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Health-Related Quality of Life of Women With Polycystic Ovary Syndrome in Malaysia

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Walden University

College of Psychology and Community Services

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Stephanie Yang

has been found to be complete and satisfactory in all respects,
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Walden University
2026

Abstract

Health-Related Quality of Life of Women With Polycystic Ovary Syndrome in Malaysia

by

Stephanie Yang

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

May 2026

Abstract

Polycystic ovarian syndrome (PCOS) is the most prevalent endocrine condition among women of reproductive age. PCOS is known to be a chronic disease that presents significant physical and body image issues, which in turn are associated with lowered emotional and health-related quality of life. Previous studies point to widespread dissatisfaction and delays with the diagnosis of PCOS and a lack of information provided by doctors. This phenomenological study was guided by Wilson and Cleary's model of health-related quality of life to explore the health-related quality of life in Malaysian women with PCOS. Seven Malaysian women aged 29 to 50 years participated in semi-structured interviews conducted via the online meeting platform Zoom. A series of themes emerged from the data. Specifically, participants described emotional burden and psychological strain, concerns related to physical appearance and identity, relational and role strain within family and social contexts, experiences of cultural stigma and misunderstanding, and gradual processes of coping and acceptance over time. The findings indicated that PCOS was experienced as an ongoing and unpredictable condition that affected multiple dimensions of health-related quality of life beyond physical symptoms alone. This study may contribute to positive social change in that more and continuous medical education is necessary for strengthening the provision of patient-centered care for women with PCOS. Emphasis on integrative care and holistic approaches might prevent misdiagnosis and ensure that women with PCOS receive accurate information and appropriate support in managing their condition.

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Dedication

This study is dedicated to the memory of my grandmother, whose life embodied warmth, discipline, social responsibility, and integrity. Although she is no longer with us, her words of wisdom and enduring love continue to guide my motivation and perseverance. I also dedicate this work to my parents, my husband, and our two beautiful daughters, who have been my constant source of inspiration and strength throughout this journey. Your sacrifices, patience, and unwavering support made this achievement possible. To my daughters, thank you for your understanding and resilience during the many moments when “Mummy had to work on the laptop,” even during holidays. I am deeply proud of the independence and strength you have shown during this time. I would also like to extend my heartfelt appreciation to my chair, faculty members, and friends whose guidance and encouragement have supported me at every stage of my academic journey. Finally, this study is dedicated to all women living with PCOS. May this work stand as a reflection of your strength, resilience, and courage – we are stronger than we know.

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Chapter 1: Introduction to the Study

Introduction

Polycystic ovary syndrome (PCOS) has been classified as a complex disease with heterogeneous clinical presentation, characterized by chronic anovulation and hyperandrogenism (Azziz et al., 2016; Deswal et al., 2020; Guo et al., 2023). Many of the symptoms of PCOS, such as hirsutism, obesity, acne, and infertility, are uncomfortable, painful, and unpredictable (Habib et al., 2021; Light et al., 2021; Lizneva et al., 2016). They are also linked to traits that are viewed as unfeminine and undesirable in society or most cultures (Chaudhari et al., 2018; Nasiri-Amiri et al., 2018; Wang et al., 2023). Furthermore, the disorder is linked to biochemical abnormalities, which can cause mood disorders on their own (Gnawali et al., 2021; Guo et al., 2023). Research has shown that psychological distress, including stress, anxiety, and depression, is more common in women with PCOS, and that PCOS itself is a risk factor for both depression and anxiety (Tabassum et al., 2021; Yin et al., 2021). This is because adverse clinical complications associated with PCOS include infertility and irregular menstruation, metabolic disorders such as diabetes, insulin resistance, and cardiovascular risk—all of which have been identified as the cause of the decline in quality of life (Barnard et al., 2007; Brady et al., 2009; Habib et al., 2021; Li et al., 2011).

Quality of life in women with PCOS is significantly affected due to a combination of physical symptoms alongside psychological challenges, which can lead to social stigma, reduced self-esteem, and impaired daily functioning, which can in turn impact overall well-being (Dewani et al., 2023). In Asia, particularly in regions like Malaysia,

the understanding of this impact is limited due to a lack of region-specific studies. Therefore, the aim of this study was to explore the health-related quality of life of women with PCOS in Malaysia. The understanding of different aspects affecting the quality of life in these women might help in the development of culturally sensitive interventions and comprehensive healthcare strategies that can be tailored to the unique needs of Malaysian women with PCOS.

This chapter explored an in-depth understanding of women with PCOS and their quality of life, identifying the problem that will be investigated and discussing the purpose of this study. This chapter also introduced the theoretical framework that helps to explain the quality of life and its influencing factors among women with PCOS. Additionally, terms used in this study were defined together with the study's assumptions, scope, limitations and delimitations. These topics helped shed light on the study's importance in promoting optimal social change for women with PCOS and improving their quality of life(s).

Background

PCOS was first identified in 1935 when American gynecologists Irving Stein and Michael Levanthal associated the existence of ovarian cysts with anovulation (Khadilkar, 2016). According to research, insulin resistance coupled with hyperandrogenism and hyperinsulinemia is the primary cause of the disease. These two elevated hormones control ovarian activity while interfering with other hormones that regulate menstruation. A constant upset in this hormonal balance affects how well the ovaries are able to function which then leads to the development of cysts inside the ovarian sac—and this is

how the term *polycystic ovarian syndrome* was derived (Ajmal et al., 2019). These factors served as the syndrome's diagnostic criteria for a long time and it was only in the last two decades that PCOS has grown in scope to an endocrine-metabolic disorder with a number of implications to female health. This includes for example, the association of PCOS with reproductive disorders and cardiovascular disturbances such as insulin resistance, hirsutism, obesity, hypertension, diabetes and dyslipidemia (Barber et al., 2019; Osibogun et al., 2020; Sangaraju et al., 2022). Hyperandrogenism, which is brought on by an excess of androgens, is the root cause of many of the clinical signs of PCOS (Guo et al., 2023). Women who have hyperandrogenism may have a number of negative side effects, including the growth of ovarian cysts, weight gain, hirsutism, or increased body and facial hair, acne, and alopecia. Due to elevated levels of androgens, women with PCOS may also have anomalies in their menstrual cycles, such as oligomenorrhea, amenorrhea, and oligo-ovulation or anovulation (Krug et al., 2019; Yasmin et al., 2022). As a result of this, PCOS is known to also be a chronic disease that presents significant physical and body image issues, which in turn is associated with lowered emotional and health-related quality of life.

PCOS can have profound emotional and psychological effects, including heightened levels of anxiety, depression, and stress (Almeshari et al., 2021; Brady et al., 2009; Douglas et al., 2021). Studies from various parts of the world indicate that women with PCOS often feel “freakish” and “abnormal,” reflecting a perceived inability to conform to social norms of femininity (Kitzinger & Willmott, 2002). For example, research in Oman (Sulaiman et al., 2017) and the United Kingdom (Light et al., 2020) has

shown that PCOS is associated with increased psychological burden and that the severity of psychological distress correlates with the number of PCOS symptoms. Women with PCOS frequently struggle with body image issues due to symptoms like hirsutism, acne, and weight gain, leading to low self-esteem and social withdrawal (Habib et al., 2021; Ligocka et al., 2024; Spritzer et al., 2022; Taghavi et al., 2015). The condition's impact on fertility can also cause significant emotional distress and feelings of inadequacy (Taghavi et al., 2015; Wang et al., 2023). PCOS is one of the most common endocrine conditions among women of reproductive age, with a prevalence of approximately 6%–21% (Deswal et al., 2020; Lizneva et al., 2016). However, information regarding the prevalence and severity of PCOS was still lacking in many areas of the world, especially in low-income and middle-income regions in Asia. Despite being one of the most reported endocrine disorders, PCOS continued to be largely ignored in the social scientific literature (Pathak & Nichter, 2015). The research on PCOS in Malaysia to date has mostly explored the prevalence of the disease (e.g., Dashti et al., 2019; Goh et al., 2022; Mei et al., 2022). Data from the research indicated an estimated prevalence of 10.49%–12.6% in Malaysia (Dashti et al., 2019; Goh et al., 2022); however, little or no attention has been given to how women with PCOS describe their quality of life.

Problem Statement

PCOS has been classified as a complex disease or disorder with heterogeneous clinical presentation, characterized by chronic anovulation and hyperandrogenism. According to numerous studies, anxiety levels, psychological distress, depression, and social fears are significantly higher in women with PCOS (e.g., Almeshari et al., 2021;

Chaudhari et al., 2018; Habib et al., 2021). In addition, women with PCOS may also present with clinically relevant psychopathology and impaired emotional well-being (Sayyah-Melli et al., 2015). Previous studies in other countries indicated that PCOS has mental health impacts and is associated with a reduction in quality of life and increases in depressive symptoms, especially with the presence of comorbidities (Habib et al., 2021; Tabassum et al., 2021). Yet to date, there has been a paucity of studies exploring the quality of life of Malaysian women with PCOS. For women with PCOS, coping with the condition, fears surrounding infertility, loss of femininity and sexuality, body image concerns, and lowered self-worth typically contributed to poorer mental health outcomes (e.g., Light et al., 2021). The current research on PCOS in Malaysia has mostly explored the prevalence of the disease (e.g., Dashti et al., 2019; Goh et al., 2022; Mei et al., 2022); however, little or no attention has been given to how Malaysian women with PCOS perceive their quality of life. The challenges in diagnosing PCOS and sustaining long-term follow-up highlights the uncertainties surrounding patient care, therefore, understanding quality of life could provide a basis for the development of targeted psychological intervention programs for women with PCOS in Malaysia.

Purpose of the Study

The purpose of this phenomenological study was to explore the quality of life of women with PCOS in Malaysia. Considering how women with PCOS are at higher risk for many health problems from endometrial cancer to obesity, or infertility, cardiovascular risks, depression and eating disorders, the findings from this research was able to add to the current body of evidence on useable knowledge that healthcare

providers, educators, and stakeholders could take into consideration to optimize both clinical responses and help overall well-being for women with PCOS in Malaysia.

Research Question

RQ-Qualitative: What is the health-related quality of life of women with PCOS in Malaysia?

Conceptual Framework for the Study

The conceptual framework for this study was Wilson and Cleary's (1995) health-related quality of life model, which goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life. As the model integrates both psychological and biological aspects of health outcomes, it was able to provide a useful framework to describe the physical, emotional, and social aspects of PCOS as a disease/disorder. Evidently, in addition to its association with metabolic consequences, PCOS is also most likely to have detrimental effects on mental health and quality of life due to the psychological consequences of infertility and other symptoms. The semi-structured interview guide was partly developed with the concepts of this theoretical framework, and the effects of PCOS on the quality of life were explored. As a result, this theory was able to show how understanding the factors that contribute to health-related quality of life is critical for developing the most appropriate interventions for improving or maintaining the quality of life in women with PCOS. More development of this theory is provided in Chapter 2.

Nature of the Study

Interpretative phenomenological analysis (IPA; Smith et al., 2009) was used as the research design in this study to explore the quality of life of women with PCOS in Malaysia. There was limited literature regarding the quality of life of Malaysian women with PCOS. Considering how phenomenology is a philosophical approach, the aim of this study was to produce an account of lived experiences of research participants in their own terms rather than one prescribed by pre-existing theoretical preconceptions (Smith & Osborn, 2015). As the focus of the study related to understanding the personal experiences of women with PCOS and how living with symptoms of PCOS affects their quality of life, the IPA approach was especially valuable in this sense because PCOS as a condition itself is ambiguous, complex and emotionally laden.

Participants for this study were recruited throughout Malaysia via social media through friends and family. Women with a confirmed PCOS diagnosis were invited to participate, and recruitment used a purposeful snowball sampling method. I interviewed 10 women who met the inclusion criteria and indicated their willingness to participate after reviewing the informed consent form and details of the study. Interviews were semi-structured, recorded, and transcribed after data collection. To maintain confidentiality, I assigned participants a number instead of a pseudonym and identifying details such as occupation and demographic information were generalized. This approach ensured compliance with ethical and confidentiality standards. Additionally, measures were implemented to ensure the trustworthiness of the data, including maintaining an audit

trail that documented each step of the data analysis process and the rationale behind the decisions made.

Definitions

Anovulation: The term anovulation is a medical condition whereby the ovaries do not release an egg during the menstrual cycle, which could in turn cause infertility in women of childbearing age (Escobar-Morreale, 2018). About one third of couples visiting infertility clinics have anovulatory infertility, with PCOS responsible for 90% of such cases (Balen et al., 2016). The Rotterdam criteria, which are widely used worldwide, were recommended by the Endocrine Society in 2013, the American Academy of Family Physicians Guidelines in 2016, and the International Evidence-based Guideline for the assessment and management of PCOS, including the presence of oligo-/anovulation as one of the three criteria (Goh et al., 2022).

Hirsutism: Hirsutism, the primary symptom of hyperandrogenism in women, is characterized by an abnormally high amount of terminal hair distributed in a male pattern in females with PCOS (Spritzer et al., 2022). Whereas hirsutism affects 4%–11% of women in the general population, its prevalence in PCOS is estimated to be 65%–75%, and its severity varies depending on the level of androgen excess (Azziz et al., 2016). Hirsutism is the most consistent and reliable symptom used for evaluating clinical hyperandrogenism (Ashraf et al., 2019).

Hyperandrogenism: Hyperandrogenism is the defining feature of women with PCOS. It is brought on by an excess of androgen being produced as a result of abnormal ovarian or adrenal disruption (Ashraf et al., 2019). In women, hyperandrogenism

manifests clinically as hirsutism, acne, androgenic alopecia, and/or elevated testosterone levels. Additionally, other symptoms of increased androgen excess include weight gain, irregular menstruation, acanthosis nigricans, and insulin resistance (Guo et al., 2023).

Biochemically, hyperandrogenism is characterized by elevated testosterone levels as well as other determined markers of androgen excess, such as free testosterone, free androgen index, dihydrotestosterone, dehydroepiandrosterone, dehydroepiandrosterone sulfate, and androstenedione (Coskun et al., 2011).

Infertility: Infertility is a disease characterized by the failure to establish a clinical pregnancy after 12 months of regular and unprotected sexual intercourse (Vander Borgh & Wyns, 2018). In women with PCOS, the prevalence of infertility varies between 70% and 80% (Melo et al., 2015), but at the same time, PCOS is also the most common cause of infertility in women. Infertile women experience shame as a result of internalized guilt in addition to external social pressure, which then affects their overall quality of life.

Polycystic ovary syndrome (PCOS): Heterogeneous by nature, PCOS is defined by a combination of signs and symptoms of androgen excess and ovarian dysfunction in the absence of other specific diagnoses (Tabassum et al., 2021). Hyperandrogenism, abnormal ovulatory function, and enlarged ovaries with multiple follicles are the hallmarks of this disorder (Ashraf et al., 2019). In addition, insulin resistance, Type 2 diabetes mellitus, infertility, psychological issues, cardiovascular diseases, and a variety of gynecological cancers, including endometrial and ovarian cancer, are all highly probable in women with PCOS (Balen & Rutherford, 2007). The fundamental cause of

PCOS remains unknown, and the molecular underpinnings of its development remain a mystery.

Health-related quality of life: Health-related quality of life is defined as an individual's or group's self-perception of their physical and mental health over time in the context of the culture and value system in which they live (Koller & Lorenz, 2002; Tabassum et al., 2021; Yin et al., 2016). According to Felce and Perry (1995), it is an “overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values.” Clinical manifestations of PCOS, such as obesity, infertility, hirsutism, biochemical and hormonal disturbances, are often related to a deterioration in the woman's self-esteem and self-image, which may in turn affect their quality of life (Sanchez-Ferrer et al., 2020). Several measures of self-perceived health status and physical and emotional functioning are typically used to evaluate quality of life, specifically, health-related quality of life. When combined, these metrics offer a thorough evaluation of the burden of preventable illnesses, injuries, and disabilities (Centers for Disease Control and Prevention [CDC], 2023).

Assumptions

It was assumed that the women with PCOS who volunteered to be interviewed would be open and honest about their opinions, that they understood what PCOS is, as defined in this study, and the symptoms and diagnosis of their own conditions, and that they were able to understand the questions that were asked and be able to communicate

well in English so that their responses could be transcribed with ease. Lastly, it was assumed that it was possible for participants to feel hesitant, embarrassed, or ashamed when talking about their experiences; therefore, I remained professional and reassured them of my neutral standpoint.

Scope and Delimitations

Participants for this study were women with PCOS recruited via social media through friends and family throughout Malaysia. The inclusion criteria for these women were as follows: participants self-reported a PCOS diagnosis and met the 2003 Rotterdam Criteria (Benetti-Pinto et al., 2015), which required two of the following three conditions: (a) irregular or absent ovulation, (b) clinical and/or biochemical signs of hyperandrogenism, and (c) polycystic ovaries detected by ultrasound. Participants were aged 18–45 years (reproductive age) and included women with PCOS with or without comorbidities. Additionally, they had not been pregnant in the preceding 6 weeks. Pregnant women with PCOS face significantly higher risks of developing gestational diabetes, pre-eclampsia, fetal macrosomia, having infants who are small for their gestational age, and experiencing perinatal mortality (Lizneva et al., 2016). Considering the focus of this research study was on understanding the quality of life for someone with a confirmed diagnosis of PCOS, it may have been considered highly emotional and sensitive for those who were pregnant. In addition, given the focus of this study, other factors such as blood test (androgen) levels, socioeconomic status, medication history, and PCOS phenotypes were not the intended focus of this study.

The conceptual framework for this study was the health-related quality of life model (Wilson & Cleary, 1995). Several factors influenced the health-related quality of life in women with PCOS. The Wilson and Cleary model serves as a practical conceptual framework that connects various health concepts to guide quality of life research. The model suggests that health-related quality of life is influenced by individual characteristics, biological function, environmental factors, symptoms, functional status, and overall health perceptions. Another theory that was considered but not used for this study was Engel's (1977) biopsychosocial model as it posited that illness and health are the results of a combination of biological, psychological, and social factors. For example, body image and eating disorders are prevalent amongst women, especially the young adolescent age group and more so for those with PCOS. However, in comparing between the two models, the biopsychosocial model actually has a broader focus, incorporating a wide range of factors affecting health, while the health-related quality of life model on the other hand, specifically targets the relationship between health and quality of life. More importantly, the biopsychosocial model includes biological, psychological, and social factors in a more general sense, whereas the health-related quality of life model narrows these factors down to how they impact quality of life related to health conditions which is the focus of this study.

The transferability of this study's outcomes is somewhat limited due to its descriptive qualitative nature. The findings may not be representative of the larger population as the small sample size limits the ability to generalize the results to other groups or settings (Sutton & Austin, 2015). Additionally, the study's focus on a

homogenous group to deeply explore specific experiences may limit the applicability of the findings to broader or more diverse populations of women with PCOS. However, this approach may offer foundational insights for future, more targeted research. Although the study focused on a narrow, context-specific sample, the detailed descriptions may permit some comparisons with other contexts and similar populations of women with PCOS.

Limitations

Although this study aimed to provide valuable insights into the quality of life of women with PCOS, several limitations should be noted. First, the phenomenological nature of this study limited the data to the self-reported narrative accounts of the lived experiences of the women with PCOS who volunteered to participate. While it was assumed that these women would provide honest responses to the questions asked during the interview, the data may have been subject to social desirability and recall biases. Second, I recruited the study participants through my own social network of friends and family members, which may have limited the generalizability of the findings to other populations of women with PCOS. Third, the study's sample size was small, though the data were rich and detailed. As with many qualitative research exploring quality of life among women with PCOS, no validated quality of life questionnaire was administered.

Significance

The prevalence of PCOS is increasing especially in Malaysia (Goh et al., 2022). Although researchers have explored the knowledge, prevalence, and health-related practices among women in the urban areas of Malaysia, little research has been done on the quality of life of women with PCOS in Malaysia. PCOS has been shown to negatively

affect quality of life yet the literature has demonstrated that the psychological implications of PCOS are underestimated and very much ignored (e.g., Barnard et al., 2007; Li et al., 2011; Ligocka et al., 2024; Patel, 2022; Sanchez-Ferrer et al., 2020; Tabassum et al., 2021; Williams et al., 2016). The manifestations of the impact of PCOS varied from hirsutism to irregular menstrual cycle to body weight and acne concerns to infertility (Brady et al., 2009; Guo et al., 2023; Panico et al., 2017; Spritzer et al., 2022). Because PCOS has been associated with decreased fertility, many women have reported it to be the most distressing aspect of their PCOS diagnosis (Balen et al., 2016) which also suggested that women's perceptions of infertility may be exaggerated (Fossey et al., 2023). This study explored from a qualitative in-depth approach how the quality of life of women in Malaysia are affected. The findings from this research add to the current body of evidence on useable knowledge that healthcare providers, educators, and stakeholders could take into consideration to optimize both clinical responses and help overall well-being for women with PCOS in Malaysia.

Summary

This chapter introduced PCOS as an endocrine disorder or disease and provided background on several factors that might affect the quality of life in women with PCOS. The research question as well as the theoretical framework were addressed together with the nature of the study. The definitions of terms used were also introduced in this chapter and are discussed further in the next chapter. Finally, this chapter also presented the assumptions, scope, delimitations, and limitations of this study.

Chapter 2: Literature Review

Introduction

PCOS is a complex disease with varied clinical presentation, characterized by chronic anovulation and hyperandrogenism (Escobar-Morreale, 2018; Saei Ghare Naz et al., 2019; Tabassum et al., 2021). In addition, PCOS has also been associated with reproductive disorders and cardiovascular disturbances such as insulin resistance, hirsutism, obesity, hypertension, diabetes and dyslipidemia (Barber et al., 2019). These comorbidities coupled with other changes, such as endothelial dysfunction and chronic low-grade inflammatory state, contributed to a woman's higher risk of developing cardiovascular diseases and increased all-cause mortality observed in women with PCOS (Wild, 2002). Although the exact pathophysiology of this heterogeneous disease is unknown, it was thought to be the product of complex interactions between environmental, metabolic, and genetic factors. PCOS was known to have a major negative influence on a woman's quality of life, fertility, and long-term prognosis in addition to causing severe psychological distress and emotional issues (Tabassum et al., 2021). These include the increased likelihood of women with PCOS suffering from depression, nonalcoholic fatty liver disease, obstructive sleep apnea, and several types of cancer (Light et al., 2021; Luan et al., 2022). Women with PCOS were highly likely to report severe and long-term challenges in managing body weight, as well as a wide range of mental health concerns and negative effects on relationships, job, and social life (Hillman et al., 2020). Although studied significantly in other parts of the world, past and existing literature failed to provide adequate data on the impact of PCOS on the quality of

life of women diagnosed with the disorder (e.g., Brady et al., 2009; Coffey & Mason, 2003; McCook et al., 2005), which could in turn affect comprehensive care for those diagnosed. As there is also no data about the experiences of PCOS in Malaysian women, this study was therefore designed to shed light on the quality of life of women with PCOS in Malaysia.

In this chapter, I present the approach taken to conduct a comprehensive literature search. I discuss the strategy employed to ensure a thorough review of existing literature, followed by an overview of the conceptual framework adopted to encompass key concepts relevant to the study. A comprehensive overview is provided on the definition of PCOS, its diagnostic criteria, prevalence, and associated symptoms of PCOS. The chapter concludes by identifying gaps in the existing literature, emphasizing the necessity and relevance of this research study.

Literature Search Strategy

In order to obtain an inclusive and comprehensive understanding of the literature on this topic of quality of life in women with PCOS, I used a variety of different sources and subjects/keywords. PsycINFO and SAGE were among the specific psychological databases used. I also utilized Google Scholar and PubMed to search for articles that are more inclined towards healthcare as opposed to purely psychology-only databases. Through these databases, I was able to review literature that were peer-reviewed and other earlier publications. The extensive search in the databases revealed most articles that presented evidence for quality of life in women with PCOS did not focus on women

in Malaysia. It was also important to identify the literature terminology on quality of life in women with PCOS to ensure that the information is consistent across my research.

The search criteria included the keywords *polycystic ovarian syndrome* or *PCOS*, *mental health*, *quality of life*, *health-related quality of life*, *depression*, *anxiety*, and *women's health*. I also specified qualitative methods to better understand the methodology that was adopted by past research. Additionally, the reference lists of selected articles were also used to expand my search for other current literature. A handful of research that performed a systematic review and meta-analysis of published literature from various databases were able to provide insight to what has been discussed in past literature and helped us to better understand the problem and identify gaps.

Conceptual Foundation

This study was guided by Wilson and Cleary's model of health-related quality of life (1995) as it offers a clear understanding of the variables influencing health-related quality of life and clarified the relationships among them. By presenting a linear sequence of causal links along a causal pathway that starts at the bio-physiological level and moves outward to the subjective level and the interaction of the individual as a social being, the model was able to focus on relationships among various health domains. Given its robustness, the Wilson and Cleary health-related quality of life model appeared to be the most popular and suggested model for research on health-related quality of life (e.g., Bakas et al., 2012; Ojelabi et al., 2017).

A systematic review of health-related quality of life models by Bakas et al. (2012) demonstrated that the Wilson and Cleary model was specific to health-related quality of

life, and was adequate, clear, and consistent, and that it could be used with individuals of any age, health status, or cultural background. It was also demonstrated that the Wilson and Cleary model was logical enough for practical use and how it could lead to hypotheses that provided physicians a more comprehensive understanding of health-related quality of life than just biological factors and symptoms (Ojelabi et al., 2017). Their underlying presumption is that the best clinical interventions will be designed when the relationships between these concepts are understood.

Biological and Physiological Factors

The assessment of biological and physiological factors focuses on the functions of cells, organs and organ systems (Wilson & Cleary, 1995). These included for example, diagnoses of inflammatory bowel disease, polycystic ovaries, or breast cancer; laboratory values such as serum hemoglobin or in the case of women with PCOS, elevated testosterone or HbA1c levels (Lerchbaum et al., 2013); measures of physiological functioning like electrocardiogram examination or pulmonary function tests; and lastly, physical examination findings such as hirsutism, acne, alopecia, or goiter. The clinical factors included those that have a general impact on health but are mediated by modifications to the functions of cells, organs, or organ systems.

Symptoms

Symptoms are a “patient’s perception of an abnormal physical, emotional, or cognitive state” (Wilson & Cleary, 1995). Even though biological functions are frequently linked to symptoms, they are in fact different. Sometimes biological changes result in symptoms, and other times there are no biological explanations for the

symptoms such as depression which may not be clinically traceable to physiologic abnormality (Ojelabi et al., 2017). Because of these characteristics, each person's symptoms could vary completely from another who is going through the same illness process hence measuring the impact of symptoms on overall quality of life is crucial. Clinicians may in turn be able to better address the clinical and nonclinical factors associated with reported symptoms based on research that explored additional plausible determinants of patient-reported symptoms (e.g., psychological and social factors, patient expectations, and elements of the physician-patient relationship; Wilson & Cleary, 1995).

Functioning

The next level that follows symptoms is functional status which assesses the ability of the individual in performing specific tasks such as walking upstairs (Wilson & Cleary, 1995). Similar to symptom status, functional status is an important point of integration and it is also important to note that other patient-specific factors such as personality and motivation play an integral role in determining the ability of an individual to function at a higher level. This is why the four domains of functioning that are commonly assessed include physical, role, social and psychological function (Wilson & Cleary, 1995). Although physical functioning is an important aspect within quality of life, most quality of life studies for women with PCOS did not measure function as a separate variable from quality of life. For example, the use of SF-36 which is one of the most acknowledged and frequently used instruments to measure quality of life, is also frequently referred to as a measure of functional status, both physical and mental. Hence it gives the perception that health-related quality of life and functional status are

synonymous to many researchers. Whilst findings from past studies have been consistent in concluding lowered quality of life in women with PCOS, the evidence also suggested that the poor quality of life is most likely due to obesity (Moghadam et al., 2018). Similarly, Panico et al. (2017) found that body-mass index (BMI) is a predictor of physical functioning score in women with PCOS.

General Health Perceptions

The fourth link in the model is general health perceptions which is a subjective rating integrating all the previously mentioned health concepts as well as others that may not be depicted in the model, for example, mental health (Wilson & Cleary, 1995). Since general health perceptions appeared to be the best predictor of the use of general medical and mental health services, it enabled the individual to synthesize all the concepts discussed previously, assigning a value to each component. Even if it has been demonstrated to be linked to functional status, the clinical severity will unavoidably cause significant variations in the relationship to biological and physiological factors within each stratum. According to Ferrans et al. (2005), general health perception is commonly measured using a single global question that rates overall health on a Likert-type scale. By including general health perceptions, it is able to not only summarize biological function, symptoms, and functional status but also individual characteristics, environmental characteristics, and other unidentified antecedents of quality of life that can be included in a conceptual model of quality of life. Given how the concept of “quality of life” is so complex, the inclusion of general health perceptions may have contributed to explaining some aspects of quality of life that other instruments are unable

to measure. In the case of women with PCOS, it was found that stronger illness identity and greater perceived consequences were associated with greater psychological distress (Light et al., 2021). This is particularly important from a clinical standpoint as the awareness of the impact of these health perceptions on self-management behavior could help form interventions aimed at improving coping strategies, self-management, and health outcomes for women with PCOS (Fossey et al., 2023).

Literature Review Related to Key Concepts

The key concepts that contributed to the understanding of the health-related quality of life of women with PCOS included factors or symptoms affecting quality of life and the outcomes of such symptoms and/or experiences. The factors described below also explored how PCOS is derived or diagnosed and how understanding each factor is pertinent in explaining the level of health-related quality of life in women with PCOS.

Definition and Diagnosis of PCOS

Whilst it is one of the most common endocrine and metabolic disorders in premenopausal women (Escobar-Morreale, 2018), there is unfortunately no international consensus on the definition of PCOS to date. For the same reason attributed to its diverse clinical and metabolic manifestations, there is still much debate over what set of symptoms constitutes a PCOS diagnosis. There is also no consensus on biochemical or imaging indicators for the clinical diagnosis of PCOS (Lujan et al., 2008). A study by Douglas et al. (2021) discussed how PCOS did not have a single diagnostic criterion sufficient for diagnosis and that the prevalence of PCOS varies depending on diagnostic criteria used. In addition, it was indicated that despite finding associations in some mental

health disorder, there are still a number of complexities involved in assessing the relationship between PCOS and mental health disorders.

Findings from past studies have shown that when confronted with the stressful symptoms of PCOS, adolescents showed coping responses such as escaping the problem, depressive mood or coping with the disorder (Saei Ghare Naz et al., 2019). This once again stresses the importance of identifying the ways through which these adolescents cope with their syndrome is vital for recognizing the mental health needs of PCOS patients and improving their quality of life. For women with PCOS, coping with the condition, fears surrounding infertility, loss of femininity and sexuality, body image concerns and lowered self-worth typically contribute to poorer mental health outcomes (e.g., Light et al., 2021).

Diagnosis Criteria

The Rotterdam criteria appears to be widely used for the diagnosis of PCOS (Benetti-Pinto et al., 2015) which is also commonly recommended by the American Academy of Family Physicians Guidelines in 2016, the Endocrine Society in 2013, and the International Evidence-based Guideline for the Assessment and Management of Polycystic Ovarian Syndrome in 2018. According to these criteria, a woman must have at least two of the three requirements for PCOS diagnosis, which include having oligo- or anovulation, clinical or biochemical hyperandrogenism, and/or ovarian cysts by ultrasound. Additionally, other hormonal conditions should be ruled out (Williams et al., 2016). This is also in line with the CDC's (2022) diagnostic standards for PCOS.

Given how varying PCOS diagnostic criteria resulted in confusion as well as compatibility for PCOS research globally, the National Institutes of Health (NIH) consensus panel then recommended the use of four phenotypes as proposed by Azziz et al. (2006). These included Phenotype A: HA (clinical or biochemical presence) + OD + PCOM; Phenotype B: HA + OD; Phenotype C: HA + PCOM; and Phenotype D: OD + PCOM (see Table 1).

Table 1

Classification of PCOS Phenotypes Based on Diagnostic Features

| Phenotype | HA | OD | PCOM | NIH 1990 | Rotterdam 2003 | AE-PCOS 2006 |
|-----------|---------|---------|---------|----------|----------------|--------------|
| A | Present | Present | Present | Yes | Yes | Yes |
| B | Present | Present | Absent | Yes | Yes | Yes |
| C | Present | Absent | Present | No | Yes | Yes |
| D | Absent | Present | Present | No | Yes | No |

Note. HA = hyperandrogenism; OD = ovulatory dysfunction; PCOM = polycystic ovarian morphology; NIH = National Institutes of Health; AE-PCOS = Androgen Excess & PCOS Society. This table was developed by the researcher based on Lizneva et al. (2016).

Studies have indicated that the proposed phenotypic approach is very useful for epidemiologic research and clinical practice. Despite the ongoing debate over the reliability of the current PCOS criteria, phenotypic classification enabled the identification of PCOS populations based on the presence or absence of key characteristics. For example, in clinic practice, it would be beneficial to identify the PCOS patients with “classic” phenotypes (i.e., Phenotypes A and B) who are most at risk

for metabolic dysfunction (Azziz et al., 2006). The use of this classification also allowed researchers to categorize their findings on a limited number of PCOS phenotypes, allowing comparisons with other well-defined PCOS populations (Lizneva et al., 2016). For example, in some, but limited studies on phenotype prevalence and health related quality of life, it was found that PCOS women with Phenotype A had serious impairments in their health-related quality of life especially in the menstrual and emotional domains (Naous et al., 2023). This suggested that classification can be useful when conducting epidemiologic research and clinical trials as the outcomes from such studies can provide the necessary interventions to greatly improve the quality of life of women with PCOS; for example, weight loss and anti-androgen therapies would benefit Phenotypes A and B, whereas fertility enhancement combined with menstrual regulation would help improve the quality of life for Phenotype D (Li et al., 2022).

Prevalence

According to recent studies, the global prevalence of PCOS ranged from 2.2% to 48% which included nations like India, Australia, the United States, Iran, and China (Deswal et al., 2020; Goh et al., 2022; Yin et al., 2021). Despite such high prevalence, PCOS continues to be underdiagnosed. Furthermore, information regarding the prevalence and severity of PCOS was still lacking in many areas of the world, especially in low-income and middle-income regions in Asia. In Malaysia, the focus of the proposed study, a 2022 study by Goh et al. reported a prevalence rate of 10.49% for women previously diagnosed with PCOS and 2.48% who are currently diagnosed based on a self-guided, close-ended and structured questionnaire that was adapted from an earlier study

by Lin et al. (2018). The results from the study by Goh et al. (2022) also revealed that 32.93% of the respondents were suspected of PCOS. These findings suggested that the prevalence of PCOS in Malaysia was lower than the 48% reported global prevalence rate. A similar prevalence study carried out at University Putra Malaysia by Dashti et al. (2019) revealed a comparable prevalence rate of 12.6%. As prevalence estimates of PCOS are dependent on the criteria used to define and/or diagnose PCOS, it is important to note that because three diagnostic criteria, including the Rotterdam criteria, the NIH criteria, and the AE-PCOS criteria, were used to diagnose PCOS, the prevalence rate varied from study to study. Although the Rotterdam criteria is one of the diagnostic tools that is preferred and acknowledged globally, it also has the highest prevalence when compared to other diagnostic tools (Balen et al., 2016; Wolf et al., 2018).

Considering how the prevalence of PCOS and the knowledge or understanding of its symptoms, prevention, complications, and management vary greatly in different geographical locations and population groups, it is important for local governments to place more efforts in increasing awareness. In Malaysia especially, where access to healthcare can be limited in the rural and low socioeconomic populations, such information could aid in the creation of community-based educational programs and management guidelines which could in turn lead to early diagnosis and treatment for PCOS (Ismayilova & Yaya, 2022) thereby improving their quality of life.

Symptoms of PCOS

Studies have shown that PCOS has a negative impact on women's health-related quality of life and is also a major cause of psychological morbidity (Light et al., 2021;

Tabassum et al., 2021). It has also been reported that it affects the health-related quality of life of women in various ways, encompassing physical, psychological and social dimensions. Women with PCOS tend to suffer from several symptoms that are uncomfortable, unbearable, unpredictable and are often associated with certain characteristics that are culturally defined as undesirable and unfeminine (Barnard et al., 2007; Fossey et al., 2023). Additionally, PCOS is also associated with biochemical disturbances which can in turn affect their mood, indicating that women with PCOS have a higher tendency of suffering from emotional distress compared to control groups (Moghadam et al., 2018). The inability of these women to conform to “social standards” appears to have been widely mentioned in academic publications and is one of the main contributing factors to lowered quality of life in women with PCOS (Light et al., 2021).

Physical Health

The clinical presentation of PCOS includes a variety of symptoms, leading to its variable manifestation among those affected. A key feature of PCOS is hyperandrogenism, where there is an excess of male hormones, particularly androgens. Diagnosing PCOS typically involves identifying hyperandrogenism alongside other criteria such as irregular menstrual cycles, ovarian cysts, and related reproductive issues (Escobar-Morreale, 2018). The physical symptoms of PCOS are diverse and can be observed in various ways. Common symptoms include hirsutism, which is excessive hair growth due to high androgen levels, and insulin resistance, where cells are less responsive to insulin, causing metabolic issues and increasing the risk of conditions like Type 2 diabetes (Azziz et al., 2016; Brady et al., 2009; Tabassum et al., 2021). Women

with PCOS who had higher levels of insulin resistance and higher BMIs were associated with both acute and chronic depression (Yin et al., 2021). A study by Moghadam et al. (2018) also found that obesity was a significant contributor to poor quality of life which could be mostly due to its association with negative psychological symptoms. The excessive body weight in individuals diagnosed with PCOS and their prolonged effort to shed it can also negatively affect their self-esteem (Nasiri-Amiri et al., 2018). This is especially true and widely reported as the main concern for adolescents diagnosed with PCOS (Rowlands et al., 2016; Tabassum et al., 2021). Lin et al. (2018) found that women with PCOS struggled to adhere to dietary and physical activity recommendations given to them and that they had an increased risk of eating disorders given the propensity for obesity in PCOS. This in turn led to a higher likelihood of women with PCOS engaging in maladaptive dietary practices, such as smoking, fasting, or using laxatives and diuretics (Krug et al., 2019; Moran et al., 2017).

In addition to obesity, hirsutism and acne are other physical aspects which are common predictors of health-related quality of life in women with PCOS (Nasiri-Amiri et al., 2018). Hirsutism can be found in nearly 70% of women suffering from PCOS (Mohammad & Seghinsara, 2017) and has been shown to predict feelings of irritability, sadness and anxiety (Spritzer et al., 2022). This, coupled with body image concerns and loss of femininity may easily contribute to poorer mental health outcomes and decreased quality of life (Prathap et al., 2018; Yin et al., 2021). Older qualitative studies with thematic analysis reported that women with PCOS labelled “freakishness” as a

predominant theme (e.g., Kitzinger & Willmott, 2002), reflecting once again their perceived inability to conform to the norms.

Another important and common component of physical health in women with PCOS is infertility and irregular menstrual cycles, such as infrequent (oligomenorrhea) or absent (amenorrhea) periods which can be distressing and impact their reproductive health. This in turn leads to a decrease in the quality of life for these women, as the aspiration to have a child is highly significant for many of them. It symbolizes the fulfillment of their dreams and the reinforcement of family bonds with their partners (Ligocka et al., 2021). A study by Sulaiman et al. (2017) revealed that infertility affects 38.4% of women with PCOS. Additionally, women with PCOS are also at risk of neonatal, maternal and fetal complications (Balen et al., 2016). This then inevitably gives rise to the prevalence in both anxiety and depressive symptoms in women with PCOS (Almeshari et al., 2021; Chaudhari et al., 2018).

Psychological Well-being

Women with PCOS inevitably face significant challenges related to their mental health and emotional well-being. The chronic nature of the condition and its diverse symptoms can have profound psychological impacts. The less visible challenges of PCOS include dealing with societal misconceptions, enduring stigmatization, and managing the intricate relationship between physical and mental health. For example, it has been reported that women with PCOS experience heightened levels of emotional distress (Chaudhari et al., 2018). Research indicates that the prevalence of anxiety and depression is significantly higher in women with PCOS compared to those without the condition

(e.g., Almeshari et al., 2021; Chaudhari et al., 2018; Douglas et al., 2021; Habib et al., 2021; Light et al., 2021). The symptoms of PCOS such as hirsutism, menstrual irregularity and infertility have been shown to be the most distressing symptoms in adult women with PCOS (Almeshari et al., 2021; Balen et al., 2016), whereas difficulty losing weight have been identified as the most distressing symptom in adolescents and younger women with PCOS (Kitzinger & Willmott, 2002; Rowlands et al., 2016; Saei Ghare Naz et al., 2019). As a result of this, the prevalence of anxiety, depression and low self-esteem is high in women with PCOS (Barnard et al., 2007; Gnawali et al., 2021). It has also been reported that women with PCOS have lower self-esteem, negative self-image, loss of femininity, reduced perceived sexual attractiveness (Kitzinger & Willmott, 2022; Wang et al., 2023) and have higher levels of depression and psychological distress owing to the physical appearance characteristics of PCOS. In addition, societal beauty standards frequently worsen these challenges by promoting unrealistic expectations, which can be especially distressing for individuals with PCOS (Dewani et al., 2023). While PCOS may not only be induced by psychosocial factors, its main symptoms such as infertility, menstrual irregularities, hirsutism and obesity can also be caused by increased psychosocial stress and mood disorders (Wang et al., 2023).

Hollinrake et al. (2007) found that depression was associated with increased sympathetic activity, increased cortisol levels and decreased serotonin levels in the central nervous system, which, coincidentally, are also similar features associated with insulin resistance. Findings from an older study by Rasgon et al. (2003) suggested that higher levels of insulin resistance and higher BMIs were associated with depression and

anxiety in women with PCOS. Studies have shown that anxiety often leads to social withdrawal, a diminished quality of life, and a higher likelihood of other mental health issues (Hasan et al., 2022). The chronicity of PCOS means that women with the condition have to manage lifelong symptoms and uncertainties regarding their health, fertility, and physical appearance. This constant state of health vigilance can potentially lead to persistent feelings of hopelessness and helplessness, contributing to the development of mood disorders (Li et al., 2011; Lin et al., 2018; Yin et al., 2021). Because women with PCOS frequently experience anxiety symptoms, it tends to escalate alongside the progressive onset of hyperinsulinemia and hyperandrogenism (Chaudhari et al., 2018), which are characteristic of PCOS. This parallel increase in anxiety is also observed with the hormonal imbalances seen in PCOS patients.

The role of hormones in PCOS such as altered luteinizing hormone, follicle stimulating hormone, insulin resistance, and a potential predisposition to hyperandrogenism have been identified as key components in the development of PCOS (Escobar-Morreale, 2018). The interaction of hormonal factors not only leads to the defining symptoms of PCOS but also has significant long-term health consequences. While it may not be the focus of this study, it is however worthwhile to note that understanding the crucial role of hormones, particularly insulin resistance and hyperandrogenism, is essential for creating targeted treatments and interventions to address the hormonal imbalances that characterize PCOS. This can then in turn help to improve stress management and coping in women with PCOS, as the need for ongoing medical treatments and lifestyle changes can be stressful and affect overall mental health.

Social Life

The psychosocial effects of PCOS can significantly influence personal relationships, impacting both romantic and family dynamics. Fertility issues, frequently faced by those with PCOS, may put pressure on relationships and lead to emotional strain. The difficulties of fertility treatments and the unpredictability of conception can further exacerbate relationship tensions (Tabassum et al., 2021). Infertile women experience not only societal pressure but also feelings of shame due to internalized responsibilities (Yao et al., 2018). In the cultural context of China, where there is a strong emphasis on having children, women with infertility often avoid conversations about reproduction (Batoool & de Visser, 2014). Family members' comments or behaviors, even if unintentional, can exacerbate feelings of shame and self-harm among these women. Similarly, according to Islamic beliefs, marriage primarily serves the purpose of procreation and establishing a family. Consequently, infertile women experience significant pressure to conceive, potentially impacting them more than women from Western cultures (Taghavi et al., 2015). The Islamic Pakistani female participants from an older study strongly felt that their ability to bear children affects how they are treated, garnering more respect when they have children (Fido & Zahid, 2004). Infertility is perceived as a physical disability, leading these women to feel they have a physical imperfection.

Recent reports have also indicated that infertile women with PCOS exhibited notably higher depression scores and greater body dissatisfaction compared to those with infertility from other causes, highlighting additional factors related to PCOS beyond

infertility (Azziz et al., 2016; Rowlands et al., 2016). Studies have shown that cultural differences shape perceptions of fertility, body image, and gender roles, affecting how PCOS is viewed in different communities (Dewani et al., 2023; Taghavi et al., 2015; Wang et al., 2023). The societal pressure to meet expectations of femininity and fertility can heighten the emotional strain on individuals with PCOS, leading to feelings of inadequacy and isolation. This further emphasized the need to recognize and address the emotional burden on both the individuals affected and their partners to provide comprehensive support and encourage open communication in relationships affected by PCOS.

In women with PCOS, the visible symptoms can make them feel self-conscious and dissatisfied with their appearances. Studies have shown that women with PCOS reported lower body image satisfaction and higher body dissatisfaction compared to women without the condition (Alur-Gupta et al., 2019; Bazarganipour et al., 2013). The societal emphasis on being lean and slim, with clear skin can intensify these feelings, leading to social withdrawal and a decrease in overall quality of life. Moreover, the struggle with weight management is particularly challenging for women with PCOS due to the metabolic issues associated with the condition, which can make losing weight difficult despite efforts in diet and exercise (Barber et al., 2019). It is for these reasons that women with PCOS are more highly likely to avoid social interactions due to embarrassment or fear of judgment about their appearance. This social withdrawal can lead to feelings of loneliness and isolation, further exacerbating emotional distress (Dewani et al., 2023). In addition to that, women with PCOS may feel isolated due to a

lack of understanding and support from family and friends, who may not fully grasp the chronic and multifaceted nature of the condition (Ismayilova & Yaya, 2022). This once again emphasized the need for effective coping mechanisms, because many women continued to struggle to find the right balance, leading to a negative impact on their overall mental health.

Health-Related Quality of Life in PCOS

The clinical manifestations of PCOS, including obesity, infertility, hirsutism, and hormonal and biochemical imbalances have been extensively documented. These symptoms are frequently associated to a decline in a woman's sense of self and self-worth, which may in turn have an impact on her health-related quality of life, especially when it comes to the psychosocial domains (Sanchez-Ferrer et al., 2020; Taghavi et al., 2015). Following a PCOS diagnosis, it is common for PCOS patients to experience multiple hospital appointment and tests which adds to their anxiety (Bazarganipour et al., 2013). In addition, research has also shown that women with PCOS have lower health-related quality of life, marital and social problems, depression, and suicidal thoughts (Taghavi et al., 2015). This number is significantly greater than what the general public reports and comparable to that of people with various chronic medical conditions (Taghavi et al., 2015).

Culture and society can shape what an illness means to an individual. Although health-related quality of life is a subjective perception of well-being, it has been argued that one's perception may be influenced by cultural and ethnic factors such as social norms, values and beliefs (Moghadam et al., 2018). For example, in Turkish women with

PCOS, it was found that irregular menstrual cycles and hirsutism had the largest impact on quality of life (Acmaaz et al., 2013). In Iran, Bazarganipour et al. (2013) reported that menstrual irregularities and infertility were the most common quality-of-life concerns followed by hirsutism, weight, emotional concerns and acne. For women with PCOS in Brazil, body weight and infertility had the largest negative impact on quality of life (Benetti-Pinto et al., 2015). A more recent study by Ligocka et al. (2024) found a significant association between lowered quality of life and the inconveniences caused by PCOS symptoms. The women from the study that reported lower quality of life acknowledged the impact of PCOS on their lives, experienced a lack of control over the disease, struggled with depression, and were not able to accept their physical appearance. These studies collectively demonstrate the negative impact of PCOS on health-related quality of life, how this condition impacts a woman's quality of life and how the condition manifests differently across the globe. The results of these studies also highlighted the importance of healthcare practitioners taking a more holistic approach to patient care beyond treating just the physical symptoms. In addition, by adopting a qualitative approach to studies will provide women with PCOS the opportunity to express their individual concerns about health-related quality of life issues (Taghavi et al., 2015) which will vary across cultures and societies.

Summary and Conclusions

PCOS is a complicated condition that has a negative impact on an individual's quality of life. In this chapter, I have provided an overview of the current research on several factors that could contribute to affecting a woman's quality of life. There is

substantial research that explored factors related to disease perceptions and mental health experiences that impact the quality of life in women with PCOS. These factors shed light on what women with PCOS may experience around the world. Previous studies have shown that participants are likely to experience a wide range of mental health and relationship problems that has also negatively impacted employment and social life, as well as significant and ongoing difficulties in regulating body weight. The findings of several studies also showed that the adverse effects of PCOS on their appearances such as hirsutism, alopecia, and acne were the main concerns of women with PCOS, especially those of adolescent age. Additionally, the prolonged treatment process, concerns about the uncertainty of the disease, and complications of the treatment options were among other factors negatively influencing the psychological state of these women. Although the prevalence of PCOS has been reported to be from 2.2% to 48%, research on the quality of life of women with PCOS have been mostly from nations like India, Australia, the United States, Iran, Europe and China. There was a limited amount or no studies that discussed quality of life of women with PCOS in Malaysia, especially qualitative data. As a result, considering the current prevalence of about 12.6% in Malaysia, the focal point of my study was to explore the quality of life of women with PCOS in Malaysia.

The following chapter will discuss the rationale and design choice for this study which also detailed the sampling strategy, target population and the method for recruiting participants. In addition, I discuss the use of IPA, which served as an aid to understanding the method in which the interview data were analyzed. Finally, the issues of

trustworthiness of this study are discussed together with ethical considerations and the necessary steps taken to uphold ethical integrity at every point in this study.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological study was to explore the quality of life of women with PCOS in Malaysia. The study aimed to explore how this population perceived factors that affected their quality of life. Health-related quality of life was defined as an individual's self-perception of their physical and mental health over time in the context of the culture and value system in which they live (Koller & Lorenz, 2002; Tabassum et al., 2021; Yin et al., 2016). This chapter provided details on the research design and approach used for this study, as well as specific methods on participant selection, data handling, and the analysis plan. These were accomplished by following the principles of trustworthiness and ethics, which are also covered in this chapter.

Research Design and Rationale

This study explored the factors affecting the quality of life of women with PCOS in Malaysia. The central phenomenon of this study was the various types of symptoms experienced by women with PCOS, which include significant physical, mental, and body image issues, that are in turn associated with lowered emotional and health-related quality of life. Considering how PCOS is classified as a complex disorder or disease, many of the symptoms that women with PCOS commonly experience are often overlooked or misdiagnosed.

The research question that guided this research process is as follows:

RQ: What is the health-related quality of life of women with PCOS in Malaysia?

The current literature on PCOS amongst Malaysian women discusses information on prevalence, knowledge, and health-related practices; however, limited or inexistent data inform the quality of life of women with PCOS in Malaysia. Similarly, many studies on the quality of life in women with PCOS elsewhere are of a quantitative nature, especially in those with larger sample sizes (e.g., Barnard et al., 2007; Ligocka et al., 2024; Sanchez-Ferrer et al., 2020; Tabassum et al., 2021). It can be challenging to measure health-related quality of life, and while general questionnaires can be used to measure the quality of life of women with PCOS, most surveys are, however, not very sensitive to the unique aspects of PCOS on women's health (Nasiri-Amiri et al., 2018). Therefore, through this study, I used IPA to understand the factors affecting the quality of life of women with PCOS in Malaysia. IPA is a well-known qualitative method that was created to investigate individuals' lived experiences. It is focused on the unique experiences that people have and how they interpret those experiences in relation to one another. Rather than being a theory-driven analysis, IPA is collaborative since it investigates experiential meanings through the interpretive effort between the researcher and the participant (Smith & Fieldsend, 2021).

The use of the phenomenological approach enables a researcher to be part of the co-creation of the participant's meaning-making (Love et al., 2020), which is essentially a detailed focus on the participant's subjective lived experience(s). In this study, the approach provided an understanding of the subjective experiences of the respondents in relation to their quality of life. Given how the analytical process of IPA is concerned with an inductive analysis of each participant's account, this approach was well-suited to a

small, homogenous sample of individuals who had similar experiences, whereby their idiographic accounts could be highlighted while also accommodating commonalities across the group (Smith & Fieldsend, 2021). In that sense, the interview method has been reported to be the most favored and feasible approach by which to capture such accounts. While interviews can generate a large amount of data, this disadvantage can be minimized by utilizing semi-structured, in-depth interviews which are widely employed by healthcare professionals in their research (Jamshed, 2014). Semi-structured interviews are based on a semi-structured interview guide, which is typically a schematic presentation of questions and/or topics that need to be explored by the interviewer (Dicicco-Bloom & Crabtree, 2006). In order to maximize the interview time, the interview guidelines served as a useful tool by allowing me to explore a large number of respondents in a more methodical and thorough manner as well as maintain the interview's focus on the intended course of action.

Role of the Researcher

The role of the researcher “is to attempt to access the thoughts and feelings of study participants” (Sutton & Austin, 2015). As the researcher in this study, I utilized an IPA design to explore the quality of life of women with PCOS in Malaysia. This also included my responsibility to obtain the necessary approvals from the institutional review board (IRB) role, develop the surveys, manage the recruitment of participants for the research, as well as analyze and present the findings. The main data source was responses collected from semi-structured interviews, which were performed via the online meeting platform Zoom.

It is important that the integrity of the research equals the integrity of the researcher in that, given the (qualitative) nature of the study, the credibility, dependability, and transferability actually rely on the researcher. In being able to monitor and reduce bias, I ensured that I remained conscious of my previous knowledge and was able to control the intrusion of bias in interpreting the responses. My experience as someone with PCOS piqued my interest in understanding the quality of life of other women with PCOS in Malaysia, which could be a potential for bias. At the start of my working life, I experienced anxiety, susceptibility to stress, drastic hair loss, fatigue, and a rollercoaster of emotions, amongst others. Some days I felt like I was emotionally exhausted, and some other days I felt a lack of personal accomplishment. Unfortunately, I had no one to share these feelings with, medically or emotionally. I could not understand what was going on with my body, and I did not understand the importance of mental health. It was not until my diagnosis of PCOS several years later that I started putting the pieces of the puzzle together. As I then continued working in the field of preventive medicine, I started observing symptoms from other women that were similar to the ones I experienced. I also saw patterns in the affected quality of life for others with far worse and different symptoms. These differences in presentation and individual symptoms of PCOS is what drove my interest to explore the quality of life in women with PCOS other than myself.

The participants were recruited via social media through friends and family throughout Malaysia. They were invited to participate if they were able to fulfill the criteria for a confirmed PCOS diagnosis. During the recruitment process, I ensured that

the study was explained without biasing potential participants and that the interviews were conducted as per the planned design. The interview was guided by a combination of closed and open-ended questions, as it was important for me to not only be open and honest with the participants as a researcher but also to cultivate a positive rapport with them to allow the conversations to flow naturally. After each interview, I ensured that the participants' confidential information, interview notes and recordings, and transcription were stored and saved securely in my laptop which is also password protected. It was also my responsibility to ensure that all data will be destroyed 5 years after completion of my study.

Methodology

Participant Selection Logic

The target participants for this research were Malaysian women with PCOS who met the following criteria:

- self-reported having been diagnosed with PCOS, and having met the 2003 Rotterdam Criteria (Benetti-Pinto et al., 2015) which are two of the following three criteria: (a) irregular or absent ovulation, (b) clinical and/or biochemical signs of hyperandrogenism, and (b) polycystic ovaries by ultrasound;
- suffering from PCOS with or without co-morbidity between the age group 18-45 years old (i.e., reproductive age);
- no pregnancies in preceding 6 weeks; and
- fluent in English.

Women who were pregnant, or not suffering from PCOS, or unwilling to provide signed informed consent were excluded from the research. These women were recruited through a purposeful snowballing sampling method. Considering how PCOS is not something women would openly discuss, this would be the most appropriate method to ensure these participants met the given criteria and would also refer other participants who have PCOS and/or experience similar symptoms (Palinkas et al., 2015). A total of 10 individuals were selected to participate in semi-structured interviews because, according to IPA methodology, a sample size between five and 10 is sufficient to discover the nuances and complexities of people's lived experiences (Smith et al., 2009).

Instrumentation

Past research has indicated that PCOS diagnosis in most parts of the world, let alone Malaysia, is often delayed and typically involves numerous health professionals; yet women are left confused with unmet information needs (Gibson-Helm et al., 2014). To date, despite the advancements in clinical practice, PCOS as a disorder continues to be misdiagnosed or undiagnosed, together with improper or inadequate treatment options. With that in mind, the preferred method for collecting data from the participants was via semi-structured interviews. Tools from the literature, as well as adaptations from the health-related quality of life model and PCOS questionnaires from previously published research (e.g., Gibson-Helm et al., 2017; Soucie et al., 2021), helped guide the development of the interview questions. The goal in developing the interview was to compile questions (see Appendix) that would enable the participants to evoke the lived experiences that would address the research question on their health-related quality of

life. The questions were developed first with the intention for the participant to ease into the interview, to establish persona development, and to build trust/rapport. The next few questions were aimed at trying to understand their personal experiences and thoughts towards PCOS as a condition. Following that, I wished to understand better about their diagnosis experience and how their doctors explained the diagnosis to them because studies have shown that most women with PCOS were often frustrated, confused, and lost after leaving the doctor's room with no real answers or conclusion to their problem (Ligocka et al., 2024). The flow of the questions then progressed to talking about the participants' circles of support (e.g., family, friends, partners, etc.) and how their support impacted them as individuals and whether they were given the support they needed. As much as possible, I wanted to maintain positivity within the interview and the duration of the interviews should last between 40 to 60 minutes.

Procedures for Recruitment, Participation, and Data Collection

First, I requested permission from the IRB to conduct the research. Upon IRB approval, I then reached out to my circle of friends and family around Malaysia and asked them to circulate my study flyer among potential participants. If a contact or referral was given, I then proceeded to contact the individual personally to introduce the nature of my study and to then invite them to participate in the screening process if they expressed willingness to participate. Similarly, for potential participants who contacted me by email or text, I obtained their personal email address so I could send them the informed consent as well as discuss available times to schedule the interview. Interviews

were conducted via the Zoom platform. The questions were constructed with the semi-structured approach in mind (see Appendix).

Although in-person face-to-face interviewing is often believed to be the “gold standard” in qualitative research, the issue of time, travel, and interview location accessibility may be an issue for some participants. Given these constraints, I conducted all interviews on Zoom. Similar to online video calls, this option was cheaper and more time-efficient than conducting in-person interviews, as it saved the trouble of renting or utilizing a physical interview space (Krouwel et al., 2019). In addition, it also allowed participants to respond from the comfort of their own home, which took away the feeling of unease as opposed to being in a public or an unfamiliar location. In the recruitment ad, a timeframe was also specified (i.e., a duration of 1 week for respondents to provide confirmation on research participation and to then contact me for the screening process).

During the interview process, participants were reminded at the start of their rights to refuse or withdraw from the research should they feel uncomfortable or unwilling to proceed. In addition, I assured them that no question was compulsory, that they had the option to skip questions if they wished, and had the freedom to provide as much or as little information as they liked. This helped reduce the likelihood of the participants disclosing information that they were uncomfortable sharing with other people, or which they felt may trigger uncomfortable feelings. In the event a participant appeared to be distressed, I offered to bring the study session to a close and, in my effort to calm the participant, ascertained if the participant was currently receiving any support for their distress. During this time, I also checked with the participant if any of their

family members or friends were aware of how the participant was feeling and if they had considered contacting their family physician, a general practitioner, or a professional to discuss their problems. If they were already seeking help for their distress, then I encouraged the participant to reconnect with their healthcare provider at the end of the session. Otherwise, for participants who were currently not receiving any support, I recommended that they contact any one of the medical practitioners listed on the PCOS Malaysia Association's website for psychological services, or their recommended medical doctors.

Data Analysis Plan

The primary aim of IPA was to explore in depth how individuals make sense of their lived experiences and the meanings they ascribe to them (Smith & Fieldsend, 2021). Given the complexity of PCOS as a condition affecting physical, emotional, and social dimensions of life, IPA was well-suited to this study because of its commitment to detailed, idiographic analysis and its emphasis on participants' own meaning-making. In IPA, interpretation begins from the first interview and continues throughout transcription, analysis, and reflexive engagement with the data. In line with established IPA guidelines, analysis in this study proceeded through iterative and interconnected analytic processes rather than fixed stages (Smith et al., 2009). Initially, each transcript was examined in detail to capture the essence of the participant's experience through close reading, note-making, and interpretative reflection. This idiographic focus allowed for an in-depth understanding of each woman's lived experience of PCOS. Subsequently, patterns of convergence and divergence were explored across cases through a process of comparison

and abstraction, enabling the development of shared themes while preserving individual nuance. This movement between individual meaning and cross-case interpretation reflected the hermeneutic and phenomenological orientation of IPA (Davidsen, 2013).

For this study, the lived experiences of each participant were carefully analyzed through numerous readings of the transcripts and notes and listening to the audio. I jotted down my first impressions on a separate document on what I deemed to be the essence of the participants' responses. An advantage of IPA studies is the small sample size that enabled micro-level reading of the participants' accounts (Smith & Osborn, 2015). This then offered the potential for any insight into the understanding of PCOS as a condition. During this process I had to ensure that my notes taken are reflective of what the participants said and that it is relevant to the research question guiding this study: *What is the health-related quality of life of women with PCOS in Malaysia?* Once I gained an understanding on the interview transcript, I proceeded to code the participants' experiences. This essentially involved assigning labels to sentences, sections or phrases within the transcripts that reflected aspects of their health-related quality of life. In addition, the relevance of the terms was determined by what was repeatedly mentioned or emphasized by the participants. At this juncture, I also took note of parts of the transcript if a phrase caught my attention as something unexpected or perhaps even a concept that could be worth investigating further.

Once I was able to identify the patterns in which categories were related to quality of life from all the participants' responses, I then translated and formed specific themes using abstraction. These identified themes were then reflected upon to find connections

between them (Smith et al., 2009). The broad category of themes can be refined down into two main types, “topical” themes and “overarching” themes (Bailey, 2018). This distinction is useful because it led into an important task of analysis, which is conceptualization (i.e., moving codes from particular and concrete actions to a more abstract level of concepts and ideas). It was through these themes that new knowledge about the effects of PCOS on the health-related quality of life from the lived experiences of the participants emerged. As a result, the data depicted a clearer understanding of this phenomenon from the lived-experience point of view.

Issues of Trustworthiness

To ensure data trustworthiness was maintained in this study, firstly, credibility was guaranteed by adopting the correct operational measures for the phenomenon approach used. Through this, not only were the participants transparent to the data collection method, but I also provided assurance to participants on their willingness to participate and to respond to the best of their ability. As an additional measure, participants were also offered a verbatim transcript of their interview. Second, I used bracketing as a conscious effort to identify and acknowledge personal biases, which allowed me to approach the data with greater openness and impartiality. By acknowledging and setting aside preconceived notions, researchers can enhance the rigor and credibility of their qualitative findings (Tufford & Newman, 2012). Third, I utilized peer debriefing as I consulted with my dissertation chair and committee member across every point of data collection and analysis. Doing so provided me with another perspective on my own procedures. Fourth, to ensure transferability, purposive sampling

was used to maximize specific data relative to the context, which in this case, for women with PCOS, in which it was collected. Additionally, transferability of the findings can be reinforced by making in-depth descriptions of the phenomenon being studied to enhance external validity. Lastly, to assure dependability, an audit trail was also provided which highlighted every step of data analysis that was made in order to provide a rationale for the decisions made. The analysis from the audio recordings were also reviewed repeatedly to assess my reflection on the findings and to also filter out any potential bias. Considering how there were several open-ended questions, this helped to establish that the research study's findings accurately portrayed participants' responses to ensure confirmability.

Ethical Procedures

An integral part of any research is to recognize and acknowledge the importance of data collection from people. More importantly, how, during this process the people involved are protected from any harm and/or form of exploitation. This is why from the start of this study, it was kept in mind that ethical decision-making needed to be ongoing during the research process by applying the principles of respect for persons, beneficence, and justice. Respecting study participants entailed considering the researcher's influence on the participant and the research context both during the research's execution and after it is published, as well as resolving concerns about informed consent, anonymity, and confidentiality. In addition, according to the second beneficence principle, the researcher must make sure that participant safety is prioritized above all else (Farrugia, 2019). This meant that my study's participants had the option to freely ask questions about the

research and to withdraw from it in whole or in part at any point if it makes them uncomfortable. Although participants would have signed and given consent prior to participation, it was made known to them that consent was only a process and could be withdrawn at any moment. During the interview itself, questions about self-perceived stress, mental and emotional well-being were asked, which could potentially evoke psychological distress. While the questions may pose a low risk of distress, I constantly monitored their expressions and kept a lookout for signs of possible breakdowns and allowed a short break for the participants to compose themselves. I also reminded them again of their ability to continue or withdraw from the interview should they have felt uncomfortable at that point. On that note, as the interviews took place on the Zoom platform, there was always a chance that the communications could be intercepted, so it was my responsibility to ensure that my antivirus and firewall software were up to date on my computer, and that I was working on a secure and reliable data connection. I also ensured that I conducted the interview from a private office/study space to protect the participants' identities.

Given that qualitative studies often contain rich descriptions of study participants, confidentiality breaches via deductive disclosure are of particular concern to qualitative researchers (Kaiser, 2009). While it may be close to impossible to maintain anonymity in this study, measures were taken to ensure that all personal details remained confidential. The interview transcriptions were each assigned a number rather than given a pseudonym and any other possible identifying factors like occupation and demographic information

were also generalized. All transcripts, recordings, notes, and related files or materials are stored securely in my personal computer that is password-protected.

Summary

This chapter outlined the procedures and plans for exploring the factors that affect quality of life in women with PCOS in Malaysia. The rationale was also provided for the choice of qualitative methodology and why IPA was used to address the details of the given phenomenon. A sample of 10 respondents who fulfilled the criteria of having or being diagnosed with PCOS was recruited purposively from family and friends' referrals. Within the methodology section, details for instrumentation and procedures for recruitment, participation, and data collection were also discussed. The data analysis plan also highlighted the important aspects of IPA analysis and how the framework was used to identify key themes. The following chapters discuss in greater detail how the participants' lived experiences of the effects of PCOS affected their health-related quality of life.

Chapter 4: Results

The purpose of this phenomenological study was to explore the factors that influenced the health-related quality of life of women living with PCOS in Malaysia. Using an IPA approach, this study sought to understand how women with PCOS made sense of their lived experiences in relation to their condition and its impact on their physical, emotional, and social well-being. Data were collected through semi-structured interviews with women who had been diagnosed with PCOS. The interviews provided rich, descriptive narratives that offered insight into how participants experienced, interpreted, and managed life with PCOS.

In this chapter, I describe the setting of the study, participant characteristics, data collection process, and data analysis procedures. Following that, I present the emergent themes that captured the essence of participants' experiences. These findings are supported by verbatim quotes to illustrate how the women's perspectives reflected the broader meanings within the phenomenon.

Setting

After receiving approval from the Walden University IRB (Approval No. 09-10-24-1155457, with an expiration date of September 9, 2025), I began the recruitment process. Participants were contacted through personal networks and referrals from family and friends, based on the inclusion criteria described in Chapter 3. A total of 12 prospective participants initially reached out via Whatsapp; one did not finish the interview and four did not attend the scheduled interviews. The final sample size was

seven participants. All interviews were conducted via Zoom after participants provided their consent via email or text.

Each interview lasted approximately 30 minutes and was conducted in a private and quiet setting to ensure confidentiality and allowed participants to speak freely. Prior to each interview, participants were briefed about the purpose of the study, the voluntary nature of participation, and the confidentiality of their responses. Verbal consent was obtained from all participants before data collection commenced.

I employed a semi-structured interview guide, the first section of which contained demographic questions designed to capture basic participant information such as age, marital status, occupation, and years since PCOS diagnosis. To ensure participant confidentiality, I deidentified all collected data and assigned participants the codes P01 through P07. Only these codes are used throughout this chapter when presenting quotations or examples from the interviews.

Participant Demographics

A total of seven Malaysian women residing in Malaysia participated in this study. Participants ranged in age from 29 to 50 years. The sample included both single and married women, with diverse occupational backgrounds such as administrative staff, healthcare professionals, and self-employed individuals. The duration since diagnosis ranged from approximately 3 to 13 years, allowing for a wide range of lived experiences from early diagnosis and adjustment to long-term management and acceptance of PCOS (see Table 2).

Table 2*Participant Demographic Characteristics*

| Participant code | Age (years) | Marital status | Occupation/background | Duration since PCOS diagnosis |
|------------------|-------------|----------------|------------------------|-------------------------------|
| P01 | 29 | Single | Accounting/finance | 4 years |
| P02 | 42 | Married | Business/marketing | 4 years |
| P03 | 36 | Single | Administrative | 10 years |
| P04 | 33 | Married | Nursing | 3 years |
| P05 | 34 | Single | Medical professional | 13 years |
| P06 | 50 | Single | Postgrad not specified | Couldn't recall |
| P07 | 39 | Married | Self-employed | 9 years |

Data Collection

Data for this study were collected using semi-structured, in-depth interviews, which allowed participants to express their lived experiences of living with PCOS in their own words. Each participant was provided with an information flyer outlining the study's purpose, procedures, and confidentiality measures before the interview began. Informed consent was obtained from all participants prior to participation.

The interviews were conducted over a period of 11 months following the receipt of Walden University IRB approval. I contacted participants individually and scheduled interviews at a mutually convenient time. I conducted all interviews virtually via Zoom platform, using audio-only mode, as participants expressed a preference for not meeting in person or being visible on video. This arrangement provided a sense of privacy and comfort, allowing participants to speak more openly about their personal and sensitive experiences related to PCOS. Each session took place in a quiet environment chosen by the participant to minimize distractions and ensure confidentiality.

The interviews were guided by a semi-structured interview protocol designed to elicit participants' perceptions, emotions, and coping experiences related to PCOS. The first section of the protocol gathered demographic information such as age, marital status, occupation, and duration since diagnosis. Subsequent open-ended questions explored key domains including physical health, emotional well-being, social relationships, body image, and perceptions of support systems. Probing questions were used where necessary to encourage elaboration and obtain richer descriptions of experiences.

Each interview lasted approximately 30 minutes and was audio-recorded with participants' consent. I took field notes to capture nonverbal cues, contextual observations, and researcher reflections during and immediately after the sessions. I transcribed all interviews verbatim shortly after completion. To protect participants' confidentiality, personal identifiers were removed during transcription, and each participant was assigned a unique code (P01–P07). Both digital recordings and transcripts were stored in password-protected folders accessible only to the researcher.

Data collection continued until thematic saturation was reached, when no new information or insights emerged from additional interviews. This ensured that the final dataset captured sufficient depth and variation in experiences to address the research question meaningfully.

Data Analysis

The analytic procedure followed an IPA framework as described in Chapter 3. IPA emphasizes detailed, reflective engagement with participants' accounts to understand how they make sense of their lived experiences (Smith & Fieldsend, 2021; Smith &

Osborn, 2015). In keeping with this orientation, analysis began immediately after each interview and continued throughout transcription and data familiarization. The process was hermeneutic in nature, involving a continual movement between participants' words and my interpretative efforts to understand their meanings within the broader context of living with PCOS in Malaysia.

Analysis proceeded through iterative and interconnected analytic processes rather than discrete or linear stages. Each interview transcript was transcribed verbatim and reviewed alongside the audio recording to preserve tone and nuance. Multiple readings enabled immersion in the narrative and identification of passages that captured essential aspects of each participant's health-related quality of life. Initial notes were made in a separate analytic document to record first impressions, striking phrases, emotional tone, and contextual observations.

During this phase, I produced a set of initial analytic notes for every transcript. These notes captured my first impressions, emotional tone, striking phrases, and contextual observations that appeared meaningful to the participant's lived experience. For instance, when Participant 4 shared, "Sometimes I just want to be isolated inside the room and sleep," I recorded observations about her tone and an interpretative insight that isolation functioned as a coping mechanism rather than avoidance. Another example came from Participant 2, who said, "I tried to search a lot online, but it's just too many... got irritated and frustrated." In my notes, I observed her change in speech or tone and frustration, and interpreted this as a tension between self-reliance and information overload, later informing the broader theme of diagnostic and medical uncertainty.

Alongside these notes, I also maintained reflexive memos to capture my evolving thoughts, emotional reactions, and assumptions as the analysis progressed. These memos functioned as reflective journal entries that allowed me to recognize and critically examine how my background and empathy might shape interpretation.

Through line-by-line engagement, descriptive and interpretative comments were developed to capture what the participant said and what this appeared to mean. Short labels (i.e., codes) were then assigned to phrases or sections that reflected experiences related to physical, emotional, social, or cultural well-being. These codes represented the earliest level of interpretation and were kept close to the participants' language to maintain idiographic fidelity. Within each transcript, codes sharing a common idea were clustered to form topical themes that summarized the essence of that individual's account.

Only after this in-depth within-case analysis was completed did the analysis move toward cross-case comparison. Patterns of convergence and divergence across participants were examined through abstraction and conceptualization, allowing related topical themes to be integrated into broader overarching themes that captured shared experiential meanings. This approach is consistent with IPA's idiographic emphasis and its movement from individual experience to shared meaning. Throughout this phase, I continually checked emerging themes against the original transcripts to ensure they remained grounded in participants' lived experiences. Reflexive memos were again used to document interpretative decisions and to maintain transparency in how meanings were constructed.

Evidence of Trustworthiness

To ensure methodological rigor and integrity, this study followed the four key criteria of trustworthiness which are credibility, transferability, dependability, and confirmability (Creswell & Poth, 2018; Lincoln & Guba, 1985; Nowell et al., 2017; Shenton, 2004). These principles guided every phase of the research process, from data collection through analysis, ensuring that interpretations authentically represented participants' lived experiences while maintaining transparency and reflexivity (Smith et al., 2009; Davidsen, 2013).

Credibility

Credibility was achieved through engagement with participants and iterative immersion in the data, consistent with the interpretative phenomenological approach (Ahmed et al., 2025; Smith & Osborn, 2015). Participants were informed about the study's purpose, procedures, and voluntary nature prior to their interviews, ensuring openness and honesty during data collection. At the start of the interview, I ensured that participants felt comfortable and that they were able to respond in a manner to the best of their ability with no time constraints or restrictions in their responses. Reflexivity was maintained through bracketing which is a conscious effort to identify and set aside personal assumptions that could influence interpretation (Tufford & Newman, 2012). Consistent with qualitative research best practices, I sought ongoing advice and guidance from my dissertation chair during data collection and analysis. These supervisory consultations provided external input that supported analytic transparency and strengthened the credibility of the findings.

Transferability

Transferability was supported through purposive sampling, which ensured that participants were selected based on their lived experience with PCOS, thus providing data relevant to the study's context. The sample reflected diversity in age, ethnicity, marital status, and occupation, capturing a rich range of perspectives among Malaysian women. Detailed demographic information and thick, contextual descriptions of the phenomenon have been included to allow readers to determine the potential applicability of the findings to other contexts (Creswell & Poth, 2018; Nowell et al., 2017). While IPA does not aim for statistical generalization, such in-depth contextualization facilitates naturalistic generalization (Smith et al., 2009).

Dependability

Dependability was established through a clear audit trail documenting the entire research process, from data collection to theme development. This included all reflexive memos, coding summaries, and thematic matrices that demonstrated how interpretative decisions were made and refined. Audio recordings and transcripts were reviewed repeatedly to ensure consistency between the raw data and the interpretations made. Each recording was listened to multiple times, at least five to six times at different times of the day, to ensure that no words were missed or misinterpreted, particularly given variations in accent, tone, and colloquial expression among participants. Consistent with qualitative research best practices, I engaged in ongoing consultation with my dissertation chair during the analysis process. These supervisory discussions provided analytic guidance

and oversight that supported methodological consistency and strengthened the dependability of the findings (Creswell & Poth, 2018; Shenton, 2004).

Confirmability

Confirmability was assured through reflexivity and transparent documentation of analytic decisions. The use of reflexive memos provided an outlet for examining personal reactions, assumptions, and interpretative shifts during data analysis (Davidsen, 2013). Bracketing was practiced consciously to separate preconceptions from participants' lived experiences, ensuring that themes remained grounded in their accounts rather than in researcher bias (Tufford & Newman, 2012). Consistent supervisory engagement throughout the analytic process enhanced confirmability by offering external reflection and guidance that supported the transparency and trustworthiness of the interpretations (Nowell et al., 2017; Sutton & Austin, 2015).

Results

Eight main themes and their constituent subthemes were identified from the data analysis: (a) diagnostic and medical uncertainty; (b) physical symptoms and psychological disruptions; (c) emotional burden and psychological strain; (d) physical appearance and self-confidence; (e) role strain and relationships; (f) social and cultural judgement; (g) coping and acceptance; and lastly, (h) education, awareness, and advocacy (see Table 3).

Table 3*Themes and Subthemes*

| Theme | Subthemes |
|---|--|
| Diagnostic and medical uncertainty | Conflicting medical opinions and delayed diagnosis Self-doubt and loss of trust in healthcare Searching for clarity through self-education |
| Physical symptoms and psychological disruptions | Chronic fatigue, pain and discomfort Hormonal instability and emotional distress |
| Emotional burden and psychological strain | Feelings of frustration, hopelessness, anxiety and sadness Loss of self-identity and control Emotional isolation |
| Physical appearance and self-confidence | Body image dissatisfaction and low self-esteem Embarrassment and social withdrawal Loss and rebuilding of self-esteem |
| Role strain and relationships (family/society) | Societal and familial expectations of womanhood Relational and role strain: negotiating care, conflict, and self-prioritization |
| Cultural stigma and social misunderstanding | Cultural blame and stigma Societal misconceptions Navigating judgment through silence or education |
| Coping and acceptance | Shifting mindset towards acceptance Lifestyle adaptation Drawing strength from faith or support networks |
| Education, awareness and advocacy | Seeking knowledge and self-advocacy Raising Awareness through Shared Experiences Hope for Social Change and Empowerment |

Theme 1: Diagnostic and Medical Uncertainty

This theme captures participants' confusion, frustration, and self-doubt surrounding their diagnostic journey and interactions with healthcare providers. Most of the participants described a prolonged period of uncertainty before receiving a formal diagnosis, often encountering inconsistent medical explanations or inadequate communication. The resulting ambiguity not only delayed treatment but also eroded

confidence in medical professionals and contributed to feelings of helplessness and mistrust. The three subthemes related to this theme by the participants were: conflicting medical opinions and delayed diagnosis, self-doubt and loss of trust in healthcare, and searching for clarity through self-education.

Conflicting Medical Opinions and Delayed Diagnosis

Several participants recalled visiting multiple healthcare providers before receiving a definitive diagnosis. For some, inconsistent explanations and contradictory medical advice left them feeling dismissed or misunderstood. P03 said,

Since 17 years old, I've already consulted, like, I think, a few, a few gynae specialists and even dermatologists for my acne, but most of them will just say it's a normal hormonal imbalance thing, and they just put me on meds, especially like birth control pill.

She further reflected on how different doctors had varying or conflicting explanations that did not lead to any confirmation and in turn, delayed diagnosis, "I think I already had problems dealing going through this 10 years before that." P03 also said, "GP used to say that it's very normal to have irregular periods, especially when you're schooling, because you're very stressed with exams and assignments and all that." Similarly, P04 said,

Actually, I'm not really sure it's PCOS or not, because when I saw gynae, it's kind of PCOS.... She didn't really relate it to PCOS.... Actually, I'm still doing research on it, because I didn't get a proper clarity. So I still finding, I still looking for a proper answer.

P05 said, “There were many uncertainties as most doctors would associate PCOS with infertility... not discussed and constantly dismissed.” P06 also mentioned that “actually I’ve seen a few doctors when I was younger but nobody told me it was related to PCOS. It was only until recently...that I started to connect the pieces of the puzzle together.” In addition, P02 shared that during her first diagnosis, she was feeling a little scared and worried thinking that it might affect her chances to conceive and yet her doctor “did not share much” or enough to give her the confidence to understand the actual health problem.

It was almost unanimous that, for these women, the absence of clear diagnostic communication prolonged emotional distress and uncertainty about their bodies. The inconsistency in medical guidance created a perception that PCOS was not taken seriously or fully understood within the healthcare system. This ambiguity often left participants questioning their own symptoms and seeking reassurance from non-medical sources.

Self-Doubt And Loss of Trust in Healthcare

Repeated experiences of diagnostic ambiguity and dismissal led several participants to question not only the reliability of medical advice but also their own understanding of their bodies. Over time, these encounters eroded confidence in healthcare systems that seemed to focus more on clinical data than on lived experiences. P05 expressed this disconnect vividly:

One of the hardest things I’ve realized is how the healthcare system tends to focus on numbers you know, test results, hormone levels but often misses out on what

we actually go through day to day. I don't know but I feel that the gap can feel very discouraging. I think yes, discouraging is the right word. It's just not right somehow.

She also mentioned how these experiences turned inward, saying, "At first, I kept thinking maybe I wasn't asking the 'right' questions, so I blamed myself." Similarly, P01 also described an ongoing search for meaningful support, that, "the most important is I think I'm still finding doctors that can help me."

These accounts revealed how medical uncertainty can evolve into self-doubt, where women begin to internalize the lack of validation they receive from professionals. Instead of reassurance, encounters with healthcare sometimes reinforced feelings of confusion, frustration, and inadequacy. The participants' trust in medical authority which is a key component of perceived control over health actually became fractured. The data from the interviews show that this erosion of trust represents a psychological turning point in the lived experience of PCOS. The women's attempts to seek understanding and care were met with clinical detachment, leading to a profound sense of invisibility. This not only delayed effective management but also undermined their belief in being credible narrators of their own bodily experiences. In this way, the medical encounter itself became part of their suffering, shaping both their emotional well-being and their broader perception of health-related quality of life.

Searching for Clarity Through Self-Education

In response to inconsistent information, several participants became proactive in researching PCOS independently. P04 explained,

Finally, I learned to accept that I need to face this and then I start to Google...

Even though something is very painful for you people who go through more worse than me. So I start to adapt to this and start to move on.

P05 also shared,

To be honest, I feel like I've had to do a lot of the searching on my own. Most of the doctors I saw only focused on the infertility part of PCOS. They rarely talked about the other risks, like diabetes, cardiovascular issues, or even malignancy.

That part was almost never explained unless I asked directly, and even then, the answers felt very brief.

For some participants, self-education became both a coping mechanism and a form of empowerment. Participant 04 reflected,

And then I try to a certain point, start to be myself. I try to Google a lot. I try to ask whatever question I have in my mind. I try to search online and ask myself, I have to realize this thing is, is I'm not alone... And I shouldn't, like give up with this, that I should start finding with the treatment, anything. So I need to accept this. So actually, the research is the one really helped me a lot.

This self-directed learning allowed participants to reclaim agency, yet also placed an emotional burden of responsibility that should ideally rest with healthcare professionals.

The tension between empowerment and fatigue highlights how diagnostic uncertainty shapes not only knowledge but also emotional well-being.

Theme 2: Physical Symptoms and Psychological Disruptions

This theme explores how the participants' lived experiences of PCOS intertwined physical symptoms with psychological and emotional disturbances. These accounts directly addressed the study's central question on health-related quality of life, illustrating how physical and emotional well-being were deeply connected in the participants' daily lives. Across interviews, participants described exhaustion, bodily discomfort, hormonal fluctuations, and emotional distress that shaped how they perceived control, normalcy, and self-worth. For many, the body became both a source of pain and frustration, as well as a reminder of the unpredictability of their condition. Two interconnected yet distinct subthemes emerged which are chronic fatigue, pain, and discomfort; and hormonal instability and emotional distress. Together, these experiences revealed how physical and emotional struggles merged to define the participants' overall quality of life.

Chronic Fatigue, Pain and Discomfort

Several participants spoke of continuous tiredness, pain, or hormonal fluctuations that affected work, concentration, and motivation. These sensations were not occasional but constant, forming the backdrop of their everyday lives. P04 explained,

I have trouble in concentrating... it's like, sometime you are emotionally breakdown. And then sometimes you are extremely tired. And sometimes, like even some people like talk, you casually joke with you, or anything you feel like it's nothing very funny for you. Just want to finish your job and go back.

Similarly, P05 shared, "And at work, my confidence takes a hit. The fatigue and mood swings make me worry people see me as unreliable." P07 also mentioned that "You

know the severe stress and emotional load caused my PCOS to flare up really badly and then I had a heart attack.”

These accounts revealed how chronic fatigue and physical discomfort disrupted participants’ sense of normalcy, compelling them to adjust routines and social interactions. The constant negotiation between bodily limitation and daily expectations diminished their sense of capability and control. When participants felt physically unwell, their mood and motivation often deteriorated, creating a cyclical strain that reinforced both emotional frustration and social withdrawal. This embodied exhaustion was not merely physical, it actually symbolized the persistent drain on their emotional and social well-being, illustrating the profound ways PCOS shaped their lived quality of life.

Hormonal Instability and Emotional Distress

Many participants described a fluctuating emotional landscape tied closely to hormonal changes. Feelings of irritability, sadness, and sudden tearfulness were attributed to hormonal imbalance, which they experienced as both uncontrollable and exhausting. P05, who had medical knowledge of PCOS, described it as “the fatigue and sudden outburst at home or work. Having to deal with emotions like anxiety and low moods hinder completion in task. You know sometimes, overthinking leading up to the thought of incompetency in many ways also.” P01 also explained that the irregularity of her period affected her daily life and she felt like she always had mood swings. Similarly, P07 shared that “there’s this horrible gloomy cloud over you that will never go away.”

These reflections highlighted the participants’ awareness of the physical basis of their emotions, yet also their frustration at being unable to manage them. P03 said,

The one that I'm very, very can be very frustrating is definitely irregular cycles anyway, because I think that is something I'll say it's not easily that I can change...Also sometimes when you have cravings, then and you have, like, hormonal shift, your mood swings, I think at times, yeah.

For several, this unpredictability led to guilt or self-blame, as they questioned their ability to maintain emotional stability in relationships or work environments. The distress was compounded by the cyclical nature of hormonal symptoms, which made it difficult to separate moments of calm from those of instability. P04 elaborated on this ongoing tension, stating that "the main thing is the irregular periods, it always made me, like worried, and then mood swing, because my mood swing extremely went until I beat my son." This continues to show that, across participants, PCOS was experienced as a continuous interplay between physical strain and emotional disturbance. Fatigue, pain, and hormonal instability were not simply symptoms to be managed but part of a larger existential challenge, that is, living within a body that felt unreliable and unpredictable.

The women's narratives revealed that hormonal changes were experienced not only as biochemical events but as profound disruptions to identity and emotional confidence. Living with an unpredictable body that directly influenced emotions created feelings of loss of control and heightened self-consciousness. Over time, this embodied volatility contributed to anxiety, frustration, and lowered self-esteem, underscoring how biological and psychological experiences were deeply interconnected in their perceptions of health and quality of life. Ultimately, PCOS extended beyond a medical diagnosis to

encompass the daily lived struggle(s) of maintaining stability, identity, and emotional resilience amid chronic bodily disruptions.

Theme 3: Emotional Burden and Psychological Strain

This third theme explores the deep emotional toll experienced by participants as they navigated the daily challenges and uncertainties of living with PCOS. The women described a constant internal struggle, balancing frustration, sadness, and anxiety with attempts to maintain composure and optimism. Emotional distress was often compounded by the unpredictable nature of PCOS, creating a sense of helplessness that influenced their health-related quality of life in profound ways. Three interrelated subthemes emerged: feelings of frustration, hopelessness, anxiety and sadness; loss of self-identity and control; and emotional isolation. Together, these experiences reflected how PCOS disrupted not only participants' physical health but also their emotional stability, sense of self, and social connectedness.

Feelings of Frustration, Hopelessness, Anxiety and Sadness

Participants described enduring emotional strain characterized by recurring frustration, worry, and sadness. For many, living with PCOS felt like being trapped in an unpredictable cycle of symptoms and disappointment. P04 expressed,

So I feel like hopeless, because I experienced the same thing on my first miscarriage... So I was like, blaming is it like something I didn't take care of myself?... I didn't even understand what is actually happening to me. And I didn't know, like, how to overcome from this environment... So I always like I didn't at

one point I didn't want to ask anyone anything. I just, like, keep it within me, I think. And then I start to cry. Cry. I feel like this is the end.

P07 similarly shared "I wasn't sure where to start or what would actually help. I was actually very confused and felt hopeless when I found out about PCOS so..."

Anxiety about fertility, physical appearance, and long-term health further intensified these emotions. P02 mentioned,

I tried to search, like, a lot of information online, but it's just too many, you know, like too much information...I just got irritated and, you know, like frustrated, and I was also worried that if my health would be affected. And obviously, most importantly is that I was not able...to have a baby.

Similarly, P04 shared,

Is this one will link to your infertility? And sometimes...curious whether it's really this PCOS it's the one really making you to look tired, making you to lack of sleep and depression and self-confidence...They really doesn't, doesn't know what is PCOS...So it's just like something you will thinking, thinking, thinking, at the end, like it will lead you to some psychological problem.

These accounts depict emotional fatigue that goes beyond feeling general sadness, it actually reflects an enduring psychological strain rooted in uncertainty, fear, and disappointment. The participants' experiences actually reveal that their quality of life was shaped as much by emotional endurance as by physical management.

Loss of Self-Identity and Control

Participants often expressed feeling detached from their previous sense of self. The unpredictable and visible nature of PCOS symptoms from weight gain to acne and hair loss appears to have eroded confidence and made them feel disconnected from their own bodies. P05 explained,

A lot of low moods, mixed with anxiety. It's like even the smallest obstacle, something that wouldn't usually bother me can suddenly feel overwhelming you know what I mean? It makes me feel less in control of myself at times, and that can be really hard to explain to people around me.

P03 explained: "At I think at times, I feel very agitated or stressed, especially when I have to deal with irregular period cycles, acne breakout and definitely weight issues." Similarly, P07 shared that "my weight made me feel unattractive and unsexy, and the anxiety and depression made me want to avoid people."

Such reflections revealed an existential tension, that participants were aware of their body's autonomy yet struggled with the loss of agency. This loss of control over one's physical state translated into a psychological sense of instability, where confidence and identity were constantly negotiated. The ongoing effort to regain control, through lifestyle changes, treatment, or emotional restraint often intensified or added to their exhaustion. These experiences underscore how health-related quality of life encompassed more than physical symptoms, it was also about preserving a coherent sense of self amid the body's unpredictability.

Emotional Isolation

For few of the participants, the cumulative emotional strain of PCOS led to an inward withdrawal rather than active social disengagement. The sense of being “different” or unable to control their symptoms often prompted them to retreat emotionally and psychologically, preferring solitