis leading to anovulation for PCOS patients (Al-Jefout et al., 2017). Therefore, addressing obesity may improve PCOS symptoms in patients. Further, women with PCOS are at a greater risk of decreased hormonal and antioxidant levels, which lower their immunity and ability to fight diseases (Sulaiman et al., 2018).

PCOS Research Related to Infertility

Research on PCOS has addressed its association with infertility as a major concern for women with PCOS. Infertility is one of the main implications of PCOS diagnosis (AlSumri, 2019). Women with higher Body Mass Index (BMI) and PCOS may have a challenging time conceiving normally (Al-Ruthia et al., 2017), which leads to infertility treatment. Among the infertility treatments used to help women conceive are in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI) options. However, the success of IVF/ICSI for obese women with PCOS is significantly decreased due to a decrease of retrieved oocytes related to increased BMI in PCOS patients in a clinical pregnancy (Hasan et al., 2020). Furthermore, the duration and dosage of gonadotropin are significantly increased in overweight and obese PCOS patients (Hasan et al., 2020).

Infertility issues for PCOS women seemed to increase with higher BMI as it would significantly decrease the clinical pregnancy rate (Hasan et al., 2020).

Other research has also associated lifestyle habits among women with PCOS with infertility. Research that assessed reproductive health among ME Emirati females showed that they lack appropriate lifestyle choices that support PCOS treatment (Pramodh, 2020). Early detection and management of PCOS coupled with a dynamic awareness campaign for reproductive health can help improve the fertility rates of ME Emirati women. Developing interventions to address PCOS in adolescent girls with unhealthy habits is also needed to provide health education to young women with PCOS to manage the high risk of infertility and encourage healthy habits to improve health complications (Hajivandi et al., 2020). Unhealthy eating habits adopted by adolescent girls with PCOS can also lead to complications such as infertility (Hajivandi et al., 2020).

PCOS Research Related to Psychological Issues

Emotional distress is another issue associated with PCOS-related infertility, which can cause depression symptoms. PCOS patients without the current desire to conceive indicates that stress-related infertility may increase regardless of the current situation or if they have partners (AlSumri, 2019). Concerning signs and symptoms associated with PCOS, others may feel bad about having this diagnosis as it can impact their psychological well-being, lifestyle, and behavior, over the short and long term (Copp et al., 2019). A negative consequence on some women with health awareness, specifically with PCOS complications and how it will affect their health and quality of life, can induce anxiety and depression. On the other hand, understanding of PCOS may help women make lifestyle modifications that improve their health and prevent other comorbidity diseases associated with PCOS. It is also important for attention from health care specialists and policymakers in areas experiencing war, which can influence women's development of PCOS by increasing the chances of developing anxiety and depression (Alkoudsi & Basheti, 2020).

PCOS Research Related to Genetic Factors

Genetic predisposition is found to be one of the causes of PCOS. ME women have higher risks of developing PCOS due to environmental and genetic factors in the region (Mousa et al., 2021). The authors argued that the prevalence of obesity and comorbid conditions, such as hyperinsulinemia, type 2 diabetes mellitus, cardiovascular disease, and dyslipidemia, were reported to be associated with the highest prevalence in the Arab Gulf countries related to developing PCOS (Mousa et al., 2021). The high heterogeneity was assessed based on the variety of ages of ME women studied and found to have PCOS, whether pre-or post-menopausal (Mousa et al., 2021). Based on the NIH criteria, there is a higher prevalence of PCOS among women from the Gulf Region at 18.8% compared to women from the Levant at 6.3% and the Persian Region at 6.7% (Mousa et al., 2021).

Dallel et al. (2021) looked at the leptin receptor rs1137100 and rs1137101 gene (LEPR) gene variants with polycystic ovary syndrome (PCOS) in Tunisian and Bahraini Arabic-speaking women confirmed what Mousa et al. (2021) research has reported that golf region women are ethically predisposed to PCOS. Bahraini women had a negative association of rs1137100 and a positive association of rs1137101 with PCOS, compared to Tunisian women with no association of either variant with developing PCOS (Dallel et al., 2021). The findings that associate women from the golf region with having a genetic predisposition that increases their chances of developing PCOS may be associated with the obesity issue discussed earlier in the ME region. The increase in rates of obesity and genetic variants among ME women, specifically golf region women, could be associated with the development of PCOS.

Douma et al. (2019) discussed the findings of the Genome-Wide Association Studies (GWAS) associated with genetic diversity in Mediterranean populations related to PCOS. The fact that Mediterranean populations have a mixture of genetics due to different races and international marriages from European, African, and Asian ethnicities. The mix of races in the ME populations is responsible for discovering twenty genes from the Wide Association Studies (GWAS), which can be beneficial in the diagnosis of PCOS (Douma et al., 2019).

According to Douma et al. (2019) on the Middle East and North Africa (MENA), the geographic region revealed that the infertility rate in women between 20 and 44 years in the MENA region is higher than in the European population. In contrast to infertility’s higher prevalence, PCOS prevalence was detected in some ME populations such as Palestinians, Iranians, and Iranians (Douma et al., 2019). The GWAS studies on PCOS cases reveal that European populations, such as the French population, have the most substantial single nucleotide variations (SNV) linked by linkage disequilibrium (LD) to causative mutations compared to the Tunisian population from North Africa. This indicated that weaker linkage disequilibrium (LD) could be associated with the admixed of ethical groups in the Tunisian population causing a unique genetic structure in this population genetic (Douma et al., 2019). Adding the finding of the Mendelian Randomization (MR) study that genetic variants for PCOS are associated with BMI, insulin resistance, and sex hormone-binding globulin (SHBG) levels (Douma et al., 2019).

PCOS Research Related to Lifestyle

Changes in lifestyle for PCOS patients may require the assistance of healthcare professionals to help guide women with PCOS symptoms. Non-pharmacological treatments options include lifestyle intervention (Dutkowska et al., 2019). Adopting interventions that promote lifestyle changes requires time, money, and guidance from professionals. Those professionals are aware of the consequence of PCOS and can empower women struggling with PCOS to adopt these lifestyle changes for better health outcomes.

Dutkowska et al. (2019) revealed that women with PCOS are characterized by a number of mental disorders, therefore, a psychologist-therapist should be involved in the process of changing their lifestyle and eating habits. A Dietitian or Nutritionist can be a great assistant to guide PCOS patients through making dietary habits that help manage PCOS. The recommendation for PCOS patients is to use dietary supplements to supplement micronutrients (vitamins, dietary minerals), and vitamin D, which are important to relieve PCOS symptoms. Encouraging reducing obesity through physical activity and eating a healthy diet are the main methods for PCOS patients that require emphasis and monitoring by PCOS HCPs.

A crucial factor of lifestyle that is associated with PCOS is unhealthy food habits that lead to overweight or obesity. The presence of high consumption of unhealthy food in adolescent girls' lifestyles was determined to increase the chances of obesity (Hajivandi et al., 2020). Adolescent girls with PCOS reported unhealthy habits such as eating a high amount of fast food, low consumption of healthy foods and dairy, snacking very often, and eating desserts regularly. Along with unhealthy eating habits, adolescent girls with PCOS reported a lack of physical activity (Hajivandi et al., 2020). This research established the need for the development of interventions that address inappropriate food habits, to avoid PCOS-associated complications (Hajivandi et al., 2020).

Ee et al. (2021) studied the lifestyle changes that are needed to improve PCOS symptoms, by focusing on finding solutions to the barriers to lifestyle changes. Improving patients' self-management practices and increasing health literacy related to PCOS signs and symptoms to encourage lifestyle changes and improve women's health outcomes. Lifestyles and dietary factors may indirectly contribute to the development of PCOS because exposure to these factors has been linked with the appearance of PCOS in girls who are susceptible to PCOS. Lifestyle plays a significant role in PCOS recurrence, developing a supportive lifestyle for PCOS is an essential factor in preventing PCOS.

Badri-Fariman et al. (2021) assessed the connection between food insecurity (FI) and PCOS and found that FI, especially with moderate to severe hunger, was significantly higher among women with PCOS than in healthy women. The challenge for women with PCOS living at low economic levels could be the lack of knowledge or ability to practice good physical activity and healthy dietary patterns, leading these women to be overweight or obese and develop PCOS (Badri-Fariman et al., 2021). As, it was reported that almost 60% of PCOS women and 30% of non-PCOS women had FI (Badri-Fariman et al., 2021). The effect of PCOS on women's health is related to their food intake habits and the ability to engage in healthy eating habits such as including fruits and vegetables and lowering carbohydrates intake. If healthy eating patterns are associated with regular physical activities, the results can be an improvement in insulin resistance, type 2 diabetes, androgen concentrations, and the prevalence of PCOS (Badri-Fariman et al., 2021).

Kshetrimayum et al. (2019) argued that lifestyles and dietary factors may indirectly contribute to the occurrence of PCOS because exposure to these factors has been linked with the appearance of PCOS in girls who are susceptible to PCOS. In their study, the authors highlighted the factors associated with healthy lifestyle practices such as appropriate diet, exercise, optimization of body weight, and improving insulin sensitivity, to target PCOS-related health apprehensions (Kshetrimayum et al., 2019).

The condition PCOS requires significant lifestyle modifications that can improve levels of FSH, sex hormone-binding globulin, androstenedione, total testosterone, free androgen index, and Ferriman-Gallwey scores (scale for hirsutism in women) in women with PCOS (Kshetrimayum et al., 2019). Changes in lifestyle and monitoring of serum level metal were found to influence PCOS development. Studies found that serum nickel and copper concentrations were significantly higher, and zinc was significantly lower in subjects with PCOS compared with controls (Kshetrimayum et al., 2019). Metals such as copper and nickel might be implicated in the causation of PCOS and linked with impairment of reproductive hormone levels (Kshetrimayum et al., 2019).

Pramodh (2020), assessed that most metabolic problems including PCOS, are aggravated by poor lifestyle choices. Frequent consumption of fast food, high-calorie drinks, and low physical activity (PA), increases the risk factors such as obesity, cardiovascular disease (CVD), and type 2 diabetes, and escalates the severity of symptoms (Pramodh, 2020). The study found that only 2% of participating students reported smoking, and a low level of PA among ME Emirati female students at 64.5% performed 5 hours or less of physical activity per week (Pramodh, 2020). Most studies on PCOS and lifestyle changes emphasized the critical role of providing prevention and awareness campaigns to promote appropriate PCOS lifestyle choices to support reproductive health knowledge, healthy eating, and regular physical activity.

PCOS Research Related to Health Literacy

Nasiri Amiri et al. (2014) explored the experiences of Iranian women with PCOS, which aimed to assess the quality of their life with physical, psychological, emotional, social, and cognitive influences. The study provided evidence that the quality of life in women with PCOS declines in many ways, such as obesity, hirsutism, hair loss, facial acne, menstrual disorders and infertility, depression, isolation, anxiety, frustration, sexual performance (Nasiri Amiri et al., 2014). These changes in quality of life reduce self-confidence and create a pessimistic environment that leads PCOS patients to lose desire and patience. Encouraging women with PCOS to improve their quality of life should be the focus of HCPs to help these women understand their condition and how to deal with it.

Health literacy assessments are important to assess patients' health knowledge and ability to manage or prevent PCOS. Al-Ruthia et al. (2017) studied the effect of health literacy and BMI among PCOS patients in Saudi Arabia. The higher the BMI, the less likely patients with PCOS will have good health literacy, an estimated 16.1% of the screened patients had limited health literacy using the Arabic version of the short test of functional health literacy in adults (S-TOFHLA) (Al-Ruthia et al., 2017). Women with PCOS with limited health literacy are at an increased risk of obesity, endocrine disorders, as well as hypothyroidism (Al-Ruthia et al., 2017). Ee et al. (2021) just like Al-Ruthia et al. (2017) discussed improving patients' self-management practices and increasing health literacy related to PCOS.

Nasiri Amiri et al. (2014) recommended a multidimensional and dramatic effect of this disorder cultural-based approach through health education and counseling. The recommendation of a lifestyle change intervention is like this culturally based approach as a method of treatment that can help alleviate symptoms and improve the quality of life for PCOS patients.

Translating the polycystic ovarian syndrome questionnaire (PCOSQ) on a disease-specific scale to Arabic, was an effective tool to help assess PCOS in Arabic-speaking populations. The new Arabic version of the questionnaire was applicable and relevant to the Arabic population's cultures and values. The PCOSQ included twenty-six items categorized into five sections: emotions (eight items), body hair (five items), weight concerns (five items), infertility concerns (four items), and menstrual irregularities (four items) (Alghadeer et al., 2020).

Alghadeer et al. (2020) revealed the reliability and validity of the Arabic version of the PCOSQ to measure the specific health-related quality of life (HRQoL) in Saudi patients with PCOS. Based on the study by Alghadeer et al. (2020), the AR-PCOSQ identified factors such as emotions and feelings, body hair, weight, infertility, menstrual problems, weight, and body hair. These factors vary in similarities to the original scale of PCOSQ with differences in concerns related to infertility, getting cancer, being worried about having PCOS, late menstrual period, and irregular menstrual problems (Alghadeer et al., 2020).

The impact of PCOS on women's quality of life was assessed with a negative correlation since it causes many health problems that cause a decrease in quality of life. As an effective tool for assessment of the quality of life, the HRQoL questionnaires were translated to Arabic for the Arabic-speaking population. Odhaib et al. (2021) utilized the PCOSQoL-47 and PCOSQoL-42 to study married and unmarried women with polycystic ovary syndrome (PCOS) responsiveness to both questionnaires.

The two questionnaires seemed reliable and valid as HRQoL assessment tools for the Arabic-speaking women population. The study concluded that these types of Arabic versions of the HRQoL assessment tools are valid and reliable for women with PCOS. The Arabic versions of PCOSQoL could be reliable as it is easy to interpret by Arabic-speaking women suffering from PCOS. Removing the language barriers helps patients feel familiar and understandable with assessment questions.

Another important assessment tool to understand PCOS-related services and demographics in the ME communities is an Arabic version of the National Health Care Surveys (NHCS) conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). Sanchez (2018) examined the suitability of the National Health Care Surveys that are collected by the Centers for Disease Control and Prevention, to understand patient demographics and behavioral health services associated with PCOS-related medical visits. The NHCS were necessary tools that were needed to understand the impact of PCOS on US patients (Sanchez, 2018). The findings revealed that PCOS-related services lack diversity in reaching all ages (Sanchez, 2018).

Private insurance seems like the dominant type of coverage for these PCOS-related visits with white females as most patients, indicating the lack of minorities females' access to these types of services due to their inability to obtain private insurance. Race, ethnicity, and poverty could be determined as barriers to receiving PCOS-related services (Sanchez, 2018). A lack of reliable estimates of mental health and health education services that help in preventing PCOS is one of the results of these surveys (Sanchez, 2018). The surveys also reveal the disparities related to health education for women with PCOS and obesity who lack access to effective infertility treatment (Sanchez, 2018). Which provides evidence that health education for women with PCOS is critical to preventing or managing comorbidity or disease complications.

Providing educational intervention programs to improve PCOS patients' nutritional behaviors was determined an effective intervention by the Iranian study by Hajivandi et al. (2021). This research assessed the impact of an educational intervention program based on the theory of planned behavior on the nutritional behaviors of adolescents and young adults with PCOS in Iran (Hajivandi et al., 2021). Educational intervention programs, help improve attitudes, subjective norms, and perceived behavioral control in adolescents and young adults with PCOS that eventually lead to the formation of intention for healthy nutritional behaviors for the Iranian adolescent females in this study (Hajivandi et al., 2021).

The findings of research on the major benefits of behavioral and lifestyle changes that are necessary to improve PCOS needs to be implemented worldwide to help women with PCOS in all life stages (adolescent, adult, postmenopausal) understand and manage this condition. Like other research, the findings of this study presented the benefit of providing health education and healthy nutritional behavior awareness to improve or prevent PCOS. The findings of various research highlighted the benefits of lifestyle modification that included healthy eating and behavioral changes to improve PCOS complications.

Summary

This literature review demonstrated the findings of research on PCOS in the ME women population. It was apparent that the lack of research on PCOS for this specific population could be related to limited research on this women's health problem worldwide. PCOS is a health condition that is a critical public health issue for women worldwide and was addressed as part of other metabolic disorders, not as the main health issue. That is proven by limited research on the subject and the number of underdiagnosed with this condition. Women are diagnosed with PCOS only after having severe PCOS symptoms or when identifying comorbidities such as insulin resistance, type 2 diabetes, infertility issues, and menstruation disorders.

The present research has identified a lack of research on ME women's with PCOS perspectives on the PCOS health education practices provided by HCPs, from screening diagnosis to prevention or disease management education. Some research has emphasized increasing health literacy related to PCOS in women with increased risks of developing the condition. Health education regarding PCOS needs to include culturally based approaches for women at risk of developing PCOS to accommodate their cultural lifestyle.

The next chapter of this qualitative research is the Research Methodology. This chapter presents detailed information about the research design and qualitative methodology used to conduct this research. As well as including the plan for data collection, participants recruitment, and data analyses process.

Chapter 3: Research Method

Women with PCOS require access to health education and intervention strategies that increase their knowledge and self-management to prevent or manage PCOS and its associated health risks such as type 2 diabetes, depression, and infertility. This qualitative research was conducted to explore the perspectives and experiences of ME women with PCOS regarding PCOS health education provided by their HCPs. The research questions addressed participants' perspectives on health education by HCPs, their health beliefs that influenced their understanding of PCOS, and what cues to action influenced them to adopt healthy lifestyle changes as a treatment for PCOS. The intended outcome of this research is to understand the perspectives of ME women with PCOS on the health education practices provided by their HCPs is critical to creating an appropriate culturally competent health education for this population of women that have gynecological morbidity (Mousa et al., 2021). The long-term goal of this research is to inform HCPs of the benefits of providing culturally competent health education for women with PCOS. Given that this research population is ME women with PCOS presenting a culturally competent health education will improve self-management for this lifelong condition.

Research Design and Rationale

The method used to design this qualitative research was the basic interpretive approach (BIA). The interpretive approach is not guided by an explicit or established set of philosophical assumptions in the form of one of the known qualitative methodologies (Caelli et al., 2003). In the BIA, a qualitative approach aims to interpret participants' perceptions and experiences of health concerns (Thorne, 2016). I used this approach along with the HBM to create an interview protocol and formulate the interview questions to reflect the model’s constructs. Interview questions were used to collect data from ME women with PCOS to obtain information on their condition, experiences, and perspectives on the health education provided by their HCPs.

As a qualitative study that intended to explore participants’ experiences, the BIA has an exploratory nature that is appropriate to approach and explore ME women, with PCOS perspectives of PCOS health education practices provided by their HCPs. Another reason for using this approach was that BIA can be a general approach a mix of other qualitative methods such as ethnography and phenomenology (Cooper & Endacott, 2007). This interpretive general approach allowed interpretation of participants’ experiences and perspectives through interviews. This approach was flexible to investigate participants and acquire extensive and valuable data.

Method

Population

The study population ME women of reproductive age (18–45) with PCOS. The reason for focusing on this population was the limited research in studying this population regarding PCOS prevalence and culturally competent health education. PCOS as a health problem that affects one in ten women of childbearing age (U.S. Department of Health and Human Services, Office of Women’s Health, 2014). ME women have an increased variation in the prevalence of PCOS due to the ethnic diversity and under- or over-diagnosis of PCOS (Ding et al., 2017). Therefore, exploring ME women’s understanding of PCOS and experiences with PCOS education was critical for women with PCOS and HCPs treating them.

The participants were ME women of reproductive age (ages 18–45) diagnosed with PCOS living in the United States. The ME is a transcontinental region that consists of the Gulf Cooperative Council (GCC) Region (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, United Arab Emirates, Yemen), the Levant region (Cyprus, Iraq, Israel, Jordan, Lebanon, Palestine, Syria, Turkey), the North African region (Algeria, Egypt, Libya, Morocco, Somalia, Sudan, Tunisia), and the Persian region (Iran; Mousa et al., 2021). Research participants are from any of the above countries in the ME region, as the culture and religion are similar in the region.

Recruitment Procedures

After applying for IRB approval, I received an approval # 07-22-22-0987355 to begin data collection. I planned to recruit and interview ten participants. The participants were recruited from social media groups such as (Facebook and WhatsApp). The targeted social media platforms have community groups or groups that share the same health condition or ethnicity. An example was groups that provide PCOS education and information such as Nutritionist or Dietitian pages on Instagram or ME Facebook groups like the Muslim women in Dallas or United States. As the researcher and conductor of the interviews, I planned to gift participants a $20 gift card incentive as a thank you token for their participation in the study. This incentive was provided at the end of the interview.

Confidentiality and Ethical Considerations

For ethical consideration and confidentiality, an informed consent form was given to all participants. The informed consent presented information about me, the purpose of the research, procedures, nature of the study, risks, and benefits of being in the study, incentives, a notice of privacy, contact & questions, and questions, and consent signature (Walden University, n.d.). This informed consent was shared with participants through email and verbally at the beginning of interviews to reassure research purpose and confidentiality.

Participation in the study was voluntary; participants were free to opt-out of participation in the study at any time without penalties. Participants were also assured that their participation would be anonymous. Information about research findings will be shared with participants at the end of the study. Research data, documents, and interviews data are stored in files on my personal laptop. Transparency with participants was exercised throughout recruitment and during the interviews. Recruitment was through posting an invitation post/flyer on the social media platforms, briefly presenting information about the study and participants' selection criteria. Effective communication was conducted to prevent misconduct, ensure reliability of research data, and that the research is ethical.

Data Sources

The study data collection technique was interviewing. Interviews were appropriate to gain unique and detailed information and reflect participants' real experiences and perceptions. The interviews were a semi-structured approach to allow participants to feel comfortable sharing information in a conversational style. An interview protocol was created to reflect the HBM constructs (see Appendix). The interview protocol included ten sets of open-ended questions, then follow-up and probing questions were used as needed for clarification. The interview questions were shared with participants pre-interviews to allow participants to be familiar with questions and go over it as needed. Participants were allowed to ask for clarification on interviews' questions. As well as using probing questions to elaborate on participants answers. Participants were provided with informed consent to sign and return before interviewing.

Instruments

As the researcher, I was the main instrument for this research interviewing ME women with PCOS. The second instrument was the interview questionnaire. Other instruments that were used were email, phone, smartphone recording app, and qualitative data analysis software MAXQDA, and Microsoft Word. I intended to conduct interviews through phone calls using a recording app. The interviews were conducted formally to ensure all participants were asked the same questions. This ensured the reliability and validity of the data collected.

The goal of qualitative research is to uncover as much about the participants and their situations as possible (Jacob & Furgeson, 2012). Therefore, questions for this study were developed based on the desire to explore participants' perspectives and experiences. The open-ended interviews with open-ended questions were used to stimulate participants to provide answers in long sentences and in-depth details of their experiences and perspectives. The following were the questions used:

1. What were the symptoms you had that made you seek medical attention?
2. Tell me if any women in your family had PCOS. If yes who: mother, sister, aunt, grandmother, daughter? How did this person find out that they have PCOS and were the symptoms like yours?
3. What information did you know about PCOS before you were diagnosed?
4. Were you provided with the consequences of having PCOS like infertility, weight issues, or type 2 diabetes? If yes what was your perception of this information?
5. What action or lifestyle changes were suggested for you by your health providers to treat PCOS?
6. What other information was provided to you about PCOS by your healthcare providers?
7. Did your healthcare provider ask you about your ethnicity and provide you with information regarding PCOS in your culture or your first language?
8. What treatment and intervention practices were provided to you by your healthcare provider related to your culture for your PCOS condition?
9. What was your experience with health education provided to you? Did you feel it was easy or reasonable, or did you want more clarification about the treatment and intervention provided by your healthcare provider?
10. Was there a follow-up with your healthcare providers and how soon was it scheduled?

The length of the interviews was 30 minutes or less. Interviews were recorded for the process of data analysis.

Data Analysis Plan

This process was guided by the interpretative approach for the interview data. The data analysis plan for this research was flexible and involved Microsoft Word to transcribe interview data. MAXQDA is used to code transcribed data. A manual data analysis process was used by repeating interview recordings, reviewing transcribed data, and going through the identified codes to develop categories and themes. The assorted codes, categories, and themes were easier to manage, analyze and interpret. This analysis method described ME women participants’ perspectives and experiences with PCOS health education provided by their HCPs.

Summary

This research methodology chapter described the qualitative research design, approach, participant selection criteria, recruitment method, data collection methods, instruments to collect data, interview questions, and data transcription and analysis software. I also addressed the ethical considerations and confidentiality to ensure research validity. The next chapter introduces the application of the research design to recruit participants, collect data, and complete data analysis to present results.

Chapter 4: Results

This research aimed to explore the perspectives and experiences of ME women of reproductive age with PCOS health education provided by their HCPs. Data were collected from interviews with ME women ages 18–45 with PCOS and living in the United States to answer the research questions on the perspectives of participants regarding PCOS health education, their health beliefs, and their cues to action leading to lifestyle changes. This chapter presents the results of the data analysis of this qualitative study including a description of the setting, demographics, data collection process, data analysis, and evidence of trustworthiness. A correlation between research questions and themes developed during data analysis. Finally, the summary of the chapter presents an overview of this result chapter.

Setting

Interviews were conducted through a smartphone recording app (CallMaster) with participants' permission. Interviews were conducted in a private setting where participants felt safe and confident to share information and ask questions without interruption or breach of confidentiality. Participants chose the time and date of the interview. The interview duration was 30 minutes or less to respect the participants' time.

Demographics

I interviewed seven women of ME origin living in the United States. ME women participants were college and graduate school students and working professionals. Participants were ME women of reproductive age, ages ranging from early twenties to early forties. Three of the participants were married women diagnosed with PCOS and were actively trying infertility treatment. The other four participants were single and diagnosed with PCOS having symptoms related to irregular periods, weight gain, fatigue, unwanted hair growth, and pelvic pain. All participants received diagnoses and treatment of PCOS from HCPs in the United States.

Data Collection

The seven participants were recruited through Facebook and WhatsApp from July 22, 2022, to August 16, 2022. Participants were prompt in their responses to the invitation post for participation. Some participants reached out through messenger and WhatsApp to share their interest in participating in the research. After a brief conversation about the research purpose and process, participants shared their emails and phone numbers to receive the consent form and interview questions and attend the interview. The snowball recruitment method was used to recruit more participants by asking participants to share invitation posts with friends and family who could be potential participants. This method resulted in recruiting one participant. Every participant received an email with the consent form and research questions to explain the research topic and process before the interview. Participants had the chance to set the time and date for the interview based on their availability. Interviews were conducted through phone calls using a smartphone recording app (CallMaster). Participants were aware of the recording of the calls/interviews.

Interviews ranged from 15 to 30 minutes. Some participants shared more details than others. Participants who shared short answers were encouraged to share more information by using probing questions. The observation of the interviews and participants’ responses length attributed to participants’ personalities, such as being talkative versus precise. Participants appeared engaged and comfortable during the interview to share their experiences and perspectives without hesitation. Recorded interviews and transcripts of the interviews were transported from my phone to my laptop. Data collected during the interviews were saved in an encrypted file on my laptop with password access only by me.

Data Analysis

The interviews’ data was transcribed using Microsoft Word through dictate. A repeated manual data analysis was done to correct the mis transcribed recorded interviews. Then transcribed data was coded through MAXQDA and then manually via Microsoft Word. In MAXQDA documents with the transcribed data are uploaded to perform auto-coding for large text to identify codes. Listening and reviewing the recorded interviews several times to compare participants’ responses, look for repeated patterns in the data, and manually analyze the data. The manual data analysis process was appropriate and more manageable due to the small number of participants, leading to identifying codes and developing categories and themes. Data analyses through MAXQDA and manual data analyses yielded the same results. Similar codes patterns led to the development of categories and themes that represent participants’ perceptions of the study subject.

Repeating the interview records and listening to participants’ responses a few times helped capture participants’ non-verbal cues through tones like nervousness and frustration. This form of observation helped understand participants’ emotions and experiences regarding PCOS diagnoses. Non-verbal cues from participants helped interpret participants' perspectives toward HCPs' practices related to health education for PCOS.

Coding is a process of assigning meaning to data, plus a code can be a word or phrase that explains or describes what is going on in the data (Corbin & Strauss, 2015), (Ravitch & Carl, 2016). Coding the interview data helped identify repeated terms and patterns in the interview data. I chose phrases to form my codes to describe research data's repeated patterns. In this study, the coding process was an inductive process, with codes emerging from the data (Corbin & Strauss, 2015). This process involves using phrases repeated by participants such as I did my research, my doctor focused on medication, lack of lifestyle changes approach, lack of interest in patients' ethical background, and lack of proper PCOS health education.

Following assigning codes to collected data, the process of data analyses for codes begins by analyzing the emerging codes from participants' phrases. Then codes were clustered to create categories. The categories developed from the non-verbal cues observed during the interviews. It seemed fitting to present participants' feelings and emotions expressed after listening to participants' responses as part of the analyses. The process of identifying codes and categories was repeated many times to generate codes and categories that resemble the collected data. Lastly, this process led to the developing themes that represent the participants' perspectives and experiences (see Table 1).

Table 1

Codes, Categories, and Themes

Codes	Categories	Themes
Uninformative PCOS health education Doing my own research Limited PCOS awareness in at-risk women	Confusion or Unclear	Lack of PCOS health awareness for women with PCOS or at risk of having PCOS
Lack of a holistic approach Lack of lifestyle changes recommendations Medication focused treatment	Disappointment or Dissatisfaction	Inadequate health education that emphasizes lifestyle changes for PCOS
Focus on single symptom Uninterested in finding underline causes of the condition Inability to investigate patient health and activity related to PCOS HCP limited time spent with patients to discuss diagnoses	Anger	Poor communication between HCPs and PCOS patients
Lack of interest in ethical backgrounds Lack of interest in participants' cultural practices or origins	Hopelessness Helplessness	lack of culturally competent PCOS health education.

All participants provided details of their experiences and perspectives, reiterating the need to do their own research on PCOS treatment and a holistic approach due to the lack of proper health education for their condition. The participants' research included seeking advice from friends, family, or coworkers who have PCOS or internet searches on PCOS and holistic approaches and supplements for PCOS, which turned out to be effective more than the medication for all participants. Furthermore, all participants had the same perspectives regarding HCP communication of PCOS diagnosis and treatment. Participants stated that HCP provided limited PCOS health education related to PCOS symptoms, treatment options, and holistic approaches. Participants explained that HCP focused on one main symptom and did not take the time to investigate the real causes of PCOS and address them. Participants stated that HCP provided medication for the main symptoms of life hormonal treatment for women with PCOS-related infertility, metformin for PCOS-related insulin-resistant, and birth control for the irregular period. For all participants, their HCP failed or briefly mentioned lifestyle modifications to help relieve PCOS symptoms. Most participants discontinued medication for PCOS as the severity of birth control and metformin and other medication treatment was unbearable. This led participants to search for other HCPs, nutritionists, or social media dietitians to find natural treatment and follow their holistic approaches to treating PCOS.

Evidence of Trustworthiness

As mentioned in the previous chapter, this qualitative research-maintained evidence of trustworthiness. All components of credibility, transferability, dependability, and confirmability were applied and assured all through data collection to ensure the gathering of credible and reliable quality qualitative research.

Participants were recruited through social media platforms Facebook and WhatsApp. Participants reached out after seeing the invitation post/flyer and after a brief conversation providing information about the study and reiterating the inclusion criteria and research objective. Participants meeting the inclusion criteria and are interested in participation, providing their contact emails and phone for the interviews and received an email with the informed consent and interview questions. This process assured participants’ legitimacy of the research by providing the researcher and Walden IRB contact information. It informed participants of the topic and process of the study. Finally, it gave participants the chance to form a final voluntary decision to participate in the research or opt-out.

At the beginning of each interview, an introduction that resembles the consent form restating the research purpose, interview duration, and reassurance of participants' anonymity was stated to the participants. Then each participant was asked to provide verbal consent pre the start of the interview questions. Recordings and notes of the interviews were transported to an encrypted file for privacy.

After each interview, all seven participants received a $20 Amazon E-Gift Card as promised in the informed consent. Some participants stated that the gift card was not needed due to their interest in the Research topic, plus their understanding of the importance of research. After conducting seven interviews in which responses were the same, I realized that I had reached data saturation and began data analysis. All the research data is saved in secure encrypted files in a password-access laptop to prevent any data breach.

Results

This study aimed to explore the perspectives and experiences of ME women with PCOS regarding PCOS health education provided by HCPs. The process of data analysis included listening to the interview recording a few times, transcribing interview data, then analyzing transcribed data to identify codes and develop categories and themes. The findings of this study were then determined by using the developed themes to answer and correlate with the three research questions.

Table 2

Correlation Between the Themes and the Research Questions

Research Questions	Themes
RQ1: What are the perspectives and	• Lack of PCOS health awareness for

experiences with PCOS health education in healthcare settings for Middle Eastern women ages 18-45 (reproductive age)?	women with PCOS or at risk of having PCOS • Inadequate health education that emphasizes lifestyle changes for PCOS
RQ 2: How do Middle Eastern women of reproductive age (ages 18-45) health beliefs affect their perception of health education practices provided by their healthcare providers for PCOS?	• Lack of culturally competent PCOS health education
RQ 3: What are the cues to actions influencing Middle Eastern women of reproductive age (ages 18-45) diagnosed with PCOS to adopt healthy lifestyle changes as a treatment for PCOS?	• Poor communication between HCPs and PCOS patients • Inadequate health education that emphasizes lifestyle changes for PCOS

Of the three participants who were married, two were seeking fertility treatment, and one woman had children and was seeking treatment for a Menstrual cycle. They were told having PCOS causes infertility and were treated with diagonal IVF injections and hormone pills treatment to help them get pregnant. The other four were single and started having symptoms like irregular periods, weight gain, depression, acne, or excessive hair. They reach out to seek diagnoses and treatment for their symptoms only to find out they have PCOS. Only two participants have heard of PCOS before, from their friends or family members seeking fertility treatment or young girls with PCOS-related Premenstrual syndrome (PMS).

All participants received birth control or metformin treatment prescribed by their HCP, some tried the medications for months and some for days only to discontinue them due to severe side effects. All participants ended up taking supplements like Inositol, N-Acetyl Cysteine (NAC), Vitamin D, and herbs. All participants stated that they had to do their own research through the internet and social media PCOS specialists after diagnoses, as they felt their HCP provided limited information about their condition.

RQ1: What are the perspectives and experiences with PCOS health education in healthcare settings for Middle Eastern women ages 18-45 (reproductive age)?

Participants had various experiences with PCOS. Of the seven participants, only one participant (P4) stated that she was having irregular periods when she was diagnosed with PCOS and was told that this is treated by birth control. Her first HCP for PCOS was unhelpful, but as she explained her second current experience with a team of HCPs for PCOS is positive, stating that

> My provider and my nutritionist are very thorough with me, and I am very thankful for that. So honestly, I would not change the information that they give me because they do give me all the information I need to know. My doctor always goes in depth and explains blood like blood results when I do blood work and things like that. She goes over every line on that sheet that we do everything that she tested, why she tested it and with the results were and what the results mean.

All the other six participants in this research described their experiences with PCOS health education provided by their HCPs as brief and limited to treating one main symptom with medication offering birth control or metformin. Participants mentioned feeling unheard and pushed to take the medication treatment.

The theme “lack of PCOS health awareness for women with PCOS” was evident in a few of the participants’ responses when asked about What was your experience with health education provided to you for PCOS? example of Participants’ responses:

As stated by participant (P1) stating “I did not give up. I started making my own search. Because I did not hear about PCOS before, and I got pregnant before. So, I did not believe it. Why cannot I get pregnant?”

Participant (P2) explained “I did not really feel that she gave me enough information. That is why I was doing my own search all the time. She was good, but she was so brief and something like she was in rush.”

Participant (P6) stating

> Honestly, after they did the ultrasound and they saw them. They just told me; oh, you do have there, and they did not offer much information about it. It was just like they kind of just talked about it to let me know that I do have it, but not much information was provided. I went home and started educating myself by reading on the Internet, through trusted websites.

The theme “Inadequate health education that emphasizes lifestyle changes for PCOS” appeared in participants’ responses for example:

Participant (P1)

> I seek out two specialists for infertility, and they just told me you have PCOS. And that is why you are not responding well to the medication, the infertility medication, the diagonal IVF injections. And they told me there is no hope. Just save your money and time and go enjoy a vacation with your money.

RQ 2: How do Middle Eastern women of reproductive age (ages 18-45) health beliefs affect their perception of health education practices provided by their healthcare providers for PCOS?

The theme that presented an answer to this research question is the “lack of culturally competent health education provided by healthcare providers.” This theme appeared in some participants’ responses to the interview question “Did your healthcare provider ask you about your ethnicity and provide you with information regarding PCOS in your culture or your first language?”

Examples of These Responses

Participant (P3) “I felt like she just kept insisting on something I was uncomfortable with, and this connects to things culturally. Culturally, we are not very inclined to birth control. So, for her to be so. Insensitive to that, because I had mentioned to her, I told her in Arab culture it is not common, for her to not even account for that while she is talking to me. It is something by which I was very triggered.”

Participant (P2) “I really wish if there were more education provided or for us like because we are minority here. I know that that Americans talk about it a lot, but like. I am not sure if I am allowed to say. Depending on our culture, depending on our religion. They can provide us with lectures in our religious institutions talking about this, because we do not get enough education about it.”

Participant (P4) “When I worked with a nutritionist, she found out about my ethnicity, and we worked on a nutrition plan that incorporates. Foods and things like that from my culture that I can still eat in a healthier way.”

Participant (P6) “they always asked about the ethnicity when you fill the application, but they don’t give information.”.

Participant (P5) “She did not specifically say ethnicity, but. She was asking like in my family, is it like, common or like? She is asking how my mom or family hair is. Isn’t mine is similar, darker, or thicker than theirs?”

RQ 3: What are the cues to actions influencing Middle Eastern women of reproductive age (ages 18-45) diagnosed with PCOS to adopt healthy lifestyle changes as a treatment for PCOS?

The theme that emerged and aligned with the third research question is poor communication between HCPs and PCOS patients. Participants’ responses that represent this theme were presented when participants were asked “how soon was the follow-up scheduled after your diagnoses?” and What action or lifestyle changes were suggested for you by your healthcare providers?

Participant (P3) “So, I had called her and about the birth control and I was like, this is giving me suicidal thoughts and she suggested to. Put me on antidepressants. “So instead of, instead of. Changing the medication, she wanted me to she wanted to put me on antidepressants.”

Participant (P1)” No lifestyle nothing, they did not suggest even like I as I told two specialist and the three OBGYN, none of them told me about changing lifestyle. All of them said they said you have PCOS, there is no hope to get pregnant with PCOS and low AMH (Anti-Mullerian Hormone). So, they did not suggest anything. I go to my primary doctor and ask her to prescribe metformin, may it help me to get pregnant normal/natural.”

The theme “Inadequate health education that emphasizes lifestyle changes for PCOS” emerged in responses from a few participants as well. Participants’ expressions and verbal cues indicated disappointment in healthcare providers’ practices regarding intervention and PCOS health education provided for them.

Participant (P6) “they told me you have to lose weight, but I am a very petite person. I am 120 pounds, so I cannot lose weight like I am already very skinny. So, they told me that you can wait for it. Sometimes they just go by themselves but did not in my case. So, they went on with medication.”

Participant (P7) stating “they gave me metformin for insulin resistance and tried Birth control and stopped them because of the bad feeling. After I did my online research, I put myself on a strict low carb diet to manage it.”

Participant (P2) response “She only recommended the pills that I told you about it. And she just encouraged me to have a healthy lifestyle and that is it.”

Summary

In conclusion, this chapter presented the results of data analysis of interviewing seven ME women diagnosed with PCOS. Data analysis was completed using MAXQDA to identify codes. Then codes were analyzed to develop categories and themes. The themes were appropriate to answer the research questions. Describing the lack of proper PCOS health education that emphasizes lifestyle changes for PCOS, poor communication between HCPs and PCOS patients, lack of PCOS health literacy for women with PCOS, and lack of culturally competent PCOS health education. The finding presented a clear view of the participants’ experiences and perspectives regarding PCOS health education provided by their HCPs. The next chapter presents the discussion and interpretation of the study findings and recommendations for future research. As well as describing the potential positive social change implications on the multiple levels of the social-ecological model to address the PCOS health issues among ME women.

Chapter 5: Discussion, Conclusions, and Recommendations

This qualitative study was conducted to explore the perspectives and experiences of ME women with PCOS health education provided by their HCPs. The BIA was used to guide this research with flexibility in the data collection method, utilizing semi structured interviews and open-ended interview questions to gain participants' authentic experiences and perspectives. The HBM was used to interpret ME women's reactions to PCOS diagnoses and their understanding of the condition. The participants were ME women with PCOS at childbearing ages living in the United States.

The outcome of the data analysis revealed themes that represented the seven participants' responses to interview questions that gathered data regarding their experiences and perspectives regarding PCOS health education and HCP practices regarding their condition. The themes developed were a lack of PCOS health awareness for women with PCOS, inadequate health education that emphasizes lifestyle changes for PCOS, poor communication between HCPs and PCOS patients, and a lack of culturally competent PCOS health education. These themes came about as participants described their PCOS diagnoses and interaction with their HCP and the process of finding treatment and managing their condition.

Interpretation of the Findings

This study aimed to explore the perspectives and experiences of ME women with PCOS regarding PCOS condition health education provided by HCPs. Participants seemed to have feelings of confusion, disappointment, anger, and hopelessness regarding PCOS health education provided by their healthcare providers. The findings of this study confirmed the literature review of previous research on ME women with PCOS. There is limited data on ME women with PCOS, but the available research acknowledged the complex impact of PCOS among ME women regarding PCOS health risks and factors influencing the development of PCOS in ME women.

All seven participants reiterated similar responses of their HCP overlooking the connection between participants' PCOS condition and their culture and ethical background. As one of the participants (P6) stated, "when I went to the Middle East to my country, I saw a doctor there, and she told me that. This is more common for Arabian ladies than other ladies." This answer was stated in response to whether the HCP was interested in her ethical and cultural background regarding her PCOS diagnosis.

As presented in the literature review, factors leading to PCOS were ethnicity, health problems, infertility, psychological issues, genetics, and lifestyle. The second highest PCOS prevalence among females from different ethnicity are among ME women (Ding et al., 2017). HCPs' lack of culturally competent PCOS health education was apparent, as PCOS is a complex condition and requires a multidisciplinary approach. The seven ME women participants mentioned having one or more of the factors leading to PCOS. The genetic factor was apparent as all the participants stated that some women in their families had PCOS symptoms but were undiagnosed. Participants explained that PCOS-related menstruation issues looked at as women's health issues part of the menstrual cycle process, leading to many undiagnosed cases.

All participants increased their PCOS health literacy after their diagnosis by seeking Internet research to know and understand their condition and find treatment. All participants understood the importance of lifestyle changes to improve and manage PCOS symptoms. Some are adopting a strict approach to supplements and lifestyle changes such as dietary modifications and physical activity. Some participants are taking medication, but the majority discontinued medication like birth control, metformin, or hormonal treatment due to the severity of the side effects.

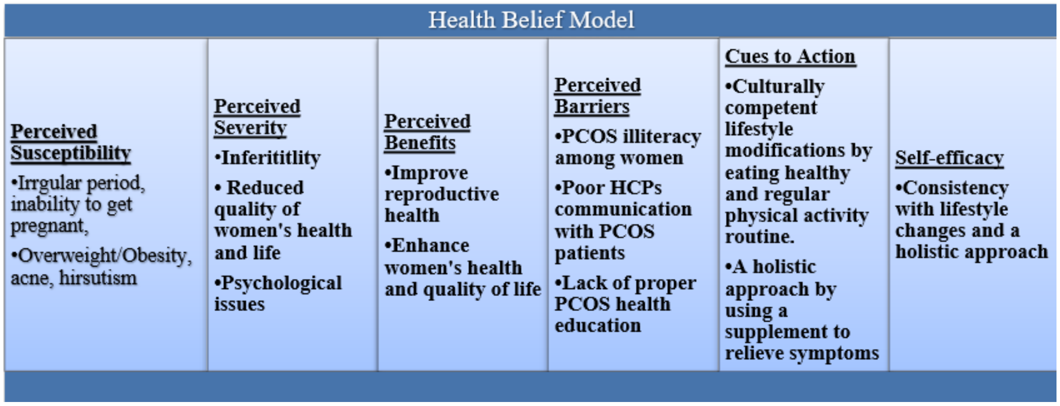
All participants described HCPs' poor communication of PCOS health education by pushing medication as the main treatment, inability to listen to ME women with PCOS cultural concerns regarding birth control, and lack of explanation of PCOS as a complex lifelong condition that requires more than medication but lifestyle changes. Participants expressed the need for HCPs to provide proper and comprehensive PCOS health education that is culturally competent. Participants felt that ME women with PCOS living in the United States need to hear from their HCPs that this condition is quite common genetically for their race. PCOS is a lifelong condition and requires lifestyle changes including dietary changes, physical activity, holistic approaches, and stress reduction.

Findings Related to Theoretical Framework

The HBMs' six main components identify perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Rural Health Information Hub, n.d.). ME women's participants expressed health behavior changes post-PCOS diagnoses as doing their research to understand PCOS and find treatment options that fit their health needs and culture. ME women participants applied the HBM constructs in their search to diagnose their symptoms or health concerns by seeking HCP treatment options (see Figure 1). Participants searched for a holistic approach due to the lack of proper PCOS health education provided by their HCPs related to their culture and ethnicity, adopting behavior changes to alleviate symptoms, and having the ability to be consistent in improving their condition.

Figure 1

Applying Health Belief Model Constructs to PCOS Patients' Behaviors



Health Belief Model

Perceived Susceptibility	Perceived Severity	Perceived Benefits	Perceived Barriers	Cues to Action	Self-efficacy
•Irrgular period, inability to get pregnant, •Overweight/Obesity, acne, hirsutism	•Inferititlity • Reduced quality of women's health and life •Psychological issues	•Improve reproductive health •Enhance women's health and quality of life	•PCOS illiteracy among women •Poor HCPs communication with PCOS patients •Lack of proper PCOS health education	•Culturally competent lifestyle modifications by eating healthy and regular physical activity routine. •A holistic approach by using a supplement to relieve symptoms	•Consistency with lifestyle changes and a holistic approach

Limitations of the Study

The limitations of this study were related to researcher bias, participant recruitment, the ability to find ME women interested in participation, and finding a location to conduct the interviews in a private setting. To eliminate researcher bias related to my personal experience as a ME woman with PCOS, I maintained a professional interview environment and refrained from sharing my personal experience with PCOS with participants until after the interview. Limitations related to participant recruitment and finding ME women with PCOS interested in participation in the research were addressed by using social media platforms such as Facebook and WhatsApp to find participants by targeting ME women groups for women's health and community activities. Limitations related to interview location were managed by conducting phone call interviews to make it convenient for participants to participate in quick 30-minute phone interviews. Participants appreciated this process of conducting interviews as some ME women were from different states, or they were unable to meet in person for the interview due to family or work responsibilities.

Recommendations

I interviewed seven ME women of reproductive age with PCOS, and the findings reflect their perspectives and experiences with PCOS health education provided by their HCPs. The results of this study cannot be generalized to this population due to the small sample size and specificity to ME women. But this research presented a glimpse of the ME women population’s reaction to PCOS diagnoses and HCPs’ delivery of health education. Further studies can target a larger population and recruit ME women in their health care settings. Applying a different data collection method, such as a focus group or in-person interviews with ME women with PCOS, can gather detailed information regarding PCOS health education. Another way to study ME women with PCOS is to study HCPs’ opinions of PCOS health education. Investigating HCPs’ perspectives on PCOS health education for ME women with PCOS can help determine whether ethnicity is essential in treating PCOS. It can also improve communication between HCPs and ME women with PCOS.

Implications

This study revealed the possibilities of creating comprehensive PCOS health education training for HCPs to better educate ME women with PCOS. At the medical level, a positive social change would be to provide proper and culturally appropriate

PCOS health education to ME women with PCOS and their families. It is critical to help ME women understand PCOS as a lifelong condition and provide appropriate treatment options (medication and supplements).

At the community level, a positive social change impact includes increasing PCOS health awareness among ME women at risk of developing PCOS. At the organizational level, a positive social impact would be to create a comprehensive PCOS health education delivered by HCP to women with a higher prevalence of developing PCOS, such as ME women. At the policy level, a positive social change impact would be to improve women's health and quality of life by mandating or requiring PCOS prevention programs statewide or nationwide. These prevention programs should include annual screenings for all women, regardless of race or ethnicity, to detect and reduce the prevalence of PCOS.

As the researcher, I noticed the need for culturally competent health education for women with PCOS from the beginning of my research. The same sentiment was reiterated by my research participants wishing for culturally competent health education that provides ME lifestyle changes to manage PCOS. As a health educator, an effective positive social change for ME women with PCOS would be to increase PCOS awareness among the ME women communities. The awareness and education program for PCOS can include comprehensive and culturally competent PCOS information like signs and symptoms, nutrition and lifestyle changes, plus holistic approaches tailored for ME women. Health educators and HCPs can collaborate to help women with PCOS by providing intervention programs based on ethnicity and lifestyle. Health education can be used to reduce the prevalence of PCOS among women and improve women’s quality of life.

Conclusion

PCOS is a complex lifelong condition; if not treated or managed, it may impair women’s quality of life and health. The ME women participants reflected on their experiences and perspectives of PCOS health education delivered by HCPs as insufficient and uninformative. HCPs can help increase women’s awareness about PCOS by listening to patients’ health problems, investigating their background culture and lifestyle related to their health condition and providing treatment accordingly. Culturally competent and comprehensive PCOS health education is needed to prevent PCOS complications and improve our quality of life.

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Appendix: Interview Questions Protocol

Introduction

I want to thank you for taking the time to meet with me today. My name is Walaa Daffaalla, I am a Ph.D. student at Walden University. I would like to talk to you about your perspectives and experiences with Polycystic Ovary Syndrome (PCOS) health education provided by your healthcare providers. The interview should take 30-45 minutes. I will be recording the session because I do not want to miss any of your comments. Also, I will be taking notes during the session. All responses will be kept confidential. This means that your interview responses will only be shared as needed with Walden University supervisors and we will ensure that any information we include in the study does not identify you as the respondent.

Remember, you do not have to talk about anything you do not want to. Are there any questions about what I have just explained? Would it be okay to give me your verbal consent before we start the interview questions?

Interview Questions

1. What were the symptoms you had that made you seek medical attention?
2. Tell me if any women in your family had PCOS. If yes who: mother, sister, aunt, grandmother, daughter? How did this person find out that they have PCOS and were the symptoms like yours?
3. What information did you know about PCOS before you were diagnosed?
   Were you provided with the consequences of having PCOS like infertility, weight issues, or type 2 diabetes? If yes what was your perception of this information?

4. What action or lifestyle changes were suggested for you by your health providers to treat PCOS?
5. What other information was provided to you about PCOS by your healthcare providers?
6. Did your healthcare provider ask you about your ethnicity and provide you with information regarding PCOS in your culture or your first language?
7. What treatment and intervention practices were provided to you by your healthcare provider related to your culture for your PCOS condition?
8. What was your experience with health education provided to you? Did you feel it was easy or reasonable, or did you want more clarification about the treatment and intervention provided by your healthcare provider?
9. Was there a follow-up with your healthcare providers and how soon was it scheduled?

Concluding/closing statement:

Thank you for taking the time to participate in this research. Your contribution is much appreciated, and the information you share is valuable. At the end of the research study, you will receive a copy of the complete research.