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The Quality of Life of Menopausal Women With Polycystic Ovary Syndrome

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This is to certify that the doctoral dissertation by

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Walden University

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Abstract

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by

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MA, Troy State University, 2000

BS, Rollins College, 1994

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Polycystic ovarian syndrome (PCOS) is a severe public and clinical health issue that puts a strain on health care resources and adversely affects the health of women throughout their life span. The syndrome has adverse reproductive and metabolic features linked to infertility, heart disease, cancer, diabetes, and psychological problems. The literature provides evidence that the quality of life (QoL) and psychological well-being of PCOS reproductive-age women is compromised due to comorbidities related to both the reproductive and metabolic features of the syndrome. Little research has been conducted to investigate the QoL of menopausal women ages 48–65 who were diagnosed with PCOS during their reproductive years, ages 18 to 45. The purpose of this phenomenological study was to understand the QoL of PCOS menopausal women diagnosed during their reproductive years. The conceptual framework the World Health Organization developed to conceptualize QoL was used in this study. Participants were recruited and interviewed via online conferencing. Data were collected from 10 semi-structured interviews and were analyzed using thematic analysis. Results indicate that the QoL of women with PCOS is aggravated. Participants described several psychological and physical conditions related to PCOS and menopause. The findings of this study could have implications for positive social change by leading to the development, implementation, and practice of interventions in health settings that may improve the QoL of menopausal women who were diagnosed with PCOS in their reproductive years.

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Dedication

I dedicate this research in loving memory of my husband of thirty years, Glynn

Pastol Stephens. He began supporting my educational pursuit during our dating years. His

encouragement, and confidence in my ability inspired me to persevere.

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Chapter 1: Introduction to the Study

Introduction

The National Institutes of Health (NIH, 2017) identified polycystic ovarian syndrome (PCOS) as a severe public health issue that puts a strain on medical resources and adversely affects women's lives. The Centers for Disease Control and Prevention (CDC, 2016) defined the syndrome as a lifelong endocrine condition with adverse reproductive and metabolic features. PCOS is linked to infertility, heart disease, cancer, diabetes, and psychological problems. The reproductive and metabolic features of PCOS present a serious economic burden to health care. Four billion dollars is spent annually to manage fertility-related treatments for reproductive age women, ages 14 to 44, (NIH, 2017). Research studies have revealed a poor quality of life (QoL) among reproductive age women (Acmaz et al., 2013; Hung et al., 2014; Panico et al., 2017; Rzonca, et al., 2018; Scaruffi, et al., 2014). However, less in known about the QoL of menopausal PCOS women, ages 48 to 65. No research has been conducted to investigate the QoL among menopausal women within this age range who were diagnosed with PCOS during the reproductive age of 18–45. Results of this study may provide insight into the QoL of menopausal women with PCOS. This research could contribute to positive social change when shared with organizations that develop educational interventions for women with the diagnosis.

In this chapter, I provide a general backdrop for understanding the effects of PCOS on women's physical and mental QoL. I describe the conceptual support for this study, leading to a discussion of the chosen methodology. I also consider the specific

scope of this project alongside its inherent delimitations and limitations. Finally, the

potential significance of the study is discussed.

Background

The existing research on this topic has largely been focused on PCOS among

reproductive age women. However, PCOS is a complex lifelong endocrine condition.

During their reproductive years, PCOS women from their mid-teens to mid 40s have a

poorer QoL compared to same age women (Acmaz et al., 2013; Hung et al., 2014; Naz et

al., 2019; Panico et al., 2017; Scaruffi, et al., 2014). Although PCOS is diagnosed in the

reproductive years, many of the physical and psychological symptoms follow patients

into menopause (Helvaci & Bulent, 2020; Sanchez, 2016). Less in known about the QoL

and psychological well-being of these women as they transition to menopause. These

women face a unique challenge because the metabolic features of PCOS and the

transition to menopause have similar health risks that may further erode their QoL

(Comim et al., 2017; Kakoly et al., 2019; Lenart-Liprnska et al., 2014; Sirmans et al.,

2014).

Developing a more comprehensive understanding of the lives of PCOS

menopausal women has significant academic and practical implications. This study

contributes to the understanding of menopausal women diagnosed with PCOS in their

reproductive years to enhance advocacy for the health and well-being of women at this

phase of life. As a result, practitioners can be better prepared to identify psychological

needs among this patient population.

Problem Statement

PCOS spans the lives of women from in utero before they are born until they die, leading to several health risks that can impair QoL (Bellever et al, 2018). Furthermore, menstrual and fertility problems evolve into metabolic complications as age advances. Nonetheless, little is known about QoL of menopausal PCOS women, ages 48–65. No researchers have investigated the QoL of menopausal women within the age range of 48–65 years who were diagnosed with PCOS during reproductive ages 18 to 45. A review of the literature indicates that menopausal PCOS women face life altering biological, physical, and psychological challenges (Bromberger et al., 2015; Helvaci & Yildiz, 2020; Winkler et al., 2015; Zheng et al., 2015). More serious chronic conditions such as cancer, cardiovascular disease, and diabetes among menopausal age PCOS women have been well-documented (Comijs et al., 2015; Kakoly et al., 2019). Furthermore, the psychological changes linked to menopause such as weight gain, disturbed sleep, and depression may exacerbate the condition of PCOS (Chau et al., 2019; Chen et al., 2013). These factors indicate that researching how PCOS menopausal women perceive their QoL is relevant and warranted.

Purpose

The purpose of this qualitative phenomenological study was to explore the QoL in women ages 48–65 previously diagnosed with PCOS during their reproductive years and how they experience and manage the disorder during menopause. Findings from this study may provide a basis for researchers and psychology intervention planners to gain

an understanding of the effects of PCOS during menopause. The results of this study

could be used to inform health care workers targeting this population.

Research Question

RQ: What are the lived experiences of QoL among menopausal PCOS women,

ages 48 to 65?

Theoretical Framework

The World Health Organization created a worldwide research group to provide a

framework for understanding QoL (Bonomi et al., 2000). This framework constitutes the

basis for this study. The World Health Organization Quality of Life (WHOQoL) group

defined QoL as individuals' assessment of their standing in life according to their culture,

values, goals, expectations, standards, and concerns (Suárez et al., 2018; WHOQoL,

1995). According to the WHOQoL group, QoL includes consideration of physical,

psychological, and environmental factors and social relationships (Bonomi et al., 2000).

Such a framework for QoL encompasses a person's physical health, psychological

condition, personal beliefs, social relationships, and relationships with the environment

(Monteleone et al., 2018; Ozkan et al., 2005).

This conceptualization of QoL was used to understand the experiences of

menopausal PCOS women. A diagnosis of PCOS causes life-altering biological, physical,

social, and psychological challenges (Bromberger et al., 2015; Dokras et al., 2018;

Winkler et al., 2015; Zheng et al., 2015). Furthermore, the transition to menopause can

adversely affect women's QoL (Jenabi et al., 2015; Nazarpour et al., 2018). Menopausal

women may experience somatic, vasomotor, sexual, and psychological symptoms related

to the decline in ovarian hormones. PCOS menopausal women are at greater risk for cancer, diabetes, and cardiovascular disease (Brand et al., 2019; Comijs et al., 2015; Ganapathy, 2018). A QoL framework including consideration of physical, psychological, and environmental factors, as well as social relationships, was used to help to better understand and explore the issues PCOS menopausal women face (Jenabi et al., 2015; Nazarpour et al., 2018). I used this conceptualization of QoL to understand the experiences of menopausal PCOS women. The different domains of QoL, including physical, psychological, social relationships, and environment, are used to better understand and explore issues PCOS menopausal women face (Jenabi et al., 2015).

Nature of the Study

In this study, I used a qualitative interpretative phenomenological analysis (IPA) to answer the research questions (Smith et al., 2009). This project aligned with an IPA methodology given that the goal of the project was to understand the lived experiences of this phenomenon (Smith, 2011; Vicary et al., 2017). Women ages 48–65 diagnosed with PCOS were interviewed regarding their experiences of managing and living with this diagnosis at this stage in life. Women also reported on their QoL and psychological well-being.

The main source of data for this study were interviews with a small sample of menopausal PCOS women ages 48 to 65, diagnosed with PCOS in the reproductive age range of 18–45. Face-to-face interviews with open-ended questions took place virtually with the use of video conference through the Zoom, Facebook, or a similar platform. I collected qualitative observation field notes on the perceptions, concerns, attitudes, and

behaviors of participants at the research location. Participants were encouraged to freely express their opinions. Thematic analysis was used to investigate data generated in the interviews (Braun & Clarke, 2006; Clarke & Braun, 2018).

Operational Definitions

The following terms were considered to be operational definitions and were implemented throughout the scope of this research:

Anovulation: Occurs when the ovaries do not release an oocyte during a menstrual cycle and ovulation does not take place. A woman who does not ovulate at each menstrual cycle is not necessarily going through menopause. Chronic anovulation is a common cause of infertility (Bellever et al., 2018; Palombo et al., 2015).

Hyperandrogenism: A medical condition characterized by high levels of androgens in women. Symptoms may include acne, seborrhea (hair loss on scalp), hirsutism (increased body and facial hair and infrequent or absent menstruation (Avery et al., 2020; Hadjiconstantinou et al., 2017).

Menopause: The condition of an absent menstrual cycle for at least l2 months (Basirat et al., 2019; Masood et al., 2016).

Metabolic syndrome: A combination of abnormal glucose metabolism, elevated blood pressure, abnormal lipid profile, and abnormal obesity (Kakoly et al., 2019; Mahalingaiah & Diamanti-Kandarakis, 2016).

Polycystic ovarian syndrome (PCOS): A heterogeneous and complex disorder with adverse reproductive and metabolic features linked to infertility, heart disease, cancer, diabetes, and psychological problems (CDC, 2016). Two of the following three

criteria must be met to diagnose PCOS: (a) clinical or biochemical hyperandrogenism, (b) oligo-anovulation, and (c) polycystic ovaries (Dumesic et al., 2015; Lim et al., 2019).

Polycystic ovaries: Presence of 12 or more follicles in each ovary measuring 2 to 9 millimeters in diameter and/or increased ovary volume (Lizneva et al., 2017; Palomba et al., 2015; Rosenfield & Ehrmann, 2016). The presence of polycystic ovaries is indicated via ultrasound.

Assumptions

I assumed the participants in the study would share their experiences in a sincere and authentic way and would answer the semistructured questions honestly. Second, I assumed that, as the main researcher, I would act only as a facilitator for the research, allowing participants to share their experiences. Lastly, I assumed that participants diagnosed with PCOS in their reproductive years would evoke similar themes as they talked about their personal experiences of transitioning to menopause.

Scope and Delimitations

A narrow focus was intentionally adopted in this study to answer the research questions and contribute to an empirical understanding of the lived experiences of women diagnosed with PCOS during their reproductive years as they transition to menopause. The precise population investigated was suggested by the existing literature that states PCOS reproductive age women have a poorer QoL than other women of the same age (Acmaz et al., 2013; Hung et al., 2014; Panico et al., 2017; Scaruffi et al., 2014). According to the conceptual lens applied to this project, the lived experiences of PCOS menopausal women must be understood from a standpoint of the QoL of these women as

they cope with the metabolic features of PCOS and menopause. The four domains of the WHOQol were used to understand the physical health, psychological condition, beliefs, social relationships, and environmental relationships of these women (Gupta & Kumari, 2021; Ozkan et al., 2005). Although the narrow focus of this project was called for based on the state of the literature, conceptual background, and methodological choices, the transferability of this study's findings is limited based on a necessarily low sample size. However, the themes that emerge from this investigation speak to the real-life experiences of PCOS menopausal women and thereby can inform advocacy on a larger scale.

Limitations

The study was limited to PCOS menopausal women who volunteered to participate following my solicitation within an online support group. This was a one-time study with no longitudinal follow up. Therefore, I was unable to assess the presence or absence of changes in perceptions over time. The findings of the study are limited to the women in the study and may not be transferable to other populations or women from outside the geographical area of those interviewed.

Significance

The study is significant because the findings provide insight into how menopausal women with PCOS experience QoL. Themes emerged from data collected during semistructured interviews, which were then analyzed. This research could contribute to positive social change when shared with organizations that develop interventions for women with this diagnosis. These interventions could include educational programs

dedicated to improving mental and physical wellness through the development of self-management skills. Society would ultimately benefit from the improved QoL of menopausal PCOS women by increasing public health and productivity.

Summary

This chapter provided a general description of the phenomenon of women diagnosed with PCOS during their reproductive years. The theoretical, conceptual, and empirical support for the research questions and purpose were described. Key words were defined in preparation for further discussion of these concepts in Chapter 2. The scope and limitations of this study were also identified. I further discussed this project's potential to bring about positive social change. Chapter 2 includes a deeper discussion of the discourse surrounding PCOS within the existing literature.

Chapter 2: Literature Review

Introduction

PCOS is the most common endocrine syndrome affecting reproductive-age women and the syndrome has reproductive and metabolic features (Naz et al., 2018; Rzonca et al., 2019). A diagnosis of PCOS results in comorbid conditions and lifelong health complications (Gilbert et al., 2018). However, the primary focus of existing research has been on fertility and diminishing the cosmetic features of the syndrome (Avery et al., 2020; Enjezab et al., 2017; Hadjiconstantinou et al., 2017). Approximately $4 billion is spent annually in the United States to manage fertility-related treatments for reproductive-age women, ages 14 to 44 (NIH, 2017). Excluded from this amount are obstetrical complications or morbidities in women who are experiencing menopause or who are postmenopausal (Brakata et al., 2017). Furthermore, more serious chronic conditions such as cancer, cardiovascular disease, obesity, and diabetes among women with PCOS who are menopausal have been well documented (Comijs et al., 2015; de Medeiros, 2020). Transitioning to menopause alone is associated with similar metabolic health risks found in women with PCOS, including psychological distress and poor QoL (Appian et al., 2016; Ratnayake et al., 2019). The reproductive features of PCOS contribute to poor QoL and psychological distress in reproductive-age women (Sanchez, 2020; Sanchez & Jones, 2016). However, less is known about the psychological well-being and QoL of these women during menopause.

The literature provides evidence that the QoL and psychological well-being of women with PCOS who are menopausal is compromised due to comorbidities related to

both the reproductive and metabolic features of the syndrome. As these women transition

to menopause, they face unique challenges because the health risks associated with

menopause are similar to those associated with the metabolic features of PCOS. These

factors may contribute to worsening physical and psychological health, resulting in

poorer QoL. The QoL of women with PCOS who are menopausal who transition to

menopause has been underresearched. Therefore, my objective in this study was to fill a

gap in the literature by exploring the lived experiences of women with PCOS who are

menopausal. I conducted the study to better understand the experiences of women in this

population to improve their lives and promote future research.

In this chapter, I explain my search strategy for a comprehensive literature review,

discuss the conceptual framework, and review the literature on the concepts of interest in

the study. In the review of literature, I provide information from studies organized by

categories as follows: defining PCOS; ramifications of PCOS; links between PCOS and

QoL (reproductive features, metabolic features); defining menopause; and similarities

between the health risk of menopause and metabolic features of PCOS, type 2 diabetes,

cardiovascular disease, obesity, and psychological distress. Finally, the chapter ends by

highlighting the gaps in literature on this topic, affirming the need for the study.

Literature Search Strategy

I searched many different sources and topics to yield an inclusive and thorough

review of the literature that supports the topic. I accessed search tools, databases, and

articles through Walden University Library's online portal. Many different databases

were used to complete this search, including PubMed, PsyArticles, Google Scholar,

PsyInfo, Medline, and Walden dissertation databases. I filtered my search to pay special

attention to peer-reviewed documents capable of suggesting future studies. I also

considered several different textbooks focusing on PCOS and menopause. I reviewed the

sources used in these works to ensure I was familiar with all authors who have

contributed to this topic. The following key terms were used in various combinations

throughout these searches: *polycystic ovary syndrome*, *aging women*, *reproductive age*

women, *menopause*, and *menopausal PCOS women*. I focused particularly on how

women incorporate the meaning of PCOS into their daily activities and identify common

factors that may support or interfere with self-management of PCOS.

Conceptual Framework

The WHOQoL provided a framework for understanding the lived experiences of

PCOS menopausal women (Bonomi et al., 2000). The WHOQoL-BREF has been tested

for validity and reliability across different populations and countries, has been used in

health research, and can help to evaluate various treatments (WHO, 1997b). The

WHOQoL-BREF instrument is a shortened version of the WHOQoL and was developed

to capture many subjective aspects of QoL (WHOQoL Group, 1993). Furthermore, it is

the best known instrument developed for cross-cultural comparisons and is available in

more than 40 languages. The WHOQoL group (1995) defines QoL as an individual's

perceptions of where they live within their culture and value judgment and their goals

expectations, standards, and concerns.

According to the WHOQoL, QoL contains four main domains: (a) physical,

(b) psychological, (c) social relationships, and (d) environment (Bonomi et al., 2000).

QoL also refers to a person's physical health, psychological condition, beliefs, social relationships, and relationships with the environment (Ozkan et al., 2005; Utian et al., 2018). I used this conceptualization of QoL to understand the experiences of women with PCOS who are menopausal. A diagnosis of PCOS causes life-altering biological, physical, and psychological challenges (Bromberger et al., 2015; Maki et al., 2018; Winkler et al., 2015; Zheng et al., 2015). Furthermore, the transition to menopause affects QoL (Ganapathy, 2018; Jenabi et al., 2015). Women who are menopausal may experience somatic, vasomotor, sexual, and psychological symptoms related to the decline in ovarian hormones (Monteleone et al., 2018; Ozkan et al., 2005).

In addition, women with PCOS who are menopausal are at greater risk for cancer, diabetes, and cardiovascular disease (Brand et al., 2019; Comijs et al., 2015). Therefore, the different domains of the WHOQoL-BREF, including physical, psychological, social relationships, and environment, were used to better understand the QoL of women with PCOS who are menopausal (Jenabi et al., 2015; Monteleone, 2018).

Literature Review Related to Key Variables and Concepts

My research was supported by disciplines that highlight a range of health and social issues that need to be explored further. These issues relate to the lived experiences of women with PCOS who are menopausal. The key terms I describe in the next section explore central areas of focus across the literature on women with PCOS, including reproductive features, metabolic features, and QoL. In addition, I review the literature on menopause and QoL because this stage of life alone poses similar metabolic health risks found in women with PCOS who are menopausal.

Defining PCOS

PCOS is a severe public and clinical health issue that puts a strain on health care resources and adversely affects the health of women throughout their life span (Mohsin et al., 2018; Patel, 2018; Rosenfield et al., 2016). The CDC (2016) defined the syndrome as a lifelong endocrine condition with adverse reproductive and metabolic features linked to infertility, heart disease, cancer, diabetes, and psychological problems. PCOS is diagnosed during the reproductive age of women using the 2003 Rotterdam diagnostic criteria (Mohsin et al., 2018). Two of the following three criteria must be met to diagnose PCOS: (a) clinical or biochemical hyperandrogenism, (b) oligo-anovulation, and (c) polycystic ovaries. However, there is no criteria to identify prevalent phenotypes in PCOS menopausal women or to diagnose PCOS in menopausal women.

Phenotypes of PCOS

Dapas et al. (2020) found the phenotypes of PCOS were developed by the NIH beginning in 1990. In the classic form (Phenotype A and Phenotype B), two of three criteria were used to diagnosis PCOS as follows: hirsutism, ovulatory dysfunction, and polycystic ovaries. Researchers explained that in 2003, at a meeting of European and U.S. reproductive societies and conferences, two additional phenotypes were introduced (Lizneva et al., 2016). These were Phenotype C, or *ovulatory PCOS*, and Phenotype D, or *non-hyperandrogenic*, which increased the number of patients diagnosed with PCOS (Al-Jefout et al., 2017). The phenotypes are linked to reproductive, dermatological, and metabolic features and continue to affect women with PCOS who are menopausal. For instance, Phenotypes A and C represent a greater lifelong risk for a metabolic condition,

and Phenotypes A and B are linked to greater insulin resistance regardless of body mass index (BMI; Cooney et al., 2017; Helvacia & Bulent, 2020).

Lizneva et al. (2017) identified a medical bias in diagnoses of PCOS in a meta-analysis of 13,796 patients with PCOS from 43 populations. The findings indicated that the prevalence of PCOS in referral versus unselected populations was higher for Phenotype A (50% vs. 19%) and lower for Phenotype B (13% vs. 25%) with little difference between Phenotypes C (14% vs. 34%) and D (17 vs. 19%). In addition, a 20-year longitudinal follow-up study found that, by age 40 years, the more severe phenotypes were reduced with improved ovulation and a lessening in the degree of hyperandrogenism (Helvacia & Bulent, 2020). Furthermore, referral status had greater BMI than local controls, a difference not apparent in unselected PCOS subjects (Lim et al., 2012). Lizneva et al. concluded that the phenotype, effects of referral status, and age must be considered in understanding the PCOS condition and plan effective interventions.

Aziz (2018) suggested therapeutic decisions in PCOS depend on the patients' phenotype, concerns, and goals and should focus on improving fertility, improving metabolic status, and suppressing and counteracting androgen secretion and actions. Further, the evaluation of patients suspected of having PCOS includes a thorough history and physical examination, assessment for the presence of hirsutism, ovarian ultrasonography, and hormonal testing to confirm hyperandrogenism and oligo-anovulation as needed and to exclude similar mimicking disorders (Aziz, 2018). Zore et al. (2017) noted phenotypes play an important role in determining metabolic and other

risks of PCOS. Furthermore, Fauser et al. (2012) and Rzonca et al. (2018) suggested that phenotypes should not be aggregated into one disorder because a critical understanding of PCOS phenotypes is needed to determine patients at risk of long-term complication. For instance, hirsutism is associated with Phenotype A and affects 70% of women with PCOS (Escobar-Morreale et al., 2012; Escobar-Morreale, 2018). The authors further noted that acne affects 15% to 25% of women with PCOS and contributes to androgenic alopecia (AGA), permanent hair loss.

In addition, patients with PCOS as defined by the NIH criteria consisting of Phenotypes A and B have higher rates of insulin resistance than the general population, regardless of BMI (Bienenfeld et al., 2019 Diamanti-Kandarakis & Pinidis, 2007). Authors noted that other phenotypes did not, implying that hyperandrogenism contributes to insulin resistance (Bienenfeld et al., 2019 Diamanti-Kandarakis & Pinidis, 2007). For instance, Phenotype D was not associated with increased risk of metabolic syndrome; however, women exhibiting hyperandrogenism have increased prevalence of metabolic syndrome compared with those with oligo-ovulation and PCOS ovaries alone (Behboudi-Gandevani et al., 2018; Shroff et al., 2007). Additionally, González et al. (2020) and Zhoa et al. (2010) found that hyperandrogenism is independently connected to Type 2 diabetes mellitus, which supports that Phenotypes A and C are associated with greater risk for metabolic syndrome. Furthermore, a 35-day menstrual cycle within the anovulatory phenotypes has been found to predict insulin resistance (Cower et al., 2013).

PCOS Diagnosis and QoL Among Reproductive-Age Women

Despite significant progress in understanding the pathophysiology and diagnosis of the disorder over the past 20 years, the disorder remains undiagnosed and misunderstood (Aziz, 2018). Studies have identified a poor QoL among reproductive-age women with PCOS 14 to 44 years of age (Amiri et al., 2014; Sanchez, 2020; Taghavi et al., 2015). Similar themes related to poor QoL have been found in qualitative studies of the lived experience of reproductive-age women with PCOS. The themes were sexual problems: an unsexualized self; physical problems such as pain, invasion, rejection/invasion by the social world; and avoiding public scrutiny (Sanchez, 2020; Taghavi et al., 2015). PCOS challenges women's perceptions of themselves due to reproductive and cosmetic features such as lack of fertility, a hairy appearance, and irregular menses (Amiri et al., 2014; Moghadam et al., 2018). Reproductive-age women with PCOS (ages 14 to 44 years) have been found to have a poorer QoL and increased psychological problems compared with healthy women of the same age (Acmaz et al., 2013; Basirat et al., 2019; Hung et al., 2014; Panico et al., 2017). Researchers have found a considerable amount of depression in the population related to QoL and disease manifestation such as obesity, hirsutism, hair loss, acne, and menstrual disorder (Enjezab et al., 2017; Hadjiconstantinon et al., 2017; Sanchez, 2020). The clinical features of PCOS diagnosed during reproductive years follow patients into menopause.

Lived Experiences of Reproductive-Age Women With PCOS

Dermatologic manifestations hyperandrogenism are clinical features that result in hirsutism, acne, and AGA in 70% of women with PCOS affected by hirsutism or

excessive male-like hair (Escobar-Morreale et al., 2020). Acne affects 15% to 25% of

women with PCOS and contributes to AGA, androgenic alopecia, or hair loss with no

racial difference in women's complaints of hirsutism and acne (Bienenfeld et al., 2018;

Quinn et al., 2014). In a study of 70 reproductive-age women, 18–45, Chaudhari et al.

(2018) found prevalence of anxiety was 38.6% and depression was 25.7%. Infertility and

alopecia are associated with anxiety, while acne is associated with depression (Chaudhari

et al., 2018). Hirsutism is associated with a lower psychological QoL (Chaudhari et al.,

2018). Belever et al. (2018) conducted a study of postmenopausal women with PCOS,

ages 41 to 55, and found they frequently reported hirsutism or excessive hairiness on

face, hands, arms, legs, and overall body. Comim et al. (2017) identified the presence of

hirsutism and oligo-amenorrhea during female reproductive years predicts susceptibility

to diseases such as stroke, angina, cancer, and cardiovascular disease. Other researchers

have highlighted the need for more and better tests to determine the association between

infertility, cosmetic features, and psychological problems in women with PCOS based on

phenotype, age, and ethnicity (Chaudhari et al., 2018; Quinn et al., 2014).

Measurements of QoL in Reproductive-Age Women With PCOS

PCOS causes a reduction in health-related quality of life (HRQoL) due to

complaints of irregular menstrual periods and/or heavy menstrual bleeding and infertility.

In addition, symptoms include excessive growth of coarse facial and body hair, obesity,

oiliness of the skin, seborrhoea (dandruff patches), and cystic acne. Therefore, Cronin et

al. (1998) developed a quality-of-life questionnaire to promote interventions to reduce or

eliminate the symptoms of the disorder. The self-administered questionnaire includes a

total of 26 items and takes 10 to 15 minutes to complete. The content validity of the

questionnaire was ensured by the comprehensive approach to item selection and the

involvement of 100 women with PCOS in item reduction (Cronin et al., 1998). Currently,

researchers have used the Modified Polycystic Ovary Syndrome QoL Questionnaire to

determine health-related QoL in women with PCOS. However, study samples have

differed in the degree of impairment in each domain of the Modified Polycystic Ovary

Syndrome QoL Questionnaire. Therefore, Bottcher et al. (2018) conducted a study to

validate the PCOSQ-G (German) to validate the questionnaire's ability to assess the

impact of PCOS on patients' lives. The research consisted of 199 patients aged between

18 and 45 years who were diagnosed with PCOS . They were recruited from the

outpatient department of the University Clinic of Gynecologic Endocrinology and

Reproductive Medicine Innsbruck, Austria, between 2012 and 2014. The analyses

showed satisfying psychometric properties and good internal consistency and retest

reliability values. The patients reported significantly higher impairment on the emotion,

body hair, infertility, menstrual problems, and weight domains than the healthy controls.

The findings indicate a need for a disease-specific questionnaire, and that the now-

validated German version of the PCOSQ-G may help select patients with an impaired

HRQoL and consequently a possible higher risk for psychological disorders.

    In a similar study to Bazarganipour et al. systematically reviewed specific

domains of PCOS in the questionnaire. For their systematic review, Bazarganipour et al.

used the following search engines to locate articles published between 1998 to 2013:

PubMed, Psych Info, CINAHL, CENTRAL, and Scopus. The search yielded six relevant

publications, and Bazarganipour et al. found that the studies included two questionnaires: the Polycystic Ovary Syndrome Questionnaire (PCOSQ) and the Modified Polycystic Ovary Syndrome Questionnaire (MPCOSQ). The PCOSQ contained questions related to emotions, obesity, irregular menses, and infertility. The MPCOSQ, a modified version of the PCOSQ, included four additional questions to address concerns about acne. According to Bazarganipour et al., the two instruments were used to gather appropriate information to assess the QoL of reproductive-age women with PCOS. Thus, the six relevant publications and scores of each domain of the PCOSQ or the MPCOSQ of 1140 participants with PCOS were collected to create the meta-analysis.

The findings of the meta-analysis showed that the most affected domains in specific HRQoL were hirsutism and menstruation (Bazarganipour et al., 2015). Bazarganipour et al. elaborated by explaining the features and distress associated with each. For instance, the loss of menstruation (amenorrhea) was described as a nonvisible characteristic of PCOS. The condition also causes emotional distress due to feminine role expectations, religious practices, and sociocultural norms (Bazarganipour et al., 2015). Furthermore, menstruation is a major component of role expectation, whereby women are to become mothers. Religion can be a source of distress in some groups such as Islam, where menstruating women are not allowed to pray. In addition, the family and social group of a woman who misses more than 5 days of prayer monthly would be aware of her menstrual irregularities (Bazarganipour et al., 2015).

Last, social and cultural generalizations also contribute to distress for women with PCOS who are not menstruating due to the expectation that women become pregnant in

the first year of marriage. According to Bazarganipour et al. (2015), these factors

highlight the need for future research to emphasize both the importance of hirsutism and

menstruation as a contributor to impaired HRQoL in PCOS.

Various generic and specific questionnaires have been used for assessing different

dimensions of HRQoL in PCOS women. Therefore, Behboddi et al. (2018) examined the

general and specific instruments used to determine factors that affect HRQoL in women

with PCOS. Behboddi et al. reviewed studies published between 1945 and 2017 and were

indexed in MEDLINE, ISI Web of Science, and Scopus. Behboddi et al.'s (2018) search

yielded 52 studies (nine qualitative and 43 quantitative). In addition, the forms used most

frequently in the studies were the 36-item Short Form Health Survey-SF-3 and the

Polycystic Ovary Syndrome Questionnaire Health-related QoL Questionnaire. Overall,

five general measures and three specific measures used to assess the QoL in PCOS

women. The five general measurements were as follows: Short Form -36, Symptom

Checklist-90-Revised, World Health Organization Quality of-Life-BREF (WHOQoL-

BREF, Child Health Questionnaire-Child Form, and the General Health Questionnaire-

28. The three specific instruments were the Short Form Health Survey- 36 (SF-36), the

Polycystic Ovary Syndrome Questionnaire Health-related QoL Questionnaire and the

Modified Polycystic Ovary Syndrome Questionnaire Health-related QoL Questionnaire.

Behboddi et al. found that the Polycystic Syndrome Health-related QoL Questionnaire

(PCOSQ), a disease-specific instrument, was used more frequently to determine QoL in

women diagnosed with PCOS. Behboddi et al. further noted that the questionnaire

contains 50 items representing six areas, namely emotions, obesity and menstrual

disorders, fertility, sexual function, hirsutism, and coping. Each item is answered by selecting from options on a 5-point Likert scale with higher scores meaning better condition. Behboddi et al. found the Short Form Health Survey-SF-36 was used to determine QoL those diagnosed with PCOS. The form consists of 36 items tapping into eight subscales, namely physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. The scores on each domain range from 0 to 100, with higher scores indicating better conditions.

Lastly, Behboddi et al. (2018) found the SF-36 instrument has proven to be reliable, widely validated, and employed in the assessment of HRQoL for various medical conditions, as well as soliciting general information about health conditions and emotional responses to PCOS. However, an important feature of the PCOSQ was providing more specific information related to health conditions such as obesity, infertility, and hirsutism (Behboddi et al., 2018). Both or either instrument with a generic measure would be appropriate when measuring QoL in PCOS women and identifying areas to help improve QoL in these women. Behboddi et al. concluded that all the instruments assessed different aspects of QoL in PCOS women and found that PCOS had negative effects on QoL in this population. Researchers have used all instruments to identify the issues facing reproductive age women, including adverse clinical complications, reproductive issues (menstrual irregularity and infertility), metabolic issues (insulin resistance, diabetes, and cardiovascular risk), and psychological disabilities (anxiety and depression). Bazarganipour et al. (2015) noted treatment of

hyperandrogenism and menstrual irregularities can improve psychological functions in

PCOS reproductive age women.

In sum, the most widely used instrument used to measure PCOS are the Short

Form-36 (Sf-36), (PCOSQ) and (MPCOSQ). The SF-36 consists of 36 items tapping into

8 subscales, namely physical functioning, role physical, bodily pain, general health,

vitality, social functioning, role emotional, and mental health.

The PCOSQ contains the following domains: emotions (8 items), hirsutism (5

items), weight (5 items), infertility (4 items), and menstrual disorders (4 items). Lastly,

the MPCOSQ includes 30 questions from 6 HRQoL domains: emotional disturbance (8

items), weight concerns (5 items), infertility (4 items), acne (4 items), menstrual

symptoms and predictability (4 items), and hirsutism (5 items). Each item was rated on a

7-point Likert scale where higher scores represent better function for both instruments

(PCOSQ and MPCOSQ).

Each of the above- mentioned instruments identified the poor QoL in PCOS

reproductive age women. However, PCOS is a lifelong condition with continuing

metabolic features and health risks (Gurka, et al., 2018; Hildreth et al., 2018; Wang et al.,

2018) similar to those of women transitioning to menopause due to the natural change in

the reproductive hormones, progesterone, and estrogen (Ganapathy et al., 2018; Masood

et al., 2016). The transition to menopause alone is associated with metabolic issues such

as type 2 diabetes, obesity, cardiovascular disease, and certain cancers (Brand et al.,

2013; Lenart-Liprnska et al., 2014; Monteleone et al., 2018). For instance, Chedraui and

Pérez-López (2019) found after menopause women exhibit higher prevalence of

metabolic syndromes and higher risk of heart disease. In addition, chronic physical diseases such as polycystic ovary disease are associated with risk for depressive symptoms (Gurka et al., 2016; Park et al., 2017). These factors highlight the need to better understand the lived experience of women diagnosed with PCOS in their reproductive years as they transition to menopause.

Economic Burden of PCOS

The reproductive and metabolic features of PCOS presents a serious economic burden to health care. Four billion dollars is spent annually in the United States to manage fertility-related treatments for reproductive age women 14-44 (NIH, 2017). Approximately 40% of the economic burden is a result of the increased prevalence of diabetes associated with PCOS; 30% arises from the treatment of the associated menstrual dysfunction/AUB, 14% from the treatment of hirsutism and 12% provision for infertility services (Albahar, 2015; Rosenfield, 2020). This breakdown does not include the cost of obstetrical complications or morbidities in menopause and postmenopausal women (Brakata, et al., 2017).

Metabolic Features of PCOS

PCOS reproductive age women are at increased risk of hypertension, insulin resistance, diabetes, central obesity and myocardial infarction compared to age-related referents (Chedraui, P., & Pérez-López, 2019; Mahalingaiah et al., 2015). Further noting the risk of metabolic syndrome was found in 45% prevalence in women aged 20-29 years and 53% in women ages 30-39. In addition, the more serious chronic conditions such as

cancer, cardiovascular disease and diabetes become more pronounced with age among PCOS women (Comijs, et al., 2015; de Medeiros, 2020).

Ezeh et al. (2020) found visceral adiposity has been reported to negatively affect metabolic function to a greater degree than non-visceral adiposity. Further noting, in PCOS women both visceral and subcutaneous adipose mass independently and negatively predict insulin insensitivity. Previous studied noted adipose tissue is the largest endocrine organ and the insulin resistance of PCOS may also result from altered production in adipocyte by products regardless of obesity (Chazenbalk et al., 2010; Ezeh et al., 2012: Ezeh et al., 2020). Furthermore, reduced levels of adiponectin or production of by adipocytes may contribute to insulin resistance in addition to endothelial dysfunction and cardiovascular risk of PCOS (Carmina et al., 2008: Dunaif & Finegood, 1996; Ezeh et al. 2020).

Obesity

Zore et al. (2017) suggest obesity represents a more severe phenotype with greater degree of insulin resistance, hyperinsulinemia, metabolic dysfunction and hyperandrogenism. Further noting, obesity exacerbates or fosters other long-term morbidities including metabolic complications, risk for certain types of cancers due to chronic unopposed estrogen. Concluding that obesity leads to a poor QoL and low self-esteem, which can cause a variety of mood disturbance.

In the United States obesity affects 30 to 75% of women with PCOS (Carmina et al., 2013), a prevalence higher than Europe (Ehrmann, 2005; Mohsin, 2018). Multiple studies have concluded that there is a greater degree of insulin resistance in obese

compared to lean women with PCOS (Gonzales et al., 2020; Morales et al., 1996: Vrbikiva et al., 2014). PCOS women have higher rates of hyperinsulinemia, and insulin resistance, independent of obesity (Lugue-Ramirez et al., 2015; Toosy et al., 2018). The concomitant presence of obesity is associated with further increase in the long-term risk for metabolic dysfunction (Zore et al., 2017).

Zore et al. (2017) found the long-term effects of PCOS are at a greater risk for insulin resistance and hyperinsulinemia than matched controls resulting a greater risk of developing long-term complications associated with metabolic syndrome. Further noting, this includes higher lifetime risk of type 2 diabetes mellitus (T2DM), non-fatty alcoholic liver (NAFLD), metabolic syndrome, hypertension and potential vascular complications. In addition, the risk of cardiovascular is elevated in individuals with metabolic syndrome, based on a retrospective analysis of women with PCOS, the prevalence of metabolic syndrome as defined by NIH criteria may be higher than 33 to 43% approximately twice that of the general population. Concluding that the study was based on estimates using the National Health and Nutrition Examination Survey and even higher in age-matched study.

Cancers

PCOS women are at increased risk of developing endometrial, ovarian and breast cancer (Zore et al., 2017). Further noting, the risk is associated with unopposed estrogen exposure from persistent hyperandrogenemia with subsequent aromatization, chronic anovulation, hyperinsulinemia and hyperglycemia. The researchers identified obesity as a factor in endometrial, breast cancer and possibly ovarian cancer with the malignancy of

PCOS increased by the prevalence of obesity. Furthermore, the presence of the circulating sex steroids and insulin characteristic of PCOS put the hormonally sensitive cancers such as endometrial cancer at risk. Most studies have demonstrated an increased risk of endometrial cancer in women with a PCOS (Azizia & Hardiman, 2014; Bellver et al., 2018; Gottschau et al., 2015). For instance, a large cohort study from the Danish Cancer Registry consisting of 12,000 women with PCOS found they were four times more likely to develop endometrial cancer compared general Danish female population (Gottschau et al., 2015; Neven et al., 2020). Further noting, the women were diagnosed with type1endometrial cancer. These findings were consistent with a systematic review and meta-analysis exploring the risk of endometrial cancer among PCOS women and found an increased risk of neoplasia in the syndrome (Azizia & Hardiman, 2014; Bellver et al., 2018).

Lundberg (2019) found in a population-based cohort of 2,882,847 women, cox regression analysis was used to investigate cancer incidence among infertile women. Overall, infertility was associated with a higher incidence rate of ovarian endometrial cancer, but not of breast cancer. Previous studies found PCOS women are not at increased risk for breast cancer (Azizia & Hardiman, 2014; Gottschau et al., 2015; Neven et al., 2020; Shobeiri & Jenabi, 2016). For example, a large cohort study of 45,000 patients failed to find an increased risk of breast cancer among PCOS women (Shobeiri & Jenabi, 2016). Another systematic review and meta-analysis also failed to find increased risk of breast cancer with no change in results when the analysis excluded women older than 54 years (Azizia & Hardiman, 2014; Bellver et al., 2018. Kim et al. (2016)

conducted a similar study of more than 1500 women with newly diagnosed or in suti or invasive breast cancer and compared to age-matched controls. The investigators found breast cancer incidence of threefold increase in premenopausal women which contrasted to post-menopausal PCOS women in whom breast cancer incidence decreased by 33%. The results were hypothesized as due to the abnormal hormones associated with a PCOS diagnosis which impacts the pre-menopausal breast and ameliorates over time.

There have been mixed results regarding PCOS and ovarian cancer (Zore et al., 2017). The increase in ovarian cancer in PCOS women significantly increases when women over the age of 54 are excluded from studies. For instance, a large cohort Danish Cancer Registry study of 12,000 PCOS women did not find an association between ovarian cancer and PCOS (Barry et al. 2014; Gottshau et al., 2015; Neven et al., 2019; Shobeiri & Jenabi, 2016). However, a case-controlled Cancer and Steroid Hormone consisting of 4000 controls and 476 women diagnosed with epithelial cancer found 7 women with ovarian cancer and 24 control reported a diagnosis of PCOS. The risk for ovarian cancer was 2.5 times higher for PCOS patients (Shobeiri et al., 2016; Carvalho et al., 2019)

PCOS women are at risk of leiomyomata or uterine cancer due to elevated sex steroids and insulin anabolic hormones (Zore et al., 2017). Furthermore, the luteinizing hormones levels of PCOS women may also be responsible for the development of uterine fibroids. For instance, a 6 year retrospective study of women from the Black Women's Health study found increased risk of fibroids. Wise et al. (2007) noted the association between hyperandrogenism or leiomyomata was supported by a diverse Study of

Women's Health Across Nations (SWAN). The study consisted of 3240 women age 45-52 of diverse backgrounds and ethnicity. Women with higher testosterone were at greater risk but not for recurring fibroids (Wong et al., 2016). The findings indicated high testosterone and estradiol were associated with greater risk, whereas higher estradiol and testosterone resulted in lower risk for recurrent fibroids. However, in a study of 1,070 women, age 18-40 with gynecological problems or infertility found fewer patients with polycystic ovaries (not necessarily PCOS) had fibroids (Abdel-Gadir et al., 2009). The findings were compared to women with normal ovaries and the negative correlation was sustained regardless of age, parity or ethnic origin. Therefore, the connection between uterine leiomyomata and PCOS remains unclear.

Defining Menopause

Menopause is defined as the condition of an absent menstrual cycle for at least l2 months (Masood et al., 2016). The transition to menopause is associated with risk for chronic diseases such as type 2 diabetes, cardiovascular disease, and bone disease (Brand et al., 2019, Wellons et al., 2012). In addition, menopausal women have a poor QoL compared to non-menopausal women (Ratynayake et al., 2019). Factors influencing depressive symptoms in menopausal women were, frequency of hot flashes, and sweating, educational level and diabetes (Zheng et al., 2017).

Menopause and Psychological Distress

Psychological distress and poor QoL related to infertility, obesity, hirsutism, acne have been identified and addressed in PCOS reproductive age women (Enjezab et al., 2017; Martin et al.,2017**;** Sanchez, 2020). For instance, reproductive age women with a

PCOS diagnosis are challenged in the perception of themselves as feminine due to their lack of fertility, obesity and a hairy appearance (Amir et al., 2014**;** Sanchez, 2020). Previous studies found that as these women transition to menopause they experience psychological distress due in part due to aging ovaries, leading to the deterioration in the fabrication of the ovarian gonadotropins such as progesterone and estrogen (Masood et al., 2016; Zheng et al., 2017).

Winnie et al. (2020) conducted a study aimed to explore the menopausal-specific QoL and assess its relationship with the sociodemographic characteristics in menopausal and post-menopausal women in Hong Kong. A cross-sectional survey was conducted with 218 women aged between 45 and 80 or over. The QoL was assessed by Menopause-Specific QoL Questionnaire (MENQoLTM). Results showed high scores in vasomotor, psychosocial, physical and sexual domains in menopausal and post-menopausal domain. With younger and less educated working post-menopausal women perceive lower QoL. The findings suggest that menopausal-related symptoms affect the QoL.

In a previous study Masood et al. (2016) conducted research to investigate the relationship between depression, anxiety, psychological distress, QoL in menopausal women. Their objective was to discover whether the QoL for menopausal women is affected by psychological distress and relative levels of anxiety and depression. They designed a cross-sectional study consisting of 100 women (50 menopausal/50 non-menopausal) in 2 hospitals located in Lahore, Pakistan. The researchers used the following tools to assess the women; Kessler Pathological Distress Scale K10, (Kessler &

Mroczek, 1992) and the Utian Quality of Life Scale (UQoL) was developed by Uitan,

Janata, Kingsberg, Schluchter and Hamilton (2002).

Menopause consists of three phases as follows, pre-menopause, peri-menopause

and post-menopause (Masood, et al., 2016; Winne et al., 2020). The phases were

explained as follows: pre-menopause, the first phase of menopause is the time around

menopause and denotes peri-menopausal stage; the time period that comes after the last

menstrual period is the post-menopause period. Further noting, menopause is a

psychological and biological event in the lives of all women. According to the

researchers, these biological changes to these hormones can cause profound biological

and psychological reactions that affect the quality of a menopausal woman's life. This is

consistent with a review of the literature that suggest reproductive hormones are often

considered to be involved in the susceptibility to depression, especially during periods of

alterations in ovarian function such as postpartum and the menopause transition (Freeman

et al., 2014; Gordon et al., 2016; Marsh et al.,2017).

The longitudinal research of (Bromberger, Schott, & Kravitz, 2015; Bromberger,

& Epperson, 2018) found in pre- to post-menopause stage of reproductive life, some

women demonstrate a greater sensitivity to gonadal steroid shifts resulting in the risk for

negative mood symptoms. Bromberger, & Epperson (2018) reviewed two well-designed

longitudinal studies of clinical depression, the Study of Women's Health Across the

Nation (SWAN) and the Penn Ovarian Aging Study (POAS) that identified an increased

risk of Major Depressive Disorder (MDD) in peri-versus late pre-menopause. Based on

their review of three similar studies, the Harvard study of Mid-life Mood and Cycles, the

Australian Longitudinal Study of Women's Health (ASWH), and the Seattle Midlife Women's Health Study, the researchers concluded that depressive disorders or symptoms during the menopause transition and early post-menopause affect a subset of vulnerable women (Bromberger, & Epperson, 2018). The researchers found evidence that reproductive aging is associated with increased risk for depression as well as the varied endocrine, genetic, behavioral and social factors.

Masood et al. (2016) noted in previous studies found 85% of menopausal women experienced sleep disturbances, hot flushes, fatigue, night sweats, forgetfulness, vaginal dryness headaches, poor concentration, palpitations and reduced libido. The studies also found menopausal women experience psychological distress such as mood disturbances, tension, depression, anxiety, and irritability. For instance, Hickey et al. (2016) identified fluctuating and unpredictable reproductive hormone concentrations, particularly estrogens (estradiol), the principal estrogen, modulates the synthesis, availability, and metabolism of serotonin, a key neurotransmitter in depression.

A review of the literature found a correlation between psychological distress and QoL for menopausal women (Bromberger, & Epperson, 2018; Gordon et al., 2016; Marsh et al.,2017). With anxiety, depression and psychological distress as strong predictors of QoL of menopausal women (Masood et al., 2016). Further noting, menopausal women spend approximately three decades of their life in the post-menopausal phase with a life expectancy of 78 years. Concluding, a major global health concern has been raised for the overall health and well-being of middle-aged women.

Similarities of Health Risks of Menopause and Metabolic Features of PCOS

PCOS is defined as the most common endocrine disorder affecting reproductive age women with reproductive and metabolic features. The metabolic conditions that plague PCOS menopausal women has been well-documented (Baldani et al., 2015; Comijs, et al., 2015, Comim et al., 2017). Furthermore, the metabolic features become more pronounced with age and associated with increased risk for insulin resistance, dyslipidemia, cardiovascular disease and abdominal obesity (Mahalingaiah et al., 2015; Torres Fenandez, 2019). The following metabolic features of PCOS are similar to the health risk for menopausal women.

Type 2 Diabetes

Several factors are linked to menopausal women and the onset of type 2 diabetes such as shortest reproductive period, age 30-45 and the longest reproductive period age 45 plus (Leblanc et al., 2018; Muka et al., 2017). Early age of natural menopause (age 45 or younger) was also a risk for type 2 diabetes based on a study of 3639 post- menopausal women (Muka, et al., 2017). With PCOS women five to seven times more likely to develop T2DM than age-matched women. PCOS women are at increased risk of insulin resistance, abdominal obesity and dyslipidemia and cardiovascular disease (Gonzalez et al., 2020; Mahalingaiah et al., 2015). While, glucose tolerance and T2DM seem to increase independent of the degree of obesity (Bazarganipur et al., 2015; Jin & Xie, 2018)). The findings indicate glucose tolerance and T2DM are at a lower rate in non-obese PCOS women.

Cardiovascular Disease and Menopause

Previous research identified the early age of natural menopause (before age 45) as associated with a greater risk of heart failure in women (Appian et al., 2016; Murka et al., 2017; Wellons et al., 2012). In a study of 5629 postmenopausal women with a mean age 56 years, 26% with bilateral oophorectomy (hysterectomy) without a history of heart failure found early age of menopause (before age 45) was associated with greater risk of heart failure. (Murka et al., 2017). Furthermore, Gurka et al. (2016) discovered in a longitudinal study of 1140 women who transitioned to menopause over a 10 year period that the women had a rate of cardiovascular disease equal or greater than those of men. Additionally, inflammation caused by the biological changes in the circulating hormones for women transitioning to menopause puts them at greater risk of cardiovascular disease due (Wang et al., 2018). While, Comim et al. (2017) found post-menopausal women who self-report hirsutism and oligo-menorrhea had a higher prevalence of cardiovascular disease. Furthermore, women with the clinical features of PCOS defined by menopausal history of irregular menses and current evidence of hyperandrogenemia were at higher risk for cardiovascular disease (Glintborg et al., 2018; Meaz et al., 2016). The findings indicate the reproductive features of PCOS continue to affect these women as they transition to menopause and during post-menopause.

Obesity

Post-menopausal women have higher central and intra-abdominal fat accumulation (Rathanayake et al, 2019). The findings indicate higher BMI has shown a negative impact on physical domain of QoL among postmenopausal women. In addition,

among PCOS women obesity may be a contributing factor in the pathogenesis of the

syndrome (Panico, et al.,2017). Additionally, glucose tolerance and T2DM are found at a

lower rate in non-obese PCOS women. Furthermore, PCOS women are five to seven

times more likely to develop T2DM than age-matched women (Zore et al., 2017).

Brennan et al. (2017) found that obesity exacerbates the condition of PCOS,

further noting that excessive weight gain negatively effects reproductive lifespan and is

associated with pregnancy complications, including gestational diabetes, preeclampsia,

and large gestational-age babies. In addition, longitudinal research revealed that women

18-23 years of age diagnosed with PCOS gained 6.32 kg/ 14 pounds over 8 to 10-year

period compared to mid age (7 pounds) and old age (3 pounds) controls (Brennan et al.,

2017). Therefore, the purpose of Brennan et al.'s narrative review was to provide

evidence supporting the use of behavioral strategies in weight management interventions

for reproductive-aged women to apply to PCOS. Brennan et al. suggested most weight

management strategies for PCOS women has focused primarily on physical activity

interventions and diet without considering the value of counseling, behavioral therapies,

and education in weight loss strategies. However, high attrition and drop-out rates of up

to 46% were associated with programs that focused on only diet and exercise, and

successful programs included behavioral and psychological components, such as regular

exercise, flexible eating, monitoring of weight/shape, and social support (Brennan et al.,

2017).

Brennan et al. (2017) cited the findings of the National Weight Control Registry,

which identified behavioral and psychosocial correlates associated with at least 30

pounds of weight loss among 3000 registrants who were able to keep the weight off for 12 months by eating less than 1500 calories daily and daily exercise. Brennan et al. attributed the long-term weight loss success to self-regulation, process change, decisional balance, self-efficacy, and autonomous motivation. Brennan et al. recommended behavioral strategies including goal setting, cognitive restructuring, problem-solving, and relapse prevention to help improve the weight loss outcomes among PCOS women.

Psychological Distress and PCOS

Studies have shown that women with PCOS have an increased prevalence of mild depressive and anxiety symptoms, as well as increased depression and anxiety scores in reproductive age women (Blay et al.,2016; Enjezab et al., 2017; Tan et al., 2017, Scaruffi, et al.,2019). Studies have identified hyperandrogenism as factor that manifest into hirsutism, acne and alopecia, all of contribute to anxiety and psychological distress.

Scaruffi et al. (2019) found PCOS affects women's physical well-being and leads to great psychological distress. In a study to assess personality characteristics, body image and alexithymia among 59 women with PCOS and 38 healthy controls, The researchers used the Toronto Alexithymia Scale (TAS), the Body Uneasiness Test (BUT) and the Minnesota Multiphasic Personality Inventory-2 (MMPI-2). The study identified a compromised QoL as well as impaired emotional well-being. In a previous study, Scaruffi et al. (2014) found anxiety and depression were independent of obesity and infertility in a study of 60 PCOS women age 25-29.

Cooney et al. (2017) sought to determine if women diagnosed with PCOS have increased prevalence of moderate to severe depression and anxiety symptoms compared

to control women (same age women not diagnosed with PCOS). Also, Cooney et al. sought to determine if the symptoms are associated with age, BMI, testosterone, hirsutism or insulin resistance. Cooney et al. conducted a comprehensive systematic review (SR) of 30 cross-sectional studies published between January 2011 to January 2016 representing 3050 participants with PCOS and 3858 controls (ages 18 -31) from 10 countries. In the cross-sectional studies reviewed, 18 were meta-analyses and showed women with PCOS have over three times the odds of depressive symptoms and over five times the odds of anxiety symptoms than controls, supporting prior research on the topic (Cooney et al., 2017).

Cooney et al.'s (2017) SR analysis also revealed a significant increase worldwide for risk of depressive and anxiety symptoms in young PCOS populations. For instance, PCOS women are three times more likely to have depressive symptoms and five times more likely to experience anxiety compared to the controls, who do not have PCOS (Cooney et al., 2017). In addition, anxiety was significant in PCOS women with diabetes, while depression and anxiety were associated with obesity, hirsutism, free testosterone, and infertility (Cooney et al., 2017). The odds of depressive symptoms increased by 53% in women with hirsutism, increased BMI, and who were older (Cooney et al., 2017). Further noting, anxiety and depression in persons with chronic conditions such as PCOS persist and may worsen over time.

Cooney et al.'s research (2017) highlighted the importance of screening PCOS women for depression and anxiety with appropriate follow-ups beyond their reproductive years because serious chronic conditions such as cancer, cardiovascular disease, and

diabetes among menopausal age PCOS women have been well-documented. (Bromberger et al., 2014; Bromberger et al, 2018; Chen et al., 2013; Comijs, et al., 2015). However, less is known about the QoL and psychological wellbeing of the reproductive age PCOS women as they transition to menopause. Furthermore, the transition to menopause has been linked to depression (Bromberger et al., 2015; Bromberger et al., 2018) and health risks similar to the metabolic features of PCOS, such as type 2 diabetes, cardiovascular disease, and obesity (Appian et al., 2016; Gurka et al., 2016; Torres Fernandez et al., 2018).

The prevalence of depression and anxiety appears increased in PCOS which in turn negatively affects health-related QoL of PCOS (Brutocao et al., 2018; Dokas et al., 2016; Dokas et al., 2018). A systematic review and meta-analysis of 2384 PCOS women and 2705 control found higher emotional distress in PCOS women than controls (Ezeh et al., 2013; Ezeh et al., 2020). Additionally, a subgroup analysis identified the development of anxiety and depression in PCOS women as associated with hirsutism, infertility, and obesity. However, the strong link between PCOS and emotional distress was not explained by the findings (Zore et al., 2017).

Previous studies suggest the link between PCOS and mental issues may be caused by the physical features of the syndrome such as hirsutism, acne, obesity and patient's concern related to long-term health risk (Dokras et al., 2018; Dokras, 2016; Torres Fernandez et al., 2018; Elsenbruch, 2007; Hollinrake, 2007). These factors may in turn lead to decreased self-esteem and QoL and manifest in a risk for mood disorders and social anxiety (Zore et al., 2017). For instance, a vast number of studies showed that

women with PCOS are more prone to suffer from psychological disorders such

depression (Brutocao et al., 2018), anxiety (Chau et al., 2019; Cooney et al., 2017),

recreational drug-related incidents (Anagnostis, et al. 2018**;** Hart and Doherty, 2015),

disordered eating, and psychosexual dysfunction **(** Doretto et al., 2020; Teede et al.,

2011) in comparison to healthy female controls. In addition, females with PCOS have a

lower self-esteem and body satisfaction (Basirat, 2019: Bottcher et al., 2018; Bottcher et

al., 2018) and subsequently tend to have more psychiatric hospital admissions than

controls (Hart and Doherty, 2015). As a result, they display a low QoL (Jones et al.,

2008; Li et al.,2011; Fauser et al.,2012) and are prone to a high degree of emotional

distress (Brutocao et al., 2018). It is worth noting that obesity (Elsenbruch et al., 2003;

Hahn et al., 2005; Barnard et al., 2007), acne, hirsutism (Weiner et al., 2004; Himelein

and Thatcher, 2006) and irregular menstrual cycles (Elsenbruch et al., 2003), all

associated with PCOS, are major contributors to the psychological stress that the patients

experience due to the challenging of the female identity and her body image (Legro et al.,

2013; Sanchez, 2020; Teede et al., 2011; Teede et al.,2018).

Major depressive disorder affects nearly 17.3 million American adults and is more

prevalent among women 8.5 compared to men at 5.3 %. (National Institute of Mental

Health, 2017). Cooney et al. (2017) conducted a comprehensive systematic review (SR)

was performed up to January 2016 and included 30 cross-sectional studies, representing

3050 subjects with PCOS and 3858 controls, from 10 different countries. According to

the researchers, the meta-analysis (MA) on depressive symptoms included 18 studies and

the MA on anxiety symptoms included 9 studies. Further noting, the findings of a

separate SR identified 15 studies for the meta-regression examining the associations with PCOS-related symptoms or comorbidities. In a previous cohort study of 103 women with PCOS reported higher instances of major depressive disorder compared to controls independent of obesity (Hollinrake et al., 2007). The study was based on the Beck Depression Scale but the correlation was not strong enough to account for the increase. A subsequent systematic review and meta-analysis found the incidence of depression was well-defined and 4 times more likely to occur in those diagnosed with PCOS than in that of controls (Dokras, 2018). Therefore, Dorreto et al. (2020) conducted a study to facilitate accurate diagnosis and timely treatment, clinicians who see female patients need to be familiar with the diversity of PCOS phenotypes. The findings indicate PCOS and psychosis, treatment with antipsychotic drugs can worsen PCOS symptomatology and lead to negative consequences for a woman's reproductive potential and her QoL.

Emeksiz et al. (2018) conducted across-sectional study to determine anxiety rates among teenage girls diagnosed with PCOS compared to controls. The study was done during the period from May 2013 to July 2014 and included 80 adolescent girls with the diagnosis of PCOS (17.23 ± 1.15 years, range: 16–19 years). The findings indicate adolescents with PCOS experience significantly more emotional distress compared to adolescents without PCOS. This emotional distress may be related, at least in part, to certain clinical features of PCOS including obesity and hirsutism. Mood disorders in women are 35 to 50 % associated with GAD General Anxiety Disorder. Less studies are available reporting the association between anxiety and PCOS, however those that have reported increased compared to controls (Zore et al., 2017; Asp et al., 2020). For

instance, Emersiz et al. (2018) identified correlation between excess weight and anxiety in a study of 80 adolescents with PCOS and 50 age- and BMI-matched controls. Higher BMI was found to be associated with higher levels of depression and generalized anxiety, and higher modified Ferriman–Gallwey score with higher level of panic disorder in adolescents affected by PCOS.

A review of meta-analysis studies found PCOS women 6.7 % higher OR of having GAD compared to controls with most of the PCOS patients and the controls were overweight or obese (Dokras, 2018). Most studies found no difference in terms of age and BMI between the two groups. Among PCOS women the association with anxiety is the same for depression including, feelings of social stigma, low self-esteem, poor body image and concerns for future health (Barry et al., 2012; Chau et al., 2019; Cinar, 2011; Dokras, 2018). Furthermore, in depressed patients, coexisting GAD may increase the risk of suicide, functional disability and decreased response to treatment (Zore et al., 2017). Dokras (2018) suggest PCOS women undergo routine screening for mental health disorder using valid screening tools and refer these women to health care professionals for treatment as indicated.

Psychosexual Dysfunction

The health-related QoL PCOS has shown to be lower on all domains compared to controls and is linked to the presence of obesity, hirsutism, mental dysfunction and infertility. PCOS women scored higher in dimensions relating to OCS (obsessive compulsive disorder, interpersonal sensitivity, depression, aggression and psychoticism than health controls (Li et al., 2011; Castello-Branco, & Naumova, 2020).). To evaluate

Qol, psychosocial well-being and sexual satisfaction, 50 PCOS women and 50 controls

were provided with three validated questionnaire (Elenbruch et al., 2003). The findings

indicate PCOS women were less satisfied with their sex life, and their partners were also

less satisfied. Furthermore, the women found themselves less sexually attractive which

was associated with feelings of sexual dissatisfaction. Another study assessed 49 women

with PCOS and age-matched women, the women with PCOS reported decreased

satisfaction with their sex life (Dokras, 2011; Dokras, 2018). Therefore, disease-specific

screening tools were recommended because when used aspects of QoL are improved

through effective interventions (Mansoon et al., 2011). The Polycystic Ovarian Syndrome

Questionnaire (PCOSQ) has been identified as a valid instrument for measuring the QoL

in PCOS women (Cronin et al., 1998; Guyatt et al., 2004). Zore et al. (2017) suggest the

findings indicate mental health problems are higher in women with greater degrees of

hyperandrogenism resulting in a greater risk of metabolic dysfunction. Further noting,

this risk is more prevalent in "classic PCOS" which affects phenotypes "A" and "B" as

PCOS criteria defined in 1990 by NIH. Concluding, that limited data exists concerning

the relationship between phenotypes and mental health in PCOS.

Strategies for Prevention of Long-Term Health Consequence of PCOS

Several strategies were recommended for the prevention of the long-term

consequences of PCOS (Zore et al, 2017). Since the exact etiology of PCOS is unclear,

and the impact of early life intervention on the disease progression is unclear, it is not

possible to recommend a specific plan for those at risk developing PCOS (Azziz et al.,

2016). The researchers noted exercise has proven effective in preventing the progression

or severity of the disorder. For instance, a study of the letrozole PCOS rat model found levels of testosterone, luteinizing hormones, fasting insulin and leptin were lower following high intensity exercise. Another strategy was routine screening for adult women diagnosed with PCOS and exhibiting metabolic abnormalities. A 2- hour fasting oral glucose tolerance test was suggested for those who have insulin glucose tolerance (IGT; Coa et al., 2017). In addition, a combination of metformin and lifestyle changes in PCOS was suggested as more effective than lifestyle change alone (Salpeter et al., 2018). Furthermore, reductase inhibitors were found to be more effective than placebos for PCOS women with altered lipid profile statins (Goa et al., 2012).

Summary and Conclusion

PCOS is defined as a lifelong endocrine condition affecting reproductive-age women with adverse reproductive and metabolic features and is linked to infertility, heart disease, cancer, diabetes, and psychological problems (CDC, 2016). Given the compromised health and poor QoL experienced by PCOS reproductive age women, it is necessary to determine their QoL during menopause. These women face a unique challenge because the metabolic features of PCOS and transitioning to menopause have similar health risks that may further erode their QoL as they age (Comim et al., 2017; Lenart-Liprnska et al., 2014; Sirmans et al., 2014).

This study contributes to the academic understanding of women diagnosed with PCOS in their reproductive years and transitioning to menopause to enhance advocacy for the health and well-being of these women at this phase of life. Both social issues are promoted while also yielding potentially significant implications for future research and

programming. Beyond the systematic and academic impact, this research can affect PCOS menopausal women at the individual level. In understanding, the QoL of PCOS menopausal women interventions can be designed to assist them in living more productive lifestyles (Barthelemess et al., 2014; Maki et al., 2018 Palomba et al., 2015). Educational and intervention materials could be created to better serve the needs of these women. The health of PCOS menopausal women may be improved through effective self-management strategies and ultimately lead to better health outcomes.

Finally, an in-depth study of the lived experience of PCOS menopausal women diagnosed during reproductive years as they transition to menopause. This provided an empirical understanding of the quality of their lives to identify and create effective interventions and treatments. Chapter 3 described the research methodology I used to reach the goals of this study.

Chapter 3: Research Method

Introduction

The purpose of this research was to explore QoL in menopausal women diagnosed with PCOS during their reproductive ages, 18 to 45. I also explored how women living with PCOS experience and manage the disorder during menopause. A review of qualitative studies of PCOS reproductive age women were similar in findings and indicate a poor QoL (Enjezab et al., 2017; Hadjiconstantinou et al., 2017; Martin et al., 2017). Less in known about the QoL and psychological well-being of these women as they transition to menopause. Although PCOS is diagnosed in the reproductive years, many of the symptoms follow the women into menopause, such as hirsutism, which is linked to psychological distress (Sanchez, 2020). In addition, hyperandrogenism has been linked to Type 2 diabetes, some cancers, and cardiovascular disease (Baldani et al., 2015; Gonzales et al., 2020). In this chapter, I discuss the rationale of the research design for this study. I also discuss the sampling strategy and data collection, data recording, and the analysis process. Trustworthiness and ethical procedures are also presented.

Research Design and Rationale

In this study, I used a qualitative IPA to answer the research question (Smith et al., 2009). This project aligns with an IPA methodology given that the goal of the project was to understand the lived experience of this phenomenon (Smith, 2011). Women in the age range of 48–65 diagnosed with PCOS were interviewed on their experiences of managing and living with this diagnosis at this stage in life. The women also reported on their QoL and psychological well-being.

Interpretative Phenomenological Approach

The qualitative method was chosen as the best fit for the goals of this study. Qualitative research is defined as a means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem (Pietkiewicz & Smith, 2014). The flexible design along with the open-ended questions show the strengths of using qualitative design for this particular topic of study. I used IPA because it provides insights into how a given person, in a given context, makes sense of a given phenomenon (Smith et al., 2009).

IPA research is distinct from other approaches, in part, because of its combination of psychological, interpretative, and idiographic components (Pietkiewicz & Smith, 2014). Participants in an IPA study are expected to have certain experiences in common with one another. Analysis consists of a researcher generating codes from the data, rather than using a pre-existing theory to identify codes that might be applied to the data. IPA studies do not test theories, but they are often relevant to the development of existing theories. The small-scale nature of a basic IPA study shows how something is understood in a given context and from a shared perspective (Smith et al., 2009). For example, my study of the lived experience of women diagnosed with PCOS during their reproductive years as they transition to menopause may generate theoretically relevant information to build on existing literature and promote further research and interventions to improve the lives of these women.

Role of the Researcher

In phenomenological research, the purpose is to understand the subjective

experiences of the participants (Larkin & Thompson, 2012). However, a researcher must

remain unbiased in gathering and analyzing data. This is best accomplished through

bracketing (Larkin & Thompson, 2012). Bracketing, which was originally a mathematical

principle, is one of the primary concepts of Husserlian phenomenology. Within this

method of phenomenology, the preconceived notions held by a researcher must be set

aside, or bracketed, to ensure they do not allow their personal expectations to influence

the data collection or shape their comprehension or analysis of the data (Polit & Beck,

2008).

Women with PCOS are frequently socially isolated (Kitzinger & Willmott, 2002);

therefore, the mode of data collection needed careful consideration. Seymour (2001)

suggested that online data collection methods enable a researcher to access inaccessible

domains, such as hard to reach populations or socially isolated groups. Kraut et al. (2004)

also noted that online research could make apparent psychological phenomena that do not

exist in traditional settings. Therefore, I conducted the interviews online using Skype,

Zoom, or Google Hangouts.

Methodology

Participant Selection

Participants were solicited from PCOS online supports groups via Facebook using

flyers to reach this socially isolated group (Williams et al., 2015). Sullivan (2012)

proposed there is potential for data collection in social research using technology such as

Skype and Google Hangouts. Accordingly, online research may enable access to a socially isolated population such as women with PCOS. Deakin and Wakefield (2013) suggested that online synchronous interviews using, for example, Skype are a useful replacement of traditional face-to-face interviews. The researchers described several advantages of using Skype to conduct interviews, including allowing more flexibility for researcher and participant and being more cost and time efficient (Deakin & Wakefield, 2013). Janghorban et al. (2014) argued that Skype offers a useful alternative to face-to-face interviews and is suitable for conducting individual interviews. Previous research using Skype has explored online health forums (Fan et al., 2013) and online psychiatric consultations (Williams et al., 2014). Williams et al. (2014) found high acceptability of online consultations via Skype among participants, further noting that Skype is a viable way to conduct online research. The specific criteria for participating in the study were: Participants must 48–65 years old and previously diagnosed with PCOS during their reproductive years.

Number of Participants and Rationale

A qualitative study typically requires between five and 25 participants (Moustakas, 1994). A variety of factors can influence sample size, but the most significant in qualitative research using interviews is saturation (Mason, 2010). The more limited the population sample is, the easier it is to reach saturation. The goal of the research project was to identify a sample of between seven and 10 PCOS menopausal women through online support groups or Craigslist.

Two major sources to recruit participants were used. I posted an announcement about the study on Craigslist, and I also sought permission from online support group leaders to submit flyers to their online environment to recruit participants. I used snowball or chain sampling as a second sampling strategy. In this strategy, participants who complete the interview are encouraged to inform others who meet the criteria and ask them to contact the researcher (Patton, 2002). The leaders of the PCOS online support group were asked to post the flyer online, and I posted information about the study on Craigslist. Interested participants were asked to contact me by email or text message. Participants were selected as candidates based on the following criteria: ages 48–65, diagnosis of PCOS during their reproductive years, and English speaking. Selected candidates were sent an informed consent form by email. Once participants consented to participate in the study, an online interview via Zoom was scheduled at a convenient time for the participant.

Guest et al. (2006) recommend that saturation is obtained with a sample size of 12 because the majority of changes in the codes occur between the first and 12th interviews. However, Smith (2004) stated that most IPA studies are of a smaller sample size (five to 10) because it is only possible to conduct the detailed analysis associated with IPA on a small sample. Similarly, Creswell (2013) stated that participants for a phenomenological study range from three to 10 individuals. In reviewing the information provided by Creswell (2013), Guest et al. (2006), and Smith (2004), I sought 10 participants. If there had been too few participants, I would have contacted the PCOS online support group

leader. I would have repeated the process to obtain participants who met the criteria and conducted interviews online or by phone until saturation was reached.

Instrumentation

I screened participants using the criteria to identify eligible participants. I used an audiotape recorder while conducting semistructured interviews with participants. A second audio-recording device was used simultaneously in case the first device malfunctioned. I also took physical notes with pencil and paper. I used a semistructured interview to explain what it means to participate in the study.

Smith (2004) stated that the best way to collect data for an IPA study is through semistructured interviews (Appendix A). Semistructured interviews allow a researcher and participant to engage in dialogue where initial questions are modified depending on the participant's responses and the researcher can probe for additional information (Smith, 2004). The interview questions were developed based on the literature review and the theoretical framework. At the beginning of the interview, I collected demographic information to understand participants' context.

Procedures for Participation, and Data Collection

Interviews were conducted using Skype or Zoom over the internet utilizing voice or face-time calls depending on the participants' preference (see Williams et al., 2015). Skype is an online application for making video or telephone calls and allows individuals to send text-based messages to one another. Interview questions were developed based on a review of the literature and included questions such as the following: Could you describe a typical day living with PCOS? Have your PCOS symptoms changed over

time? Have you changed the way you deal with your PCOS symptoms over time? (see

Williams et al., 2015).

The interviews were transcribed and then transcripts were analyzed using an

inductive thematic analysis process (see Braun & Clarke, 2006). Thematic analysis is a

method for identifying and reporting themes within the data, which organizes and

describes the data in detail (Braun & Clarke, 2006). To analyze the data according to the

six steps recommended by Braun and Clarke, I read and re-read the transcripts and then

generated initial codes. Next, I sorted the initial codes into potential themes. Then I

reviewed the themes and defined and named them. Finally, I wrote the thematic analysis.

Data Analysis Plan

To analyze data extracted from interviews, I used thematic analysis (Braun &

Clarke, 2006). Thematic analysis differs from other descriptive analytic methods as it is

not wedded to any pre-existing theoretical framework (Braun & Clarke 2006). It

qualitatively synthesizes data through the extraction of themes and sub-themes.

According to Braun and Clark, thematic analysis comprises six phases:

I familiarized myself with your data. Phase 1 consisted of becoming immersed in

the content of data through repeated reading and rereading, actively searching for

meanings and patterns that assisted in transcribing a thematic analysis.

Generating initial codes: The second phase involved using familiarity with the

data to develop initial codes based on the similarities and difference found to assess the

information in a meaningful way.

Searching for themes: The third phase involved refocus of the analysis on a broader level by analyzing the codes to develop broader potential themes of the data. The key features identified in the data were outlined in the first thematic map.

Reviewing themes. The fourth phase involved selecting permanent themes from the chosen codes. The thematic map was adjusted and the themes were written up to present a clear coherent explanation of the information.

Defining and naming themes. In the fifth phase the data was refined by identifying the core of each theme. Themes were named and a consistent, coherent accompanying narrative provided for each.

Producing a Report- The task of the six phase was to develop a write-up of the themes to provide a valid academic document. The fully developed themes illuminated the phenomenon as expressed through the voice of the participants and reflected the research question.

The following steps were used to analyze the data obtained from the interviews to create a concise, logical report. Discrepant or negative information may contradict the themes (Creswell, 2014). However, the contradictory information was discussed because it could build a case for the theme with the account becoming more valid and realistic.

Issues of Trustworthiness

Trustworthiness is an essential element of the qualitive study used to produce methodological integrity (Merriam & Tisdell, 2015). Credibility, transferability, dependability, and confirmability are criteria recommended to ensure the issue of trustworthiness is addressed in qualitative studies (Morrow, 2005). I followed Lincoln

and Guba's (1985) guidelines and recommendations in ensuring quality in my study. A few of these guidelines used to address trustworthiness of this study were as follows.

Credibility

Credibility refers to the congruency of the findings with describing reality (Connelly & Pittman, 2016). Triangulation, rich descriptions, member checking, and peer debriefing are the strategies that were used to analyze the data and draw conclusions to support credibility. I used triangulation to build coherent justification for themes of the research with use of multiple journal research sources to add to the credibility of the information (Connelly & Pitman, 2016). I acquired thick, rich, well-developed descriptions from the participants that not only included the phenomenon, but the context and culture as well was used to contribute to credibility (Morrow, 2005). I used peer debriefing to enhance the accuracy of the research by locating a person (peer debriefer) to ask questions about the qualitative study so the account would resonate with people other than the researcher (Connelly & Pitman, 2016).

Transferability

Transferability refers to the extent to which results of a study can be transferred or applied to similar contexts (Lincoln & Guba, 1985). Transferability is achieved with the researcher providing rich, thick description of the information as conveyed by the participants with detailed accounts of their individual experience (Creswell, 2014). I provided details regarding the instrument being used -the semi-structured interviews along with context, processes, participants, and relationships, which demonstrated how these findings may be transferred to a general population (Morrow, 2005). Lastly, my

research choice investigating the QoL of menopausal PCOS women who are members of a national online support group may increase transferability.

Dependability

Dependability refers to the stability and consistency of research procedures (Connelly & Pitman, 2016). Dependability was accomplished by conducting an external trail, by having a researcher not involved in the research process examine both the process and product of the research study (Lincoln, & Guba, 1985). The purpose was to evaluate the accuracy and evaluate whether or not the findings, interpretations and conclusions were supported by the data. Dependability was determined as the researcher's review of my log that consisted of my detailed records of activities, processes, influences, emerging themes, categories, and analysis of the research process. Including a review of my notebook that documented the dates and thoughts on the research and the steps taken. This contributed to dependability, which allowed others to fully understand this research and enables them to repeat this study if they should choose to do so.

Confirmability

Confirmability refers to comparable concepts of objectivity in quantitative research. Confirmability is attained by demonstrating that the study's findings represent the responses of the participants; and it does not reflect the researcher's subjective predilections and interpretations (Lincoln, & Guba, 1985). Confirmability was accomplished by overlapping or triangulating the data, conducting audit trials, using reflexivity, and the researcher documenting the process, from the designs to data

collection to analysis (Connelly & Pitman, 2016); Morrow, 2005). It is through these four

areas that this research maintained high standards. Reflexivity was used, to disclose my

biases and experiences during the procedures. Additionally, Patton (2002) indicated that a

way to mitigate bias and inaccuracy is by triangulating data sources to increase

credibility. Ensuring confirmability was an ongoing process of keeping detailed records

and constantly being aware of personal biases at all stages of the research.

Summary

This chapter explained the step-by-step process of the study. The central focus of

the study was to gain an understanding of the lived experience women diagnosed to with

PCOS as a reproductive age women as they transition to menopause. The research

indicates PCOS reproductive age women experience a poor QoL compared to same age

women. The qualitative tradition used in this study was IPA. Data were collected from

interviews with PCOS menopausal women recruited from an online support group. I used

snowball sampling, as it is the most appropriate method to ensure that participants meet

the criteria and to ensure that the research questions are answered. Having described the

methodological framework for this project, the following chapter focused on the study's

findings and outcomes.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to explore the QoL in women 48–65 previously diagnosed with PCOS during their reproductive years. Participants of this study were asked to report on their QoL and psychological well-being. For this study, data were collected through interviews with 10 women who met the study's criteria for participation to answer the research question: What are the lived experiences of QoL in menopausal PCOS women, ages 48 to 65? This chapter is divided into several sections. In the first sections, I present information regarding the setting, demographics, and data collection. Finally, I discuss study results, evidence of trustworthiness, and a summary.

Setting

Participants were recruited from PCOS online supports groups via Facebook and via Craigslist. Once a potential participant showed interest to participate, I confirmed they met the participation criteria. Then, I sent them an email containing the informed consent form to participate. Once participants reviewed the form and consented to participate in the study, I sent a follow-up email for them to schedule their interview session. I arranged a secure Zoom link for each interview according to the participant's availability. All interviews were recorded via Zoom, saved, and then transcribed. Interviews were recorded and lasted from 30 to 45 minutes. Once each interview was completed, I emailed a digital gift certificate for $20 to each participant.

Demographics

All participants involved in the study were women. The total number of participants for the study was 10, and at the time of the interviews, all women resided in the United States and their demographics were diverse. Participants were African American ($n = 7$), Caucasian ($n = 2$), Asian ($n=1$), and Latina ($n = 1$). Participants were between ages 48 and 57 years ($M = 49.8$, $SD = 2.8$). Participants' relationship status was also diverse: married ($n = 7$), single ($n = 1$), and divorced ($n = 2$).

One characteristic of PCOS is the increased production of androgens (male hormones) in women diagnosed with the disorder, causing infertility. Some of the women reported that infertility was a problem. However, the majority of the participants had children, either naturally or with the assistance of reproductive technology. Participants reported children ($n = 7$) and no children ($n = 3$). Participants also differed regarding the age of PCOS diagnosis, physical health, and mental health status. Participants reported being diagnosed with PCOS between ages 12 and 34. Participants also reported assorted physical health issues, including joint pain ($n = 5$), abdominal pain ($n = 1$), obesity ($n = 1$), and diabetes ($n = 3$). Furthermore, mental health status varied among participants as they reported depression ($n = 2$), mood disorders ($n = 4$), or being emotionally stable ($n = 4$). Table 1 depicts participants' demographic information.

Table 1

Participants' Demographics

Participant	Ethnicity	Age	Relationship	Children	Diagnosis age	Physical health	Mental health
Belma	Asian	48	Single	0	34	Obesity	Depression
Gealan	African American	48	Married	0	20	Diabetes	Stable
Amila	African American	48	Married	1	28	Joint pain	Stable
Cluy	African American	48	Married	2	27	Joint pain	Stable
Riama	African American	50	Divorced	1	27	Ab. Pain	Depression
Lynadaum	African American	51	Married	2	21	Diabetes	Mood disorder
Rasha	African American	50	Married	1	22	Joint pain	Mood disorder
Tesybe	Caucasian	57	Married	2	12	Joint pain	Mood disorder
Lenerma	Latina	48	Married	2	22	Diabetes	Stable
Fenjier	Caucasian	50	Married	0	33	Joint pain	Mood disorder

Data Collection

A total of 10 participants who responded to my flyer seeking participants from online PCOS support groups or Craigslist met the search criteria for participating in the study. After each potential participant contacted me, I verified they met the research criteria for participating. Each participant was emailed an informed consent form to read and if willing to participate reply with "I consent" in an email. Participants were informed the interview would last 30–40 minutes via Zoom and they would be compensated with a $20 gift card.

On the date of the interview, after formal introduction, I reviewed the purpose of the study and informed the interviewee the meeting would be recorded. Once the participant agreed, the interview began. I used a prepared semistructured interview with open-ended questions, as noted earlier (see Appendix A). The interview questions were formulated to guide the participants in describing their lived experiences of being diagnosed with PCOS in their reproductive years with regards to their physical health and psychological well-being as they transition to menopause. The interview emphasized the participants' entire PCOS experience with the following topics: (a) initial PCOS diagnosis, (b) transition to menopause, (c) health and psychological well-being during reproductive years, and (d) health and psychological well-being during the transition to menopause.

Data Analysis

The analysis consisted of generating codes from the data, rather than using a pre-existing theory to identify codes that might be applied to the data. Throughout the process of interviewing, I kept a reflective journal to take notes of my thoughts and feelings for each participant during the interview. Thematic analysis was conducted to determine the themes (Braun & Clarke, 2006). Interpretations and descriptions of the findings evolved as the themes were generated from the analysis, and the reflexive notes and shared feelings derived from the participants' responses.

Once all interviews were completed, all interviews were transcribed, and participants were provided a pseudonym. Next, transcripts were uploaded using Microsoft Word. I reviewed all transcripts again and highlighted text, expressions, and

opinions that gave meaning to the phenomenon of study. Lastly, I read the transcripts line-by-line again, this time concentrating on the implications hidden in the text. To understand the expressions of the participants, the interviews were coded.

The data were arranged by creating a Word file containing a large matrix of 12 columns. The matrix was used to code and cross code the common themes identified within each participant and across participants. The first column contained the following items: (a) PCOS diagnosis, (b) transition to menopause, (c) typical day, (d) physical health, (e) mood and psychological health, (f) social relationships, (g) surroundings or environment, (h) symptoms today, (i) symptoms over time, (j) cope with PCOS, and (k) recommendations. These topics reflected the content of the interview guide. The next 10 columns contained the first name pseudonym of each participant with interview transcriptions below of their thoughts pertaining to each of the 12 items. The 12th column provided a cross code summary interpretation.

The process of data analysis began with reviewing each transcript and reading carefully to immerse myself in the original data. I explored the transcripts by documenting notes regarding the content while reviewing each transcript. During this stage in the analysis, I extracted significant statements from the transcripts and assigned codes to them to reduce the data to latent meaning. I categorized the themes based on questions developed for the interview guide and common themes brought up by the participants during the interviews to best explore the lived experiences of women diagnosed with PCOS in reproductive years as they transition to menopause. The codes offered an approach to break down the interviews for interpretation.

After this first step, I began organizing merging codes together based on conceptual meaning. Coded passages determined to be conceptually similar were combined into one code to develop emergent themes. For example, codes identified in the first phase, like *symptoms–balding* or *symptoms–excessive or unwanted hair*, were both conceptually related to *feeling self-conscious*. These two codes and all their associated significant statements were compiled into a larger code.

This coding process continued for each participant until all significant statements were extracted and coded. Four major trends resulted from interviews with the 10 participants in the research study. The patterns or themes that developed from the thematic analysis were combined or categorized together to give further meaning. The following four patterns emerged: (a) concern over condition worsening, (b) satisfied with life despite health challenges, (c) symptom management – physical activity, and (d) feeling self-conscious. Examples of the codes are provided using the participants' quotes to illustrate the conceptually related content that the codes represented in Table 2.

Table 2

Examples of Coded Excerpts

Code	Excerpt
Concern over condition worsening	"I don't feel safe because my PCOS condition is bad. I am overweight and my health could get worse if I don't lose the weight."
Satisfied with life despite health challenges	"I am satisfied with my life, even though I have health problems and I am overweight, but I am doing something to get health. I also have the love and support of my husband, children, family, and friends."
Symptom management – physical activity	"My health is poor because of the PCOS. But I have been trying to follow the doctor's suggestions to take better care of myself by exercising and changing my diet, eating more fruits and vegetables."
Feeling self-conscious	"Well, the main issue is the hairs, the unwanted hairs. It's so embarrassing as a young lady then, I was too embarrassed. I didn't want short skirts.

Next, I searched for connections across the emergent patterns and refined the trends into final themes. To do this, I explored patterns or shared qualities across participant experiences. This resulted in combining themes that were related to others by some conceptual, textual, or structural thread, and those initial codes were brought together again. For example, the initial codes *emotionally painful/difficult*, *symptoms–mood swings*, and *dissatisfied with life due to health* were all connected by the thread of *mental health challenges that women experience*, and so brought together under the umbrella of a new theme, which was given a descriptive title. From this analysis, three major final themes were generated: (a) women cope with depressive symptoms and mood swings, (b) women feel helpless to the physical changes and challenges associated with co-occurring PCOS and menopause, and (c) healthy lifestyle modifications are used to manage co-occurring PCOS and menopause. Theme 2 had a related subtheme that

women experience pain during routine activities. These themes are described in the results section.

Evidence of Trustworthiness

In this study, I used a qualitative phenomenological research approach to meet the purpose of the research. Data were collected using a semistructured interview process that allowed participants to share their lived experiences of being diagnosed with PCOS in their reproductive years as they transition to menopause. The validity of the data was established by the participants' perceptions of their confirmed existence of the phenomenon in their lived experiences. The guidelines and recommendations of Lincoln and Guba (1985) were used in ensuring quality in my study. Several techniques may be necessary to build consistency or trustworthiness in research. The research dictates several techniques to support credibility as follows: dependability, confirmability, transferability, member checking, and triangulation (Morrow, 2005).

Credibility

Internal validity is one of the critical criteria addressed by researchers to ensure that their study measures what it is intended to measure (Lincoln & Guba, 1985). To ensure credibility I used triangulation to build coherent justification for themes of the research with use of multiple journal research sources to add to the credibility of the information (Connelly & Pitman, 2016). I obtained thick, rich, well-developed descriptions from the participants that not only included the phenomenon, but the context and culture (Morrow, 2005). Lastly, peer debriefing was used to enhance the accuracy of the research by locating a person (peer debriefer) to ask questions about the qualitative

study so the account would resonate with people other than the researcher (Connelly & Pitman, 2016).

Transferability

Transferability enables the replication of a research study. One of the ways I achieved transferability was providing rich, thick description of the information as conveyed by the participants with detailed accounts of their individual experience (Creswell, 2014). I provided details regarding the instrument being used: semistructured interviews along with context, processes, participants, and relationships, which demonstrated how these findings may be transferred to a general population (Morrow, 2005). My research choice investigating the QoL of menopausal PCOS women who are members of a national online support group may increase transferability.

Dependability

Dependability is based on clear and accurate documentation of the researcher throughout the research process and refers to the stability and consistency of research procedures (Connelly & Pitman, 2016). The actions required to support credibility were taken by maintaining and review a log consisting of my detailed records of activities, reflexive journals, processes, influences, emerging themes, categories, and analysis of the research process. To confirm that the sources were authentic or to establish confirmability the data was verified through peer review for accuracy and observations of the data collected to detect and correct discrepancies. This contributed to dependability of the study and allow others to fully understand this research and enable them to repeat this study if they should choose to do so.

Confirmability

Confirmability was used to prove the research is neutral and not influenced by the assumptions or biases of the researcher. Confirmability was accomplished in this research by overlapping or triangulating the data, conducting audit trials, using reflexivity, and the researcher documenting the process, from the designs to data collection to analysis (Connelly & Pitman, 2016; Morrow, 2005). It was through these four areas that this research maintained high standards. Reflexivity was used to disclose my biases and experiences during the procedures. Additionally, Patton (2002) indicated that a way to mitigate bias and inaccuracy is by triangulating data sources to increase credibility. Ensuring confirmability was an ongoing process of keeping detailed records and constantly being aware of personal biases at all stages of the research.

<div style="text-align:center">Results</div>

Three major themes represented the results of this study. The first theme was women cope with depressive symptoms and mood swings, the second theme, women feel helpless to the physical changes and challenges associated with co-occurring PCOS and menopause, and the final theme was healthy lifestyle modifications are used to manage co-occurring PCOS and menopause.

Theme 1: Women Cope With Depressive Symptom and Mood Swings

Women aged 48-65 described a complex set of challenging lived experiences related to their QoL in menopausal PCOS that contributed to depressive symptoms and mood swings. The first theme is about the way that women conceptualize their depressive

symptoms and mood swings. This theme also discusses the strategies that women use to cope with these symptoms.

Women widely reported experiencing depressive symptoms and mood swings. Culy said, "My mood has been very bad. Most times. I have this mood swing, and I could be fine this minute and the next minute I'm off." Belma, reflected on the ways in which her mental health symptoms affected those around her. She indicated that at times her feelings resulted in her snapping at those around her. She also shed light on the debilitating nature of these symptoms, indicating that they sometimes prevented her from routine activities, namely work. Of this she said,

> I think I am a little more irritable. A lot of things that I didn't notice before or didn't complain about before, I'm more snappy. Just snapping at people around me. Some days, it makes me like wanna stay home. I'm having a bad day, bad feeling day and I don't wanna leave my house sometimes that happens. I don't wanna talk to nobody.

Some participants reported using medication to mitigate the mood-related symptoms that they were experiencing. For example, Lynadaum explained her doctor's recommendation to cope with the symptoms,

> At first, I was upset with the bleeding for a month when the menopause started, and the mood swings because I already had to deal with the abdominal pain and the hairy problem with PCOS. So, I talked to my doctor, and he told me to stop worrying about it and put me on mood medication and told me try to be happy.

Amila shared that her mood swings typically occurred around the time of her period.

They shared, "Sometimes I just have like crazy mood swings. And before, it's mostly my

period that causes the whole mood swing but now it's just any little thing could make me

happy; a little thing could make me sad."

One participant, Rasha, felt particularly troubled by her PCOS because she

believed that it caused her to age more rapidly than her peers who did not have PCOS.

This comparison contributed to feelings of negative self-worth. She said, "I feel

depressed. I feel life is not worth living because I've suffered for so many ailments and I

see myself looking like I'm older than my age mates. Sometimes I feel bad." Participant

Riama was also aware of the severity of her mood swings, she shared that the progression

of her PCOS symptoms was causing significant interpersonal challenges for her, "I am

not coping well. I get depressed and have more mood swings because the menopause

seems to make the PCOS symptoms worse." Riama seemed to vocalize what many

women were feeling, likening PCOS to feeling trapped. Riama said, "My feelings are

more negative than positive because of the PCOS. I feel like I am in bondage to this

PCOS."

Although most women shared their experiences with negative mental health

symptoms resulting from their PCOS and menopause, symptom management strategies

were more often cited regarding physical symptoms. There seemed to be less of an

emphasis on specific strategies focused on mental health. The chief strategy for

addressing mental health symptoms was relaxation, as reported by Culy and Amila. Lucy

shared, "I'm getting positive. I've been told by my doctor, and he said my mood swing in

a symptom of menopause. So, when I feel that I'm overreacting, I just calm myself down." This idea of calming down in response to negative mental health symptoms was echoed by Amila who described practicing self-care by prioritizing herself,

> I would say the first step in taking care of myself is to stop thinking, because there's a saying that fear kills faster. I think relaxation is what I've got to remind myself to do every day, find time for relaxation. Like it's not even much of a bigger disease. It's just like, I would call it imbalance in your system. But some people will be like, "Oh, I have PCOS, and oh my God, what's that?" I feel the first step is to be calm and then not to try so hard to give birth. Because if you keep pushing it, you literally don't know if you're pushing yourself into danger or stuff like that. So put yourself first, take care of yourself. Children will come later. Yeah. That's what I feel, children will come later.

One participant, Lynadaum shared that her doctor had prescribed antidepressants to address her mental health symptoms, "I take mood medications twice daily for the depression and mood swings I been experiencing since the menopause."

Theme 2: Challenges Associated With Co-occurring PCOS and Menopause

This theme mainly focused on physical symptoms and challenges related to physical health. The theme has a subtheme related to how women described their experience of pain during daily life and routine activities. Co-occurring PCOS and menopause symptoms caused women to feel helpless or out of control, this was particularly true regarding physical changes and challenges with fertility. The women were initially challenged by infertility, resulting in the diagnosis of PCOS as young

married women trying to become pregnant. Although, other health issues were present during this time period such as excessive weight, insulin resistance, diabetes hirsutism, and acne, achieving reproduction was the primary focus. However, as the women transitioned to menopause the metabolic features to PCOS seems to dominate. The women reported worsening health conditions related to excessive weight gain, diabetes, joint pain, balding and hirsutism.

In the transition to menopause women experienced physical symptoms that were out of their control. The most widely reported physical symptoms included balding, excessive hair in unwanted places, weight gain, and joint pain. Balding and excessive hair in unwanted places seemed to be particularly emotionally taxing for women. Women often used the phrase "like a man" when referring to their hair-related symptoms. Riama said,

> What stands out for me is losing my hair and looking old because of the PCOS. My friends are menopausal, but they look younger than me. I don't like looking old, balding and with hair growing on my face like a man.

Lynadaum and Sebety also likened these symptoms to a man, saying, "I am growing more hair all over my body, more like a man and I am losing the hair on my head. I am going bald, and growing hair on my face and body." And "I still grow hair like a man" respectively. For most women, these hair related symptoms elicited feelings of embarrassment. Belma shared that she did not feel comfortable discussing these symptoms with others, "Actually I started noticing other things like excess hair on my face and certain areas. I don't wanna tell people, but it they were noticing" Nilada also

felt embarrassed by these symptoms because she felt they were not in alignment with her feminine identity. Of this, she said,

> The main issue is the hairs, the unwanted hairs. It's so embarrassing as a young lady them, I was too embarrassed, I didn't want short skirts. I'm too embarrassed going out and people would say, "Is she a man or is she a lady?" I was also losing my hair on my head.

The effect of hair loss on self-esteem was detailed by Belma,

> The scalp hair loss that as a woman you don't wanna see bald spots. It like diminished your self-esteem, and also with the irregular periods…I sometimes…I don't know when or if I'm gonna get my menses the next month…will it be heavy or light flow.

> In addition to symptoms related to excessive hair or balding. Participants reported excessive weight gain and retention. At times, weight was also reported as a contributing factor of feelings of low self-esteem. Belma shared that her weight made her feel self-conscious, she said, "I'm very self-conscious about my weight." Being overweight increased concerns among participants that they make experience obesity related chronic diseases or general disability. Lynadaum her perception of how her weight was affecting her mobility. She said,

> My mobility is not great because I am overweight, I can do basic things like my chores and go to the market, but I am overweight, so I get tired easily and it takes me longer to complete certain chores.

She also shared that because of her weight she did not feel safe, saying, "I am overweight, so I don't feel safe because it takes me longer to move around. I move slower because of the extra weight so that could be a problem if I need to move faster for my safety." Rasha spoke of the comorbid conditions that she was living with because of her PCOS further emphasizing the far-reaching health implications of PCOS. She said, "Well, because of so many things, when I developed the PCOS, so many things were going on. I was putting a lot of weight also and I was diagnosed with diabetes." Sebety also discussed the ways in which negative health outcomes were exacerbated, although she seemed to think that these health outcomes were normal and not related to her PCOS "I'm overweight and have high blood pressure, but that's being a person in America, in their middle age, most of us are overweight and have high blood pressure." Conversely some women shared concern over their weight or condition worsening over time. Rasha feared her condition becoming debilitating, "Sometimes I feel that maybe I might die. I'm scared of being bedridden. I'm scared of so many things. It makes me to feel insecure." Amila shared similar feelings of not being able to keep up with potential future weight gain, "Are you seeing me? If I get pregnant now, I am gonna be like on a much bigger size. Look at me. I am not even 50 yet and I'm already looking like a ball. I can't keep up with that." Amila further explained that despite their best efforts maintaining a healthy weight had not been attainable due to their PCOS. She reflected on her weight gain by saying,

> Honestly, concerning PCOS, I feel safe, but what I don't feel safe is with the
>
> weight adding, because I don't really eat much, I try my possible best to eat

healthy. I don't even eat the pastries I bake with my own hands, or the cakes I

bake with my own hands, but it keeps adding. So, for the weight aspects, I don't

feel safe.

Lastly, women reported symptoms of physical pain, most commonly join pain.

These symptoms were commonly reported in the context of inhibiting routine activities.

Pain-like symptoms that affected women's daily routine are reported in Theme 3.

Subtheme: Women Experience Pain During Routine Activities

This subtheme is part of the major theme on challenges associated with co-

occurring PCOS and menopause's physical symptoms. It refers to physical pain and

associated obstacles, but it specifically it highlights how daily and routine activities are

affected. The sample of women under study described the challenges that they faced due

to physical pain related to excessive weight gain, joint pain and physical weakness. All of

the women complained about daily joint and body pain affecting their ability to perform

activities daily. However, only two of the women were disabled and receiving

government assistance. A third woman stopped working in the physically demanding jobs

available to her due to fatigue, physical weakness, and joint and body pain. Chronic pain

impacted the QoL of participants.

Culy shared that her pain made it difficult for her to get out of bed. She said, "I

work but I'm having aches on my joints, on my nails, and sometimes I wake up, I don't

feel like standing up from my bed and most time I'm weak." Culy felt that the pain was

causing mental weakness in addition to physical weakness, "I am now beginning to

notice the weakness, not just in the body, but in my mental reasoning." Amila also described the impact of pain on her ability to engage in physical activity.

> As I said I do exercise at the gym sometimes, but the exercise causes my bones to ache all over my body. Sometimes I try to go up to the gym to kick up some fights, but then like, without even getting 20 minutes into it, I'm already feeling so dizzy or tired. Like I could…I can't physically keep up with gym activities.

Nilada also noticed that her ability to complete normal activities was diminishing due to greater physical weakness,

> I'm having this challenge of not going things I know I ought to have done or things I ought to be doing. Like of recent, the doctor said I am supposed to be more engaged in physical exercise, but I'm not physically exercising like I ought to have been doing. Because most of the time I don't really have the strength to do them, and then when I try to do it, I find myself breaking down.

For Nilada the pain was so strong that she ultimately resigned from her job,

> This thing has been, I think it was when the menopause started. I started having the pains, I think so, and that was one of the reasons I resigned from my work. The job was very demanding, and I wasn't meeting up with the demands of the job.

Similarly, Rasha noticed a progression of her physical symptoms and felt weaker because of these symptoms, "These days, I tend to be easily weak, and I don't have strength. I'm not as fit as I used to be."

Theme 4: Healthy Lifestyle Modifications used to Manage Co-Occurring PCOS and Menopause

Women varied in their management of PCOS during menopause. They employed methods such as taking medication, practicing self-care, communicating with their physician, and using cannabis oil. One symptom management strategy that all participants engaged in or strived to engage in was healthy lifestyle behaviors as recommended by their physicians such as increased physical activity and high-quality nutrition**.** Although physical activity was reported as a salient strategy to mitigate PCOS symptoms, some women did not feel that they could meet the demand of physical activity due to symptoms of physical pain, as noted in Theme 3. For some women, decreased mobility contributed to feeling unsafe, making it difficult to engage in physical activity. For at least one participant, concern about crime in the area was also reported as a barrier to engaging in physical activity, Belma explained,

> There's so many concepts, stories I hear in the news every day about high crime, especially to women, like New York crime rate has gone up so far. And also, because to Asians, and recent Asian hate crime[s]. I think somebody's gonna attack me or something.

Despite physical pain and fear of crime impeding physical activity engagement, most participants shared that they regularly engaged in physical activity or had intentions to, some participants modified the type of physical activity that they engaged in to meet their personal abilities. Culy shared her decision to walk instead of jog, "I actually

exercise during the weekends when I'm off work so I take a walk because I can't really jog. So, I mostly I just take a walk"

The women varied in the type of physical activity that they preferred. While some women like Riama shared that she enjoyed walking, others like Belma opted a variety of options including yoga, meditation, biking, and swimming. Both Riama and Belma expressed that their lifestyle changes provided relief to their symptoms. For Riama regular physical activity improved her perception of her QoL, "My doctor told me to exercise, so I walk on the street and stop when I get tired, walk, and stop. I feel better now that I do it more regularly." Belma observed weight loss because of her diet and exercise. It is important to note that the lifestyle changes were not always sustainable as indicated by Belma's testimony, "I am eating more healthy, cleaner lifestyle, more plant-based, more vegetables. No more soda, more water. I've actually lost weight, but at the same time I've lost weight and then gained it, gained weight back." Despite challenges in maintaining the lifestyle changes, Belma and others were firm in their intentions to continue engaging in these behavioral changes. Amila shared, "I try to cope as best I can by doing what the doctor recommends by eating healthy, stay positive and trying to exercise more." Belma expressed a positive outlook of her diagnosis when considering the ways in which healthy lifestyle behaviors could impact her symptoms.

I would say to other women like me, it's a condition that affects a lot of women. It's very similar to menopause, but not 100% similar, but it's not life threatening. You can get through it, control it, over time, with proper diet, exercise and counseling or take medication to help if the doctor recommends it.

Addressing the Research Question

The purpose of this study was to gain an understanding of the lived experience of women diagnosed with PCOS in the reproductive years as they transition to menopause. There was one foundational research questions to address this phenomenon What is the lived experience of QoL in menopausal PCOS women, ages 48 to 65? The first theme that emerged revealed the women experience depressive symptoms and mood swings related to the PCOS diagnosis and transitioning to menopause and how the women cope with these psychological disorders. The second theme to emerge was challenges the women experienced associated with co-occurring PCOS and menopause. As part of this theme, women revealed the experience of pain during routine activities such as working, household duties and physical exercise. Lastly, the third theme emerged as the women complied with to the recommendations of their doctor's and made healthy lifestyle modifications to manage co-occurring PCOS and menopause.

The three themes specifically responded to the research question as they identified the declining mental health, worsening physical health, challenges associated with activities of daily living, and healthy lifestyle change used to cope with PCOS and menopause. For instance, theme one emerged as several of the women reported depressive symptoms and mood swings related to the PCOS diagnosis or as a result of transitioning to menopause. The symptoms varied among the women with five of them reporting a psychiatric diagnosis and are currently prescribed medications to treat the symptoms. Whereas other participants reported using cannabis oil to cope with occasional mood swings, anxiety, and depression.

Theme two addressed the research question as participants described worsening health conditions associated the PCOS diagnosis and the transition to menopause such as joint pain, body aches, loss of strength, physical weakness and fatigue. Along with diabetic conditions and obesity that occurred during their reproductive years further eroding their health in the transition to menopause. Additionally, the reported the loss of scalp hair, and balding increased with menopause as did excessive hair growth on the face and body that began in their reproductive years. In this theme, women described worsening health conditions causing difficulty accomplishing activities of daily living. With two of the women reported being disabled and receiving government assistance due to joint and body pain that was so severe and constant it prevented gainful employment. A third woman decided to stop working due to joint and body pain that prevented her from performing adequately in a physically demanding job and relied on her partner to provide financial stability.

Finally, the third theme also addressed the research question and the women reported they followed their doctor's recommendation to use diet and exercise to cope with the symptoms of PCOS and menopause. Most of the ten participants reported sedentary lifestyles and were initially resistant to following the doctor's recommendations. However, as the majority of the women began to gradually make healthier food choices and exercise regularly, mostly by walking. They reported a lessening of the worst of the symptoms, such as joint pain, weight gain, fatigue, anxiety, and mood swings.

Summary

This chapter detailed participant recruitment procedures, data collection, storage of data, data analysis, evidence of trustworthiness, and the results of the study. The process involved semi-structured interviews and analysis of audio-recordings, transcriptions, and handwritten notes. All these procedures were used to gain an understanding of the lived experience of 10 women diagnosed with PCOS during their reproductive years as they transition to menopause. Findings from the study indicate the women experienced infertility as a result of the PCOS diagnosis along with other health issues such as diabetes, obesity, and depression. The transition to menopause seems to have worsened these conditions and added mood swings, joint pain, fatigue, and body weakness. A few of the women were disabled by the disorder and all reported challenges in performing activities of daily living due to joint and body pain. Some of their doctors prescribed medication to relieve the pain and all suggested a healthy lifestyle change through diet and exercise to ease the symptoms of PCOS and menopause. In the next chapter, the findings of the study are interpreted, limitations are noted, and implications for future research are described.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative study was to explore the lived experiences of women diagnosed with PCOS during their reproductive years as they transition to menopause at ages 48–65. PCOS is associated with a variety of comorbidities, such as cardiovascular diseases, the most significant and frequent cause of morbidity and mortality in women; metabolic disorders; insulin resistance; chronic inflammation; oxidative stress; and psychological disorders. Many of these comorbidities can be found in PCOS patients even at early age and worsen in pre-menopause and post-menopause stages (Moulana, 2020).

A large body of research has been focused on adverse reproductive and metabolic comorbidity features of PCOS that present a serious economic burden to health care (Bromberger et al., 2015; Dokras et al., 2018; Winkler et al., 2015; Zheng et al., 2015). Although there is an expansive amount of literature on the complications of PCOS for reproductive-age women, there is minimal information about the health and well-being of these women as they transition to menopause (Moulana, 2020). Thus, the current IPA study was conducted to explore the lived experiences of 10 participants diagnosed with PCOS in their reproductive years as they transition to menopause. Three themes emerged from the interview data: (a) depressive symptoms and mood swings related to the PCOS diagnosis and transitioning to menopause and how the women cope with these psychological distress/disorders, (b) the challenges and physical pain women experience associated with co-occurring PCOS and menopause, and (c) how women comply with the

recommendations of their doctors and make healthy lifestyle modifications to manage co-occurring PCOS and menopause. The following sections include an interpretation and discussion of the findings, limitations of the study, recommendations for further research, implications for positive social change, and a conclusion.

Interpretation of the Findings

The data were collected from semistructured interviews of each participant and their reactions to being diagnosed with PCOS in their reproductive years and their experiences as they transition to menopause. Three themes were identified through the data analysis. The findings of this study helps to fill a gap and extend empirical knowledge of the psychological health and well-being of PCOS menopausal women. All themes that originated from this study are supported by findings in the existing literature. By comparing the findings from this study to the foundational understanding of the lived experiences of PCOS menopausal women, health care workers targeting this population can be better informed as can future directions for research in this area.

Theme 1: Women Cope With Depressive Symptom and Mood Swings

Participants revealed feelings of depression and anxiety beginning in their reproductive years due to features related to PCOS: hairiness, obesity, irregular and painful menses prior to being officially diagnosed by a doctor as newly married women, and inability to become pregnant. Depression, anxiety, and helplessness have been associated with women who have PCOS (Moulana, 2020). As noted by Amir et al. (2014) and Sanchez (2020), reproductive-age women with a PCOS diagnosis are challenged in the perception of themselves as feminine due to their obesity, hairy appearance, and lack

of fertility. Depression and other mental health issues in women with PCOS are not only due to the psychological effects of obesity, infertility, or hairiness (Dokras et al., 2018; Dokras, 2016; Torres Fernandez et al., 2018; Elsenbruch, 2007; Hollinrake, 2007), but PCOS is also seen as an inflammatory condition; excessive inflammation caused by PCOS is an important inducer of depression (Joham et al., 2022; Kolhe et al., 2021). Anxiety and depression are seen as two major PCOS-associated psychological comorbidities, with high incidence; and they are considered as a substantial public health burden (Moulana, 2020). Further noting, it has been found that women with PCOS are at an increased risk of social phobia, painful emotional stress, suicidal ideation, bipolar disorder, and attention-deficit/hyperactivity disorder.

Participants in this study reported increasing mood swings, depression, and anxiety as they transitioned to menopause; some participants were diagnosed with mood disorders and prescribed psychotropic medication to cope with the symptoms. According to Masood et al. (2016) and Zheng et al. (2017), PCOS women who transition to menopause experience psychological distress due in part to aging ovaries, leading to the deterioration in the fabrication of the ovarian gonadotropins such as progesterone and estrogen. Furthermore, Henson and Kulkarni (2022) expanded on this information noting evidence that supports the notion that women with menopause-associated depression do not suffer from a gonadal hormone abnormality as such but have a brain response to the hormonal fluctuations, leading to depression associated with menopause transition.

Theme 2: Challenges Associated With Co-occurring PCOS and Menopause

Participants described feeling helpless and out of control due to co-occurring PCOS that began in their reproductive years and menopause symptoms such as infertility, irregular menses, diabetes, mood disorders, obesity, joint and body pain, and cosmetic features of the disorder. The women reported struggling with obesity and being diagnosed with diabetes in their reproductive years, and they found these symptoms worsened as they transitioned to menopause due to increasing weight even when dieting or eating smaller portions of food. According to Comijs (2015) and de Medeiros (2020), the more serious chronic conditions, such as cancer, cardiovascular disease, and diabetes, become more pronounced among PCOS women with age. Women diagnosed with PCOS at reproductive age have increased risk and prevalence of prediabetes and diabetes and have multiple risk factors for cardiometabolic disease. Other comorbidities include obstructive sleep apnea, endometrial cancer, and mood disorders, which contribute to the overall health burden of the syndrome (Deswal et al., 2022).

Balding and excessive hair growth in unwanted places such as the face, arms, and body (hirsutism) are two of the cosmetic features of PCOS that participants identified as emotionally taxing and threatening to their feminine identity. According to Sarfarti et al. (2022), the clinical signs of PCOS appear around puberty and progress slowly in adulthood; however, the clinical consequences of this pathology do not stop with menopause. Symptoms of hyperandrogenism can worsen with menopause and present with moderate clinical signs such as hirsutism, acne, and/or signs of virilization (alopecia, hoarseness, clitoral hypertrophy).

Participants described the challenges they face due to physical pain. They explained that, at times, pain makes it difficult for them to conduct routine activities. Chronic pain impacts the QoL of individuals (Lu et al., 2022). The majority of the participants reported a worsening of their health condition and difficulty completing activities of daily living in the transition to menopause. Two of the participants were disabled, and two reported being unemployed for several years due to poor health related to the PCOS diagnosis and transitioning to menopause. PCOS is associated with several diseases that contribute to physical pain and the interruption of activities of daily living. For example, PCOS causes anovulation and hyperandrogenism, resulting in hormonal imbalance, and is known to contribute to systemic autoimmune diseases such as rheumatoid arthritis (Sharkeem et al., 2021).

Women with PCOS are at a higher risk of developing metabolic syndrome leading to osteoarthritis development causing pain in the knees, hips, and hands (Kluzek et al., 2021). The metabolic features of PCOS become more pronounced with age and are associated with increased risk for insulin resistance, dyslipidemia, cardiovascular disease, some cancers, and abdominal obesity (Mahalingaiah et al., 2015). Endometriosis and PCOS are both associated with pelvic pain; they also have similar pathological causes (e.g., obesity and oxidative stress) and contribute to the increased risk of cancer development in the endometrium (Lu et al., 2022). Furthermore, several PCOS-related pathologic factors may exacerbate pain perception, including low-grade inflammation, oxidative stress, adipogenesis, and insulin resistance. In sum, pain expression may be dynamic and diverse in patients with PCOS because several diseases that cause bodily

pain have been identified to be associated with PCOS. PCOS health-related debilitating

symptoms predict poorer participation in working life by increasing the risk of disability-

based absences and unemployment and disability retirement in middle age (Kujanpää et

al., 2022).

Theme 3: Healthy Lifestyle Modifications Used to Manage Co-occurring PCOS and

Menopause

Women varied in their management of PCOS during menopause. They employed

methods such as medication, practicing self-care, communicating with their physician,

and using cannabis oil. Healthy lifestyle behaviors such as increased physical activity and

high-quality nutrition were two symptom strategies recommended by their physicians.

Despite physical pain and fear for physical safety due to obesity most participants shared

that they regularly engaged in some form of physical activity. Lifestyle modifications

have been gradually acknowledged as the first-line management for PCOS, especially in

obese patients with PCOS (Gu et al., 2022: Shah & Rasool, 2021; Szczuko et al., 2021)

Further noting, lifestyle modifications, including diet modifications, exercise, and

behavioral modification, appear to alleviate the metabolic dysfunction and improve the

reproductive disorders of PCOS patients (particularly in obese women).

A review done on PCOS and metabolic syndrome highlights the unhealthy

association of the PCOS and obesity and emphasizes the importance of early diagnosis,

patient education, and long-term follow-up beyond the reproductive age into menopause

to prevent the long-term serious comorbidities (Shah & Rasool, 2022). Celik and Kose

(2021) recommended that patients with defined PCOS phenotypes should be observed

and monitored from the early reproductive period into the late postmenopausal period to clarify morbidities and mortality in older women with PCOS. In addition, Lin et al. (2022) and Shadid et al. (2022) suggest a focus on weight management practices based on substantial evidence that obesity worsens reproductive and metabolic features of PCOS. They further noted the important role of nutrition professionals to provide evidence-based health care.

Conceptual Framework

The domains of the World Health Organization developed to determine QoL were used as a framework for understanding the QoL of PCOS women diagnosed in their reproductive years as they transition to menopause (Bonomi, et al, 2000). The QoL domains are physical, psychological, social relationships and environment factors. In addition, the framework for QoL encompasses a person's physical health, psychological condition, personal beliefs, social relationships, and relationships with the environment (Monteleone et al., 2018; Ozkan, et al, 2005).

Considering the QoL dimensions, it is safe to conclude that participants in this study were considerably affected in their physical health reporting low levels of QoL. The results of the study found the most widely reported physical symptoms included weight gain, joint pain, with balding and excessive hair in unwanted places seeming to be particularly emotionally taxing for women. For instance, poor physical health was a common complaint of all participants due to a history of obesity, diabetes and insulin resistance that began in their reproductive years and worsened as they transitioned to menopause. According to Deswal et al., (2022) noted women diagnosed with PCOS at

reproductive age have increased risk and prevalence of prediabetes and diabetes and have

multiple risk factors for cardiometabolic disease. In addition, the women all reported

varying degrees of joint and body pain, that affect their ability to perform activities of

daily living. Two of the participants were disabled and two stopped working during the

transition to menopause due to difficulty performing physically demanding jobs. Most of

the women reported feeling physically unsafe in their environments due to being obese

and experiencing frequent joint and body pain.

Similar to what was described regarding the physical QoL, the psychological

dimension was also affected. It can be concluded that participants reported a high level of

psychological suffering including issues of mood swings, depression, anxiety, and self-

esteem. For example, the cosmetic features, comorbidities associated with PCOS affected

the women self-perception, as they noticed same age friends were not having the same

experiences. The women struggled with poor psychological health beginning in their

reproductive years due to infertility, obesity, and the cosmetic features of PCOS. The

women reported feeling less than a woman due infertility and coping with masculine

features due to excessive facial and body hair. With the transition to menopause the

women experienced increased weight gain, mood swings, depression and anxiety. Four of

the women were diagnosed with mood disorders and prescribed psychotropic medication

to cope with the symptoms.

Limitations of the Study

The study is limited by using the online website, Craigslist, as the data collection

method to solicit volunteers. Initially, PCOS online supports groups were contacted as the

source of recruiting volunteers. However, there was no response from the members of the four support groups that granted permission to post the flyer on their site. While the use of Craigslist was mentioned as a limitation, it is relevant to notice that Craigslist can provide an effective online method that allows social science researchers to recruit from a wider range of people, especially with regards to stigmatized populations (Antoun et al., 2016; Worthen, 2014).

Conducting the interviews online via Zoom can also be seen as a limitation of the study. Face-to-face interviews would have allowed for more contact and observation of the participants (Creswell, 2014). However, I was able to build rapport, and display empathy during each session that seemed to ease participants' anxiety in sharing very personal information about their PCOS journey. It is relevant to mention that Archibald et al. (2019), found that Zoom is a viable tool for collection of qualitative data because of its relative ease of use and cost.

The study is limited by the participants' perceptions of their experience as PCOS menopausal women. In addition, the study is limited to the women in the study and may not be transferable to other populations. Lastly, this is a one-time study with no longitudinal follow-up. Therefore, I was not able to explore the presence or absence of changes in perceptions over time.

Recommendations

Previous research found women with PCOS at reproductive age have increased risk and prevalence of prediabetes, diabetes and multiple risk factors for cardiometabolic disease and other comorbidities such as obstructive sleep apnea, endometrial cancer and

mood disorders, which contribute to the overall health burden of the syndrome (Bellever et al, 2018; Deswal et al., 2022). The health risk for PCOS reproductive age women is well-documented. However, little is known about the impact of PCOS on long-term health in ageing women. This study explored the lived experienced of PCOS women diagnosed in their reproductive years as they transition to menopause. The study revealed that the women struggled with poor health related to obesity, diabetes, balding, excessive hairiness (hirsutism), joint and body pain, and psychological distress. However, sparse research for aging PCOS women makes it is difficult to determine how best to serve the physical and psychological needs of aging PCOS women. Future research can concentrate on how to support women suffering from physical and psychological issues described in the study and how to encourage varied healthy lifestyles.

This study collected data from different online groups and Craigslist and relied on participants' self-report of PCOS diagnosis. Future studies may identify participants via other sources and verify participants' diagnosis with medical records. Additionally, medical records could also serve as sources of data triangulation. Another recommendation is the need for large, prospective studies on community-based and well-phenotyped PCOS cohorts with extended follow-up into late menopause (Joham et al., 2022). Furthermore, future research should obtain clinical or biochemical confirmation of PCOS status instead of relying on self-reports. Other data approaches are also needed to determine the health risk associated with aging, transitioning to menopause and beyond. Lastly, ethnic populations should be included in PCOS longitudinal studies to contribute new knowledge to the natural history of PCOS.

Implications

PCOS is a lifelong endocrine condition with reproductive and metabolic symptoms, and cosmetic features. The research literature indicates the primary focus of PCOS research has been devoted to improving fertility in reproductive age women. The fluctuating androgen levels that contribute to physical and psychological effects of the disorder were thought to lessen as the women transition to menopause (Sharkeem et al., 2021). Furthermore, the androgens do lessen with age but remain constant, causing inflammation and worsens the health condition of PCOS menopausal women. This study was conducted to gain an understanding of the physical and psychological well- being of reproductive age women diagnosed with PCOS in their reproductive years as they transition to menopause.

The women in this study struggled with diabetes, obesity, joint and body pain, hairiness (hirsutism), balding and mood disorders. Thus, the findings of this study may contribute to social change as health providers may use the results of this study to create interventions and improve the lives of PCOS menopausal women. Health providers may also use the results of this study to encourage healthy lifestyle habits for those identified with PCOS at initial screening, which usually occurs during the reproductive years. Furthermore, health providers' encouragement of healthy lifestyle choices in the reproductive years can foster social change by preventing the debilitating health conditions associated with a PCOS diagnosis.

Counselors and clinicians who treat women presenting with psychological symptoms associated with PCOS can use the results of this study to adjust treatment to

meet the women's needs. Results of this study may also be used in recognizing and addressing the challenges that women with PCOS experienced including stigma and helplessness. Clinicians can become more aware of the long-lasting effects for women with PCOS, an understanding of these effects is relevant in treating women with PCOS in menopause. Additionally, clinicians working on psychoeducation and prevention can use the information provided in this study as a basis to encourage the promotion of healthy lifestyles for women with PCOS.

Conclusion

The purpose of this phenomenological study was to explore the perceptions and lived experiences of women between the ages of 48–65 diagnosed with PCOS as they transitioned to menopause. The women reported conditions such as irregular menses, or no menstrual cycle for several months, acne and hairiness (hirsutism). Most of the women were diagnosed with PCOS as newly married women seeking the advice of a physician due to infertility while trying to become pregnant. The women struggled with obesity, hairiness, and balding. Four women were diagnosed with mood disorders, two were disabled and two were diagnosed with diabetes. They all reported a worsening of their health conditions upon transitioning to menopause. Interventions by health providers to address the health issues of PCOS menopausal women is needed. Future research should focus on the health risks associated with menopausal women not addressed in this study and the lived experience of a similar cohort of women post menopause.

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Appendix A: Interview Guide

Demographic Questions:

Age:

Number of children:

Sexual orientation:

Marital status:

Ethnicity:

Age of PCOS diagnosis:

Age of transition to menopause:

Menopausal symptoms:

PCOS metabolic symptoms:

Research Questions

RQ.1. What is the lived experience of quality of life in menopausal women, ages 48 to 65 previously diagnosed with PCOS during their reproductive years?

S.Q.1. How do menopausal women, ages 48 to 65 previously diagnosed with PCOS during their reproductive years, manage the disorder?

Interview Questions

1. How do you make sense of your PCOS diagnosis as you transition to menopause?

2. Please describe a typical day living with PCOS at this age.

3. I am going to ask you some questions about how you relate PCOS with your quality of life and wellbeing:

a. Tell how PCOS affects your physical health.

   i. Probes:

      1. How do you manage medication?

      2. What are the activities you do in your daily living?

      3. How is your mobility?

      4. Are feelings of physical pain or discomfort that you have

         deal with?

b. Tell me how PCOS affects your mood and psychological wellbeing.

   i. Probes.

      1. On a general basis, how is your mood?

      2. How would you describe your life satisfaction?

      3. Are there positive or negative feelings you experience more

         often?

      4. Are there sources of spirituality/religion in your daily life?

c. Tell me how PCOS affects your social relationships.

   i. Probes:

      1. How do you describe your social relationships?

      2. What are the sources of social support you rely on?

d. Tell me how PCOS affects your surroundings or environment.

   i. Probes:

      1. How do you describe your health and social care?

      2. Do you participate in recreational activities?

3. How do you describe your feelings of physical safety?

4. Have your PCOS symptoms changed over time?

5. What are the PCOS symptoms that currently affect you?

6. How do you manage the symptoms in your everyday life?

7. Have you changed the way you deal with your PCOS symptoms over time?

8. How do you cope with PCOS as a menopausal woman?

9. How has this experience of coping with PCOS as a menopausal woman affected you?

10. What aspects of your menopausal PCOS experience stand out for you?

11. What changes have you made in your life as a woman diagnosed with PCOS transitioning to menopause?

12. How can your experiences as a PCOS menopausal woman help others in your situation?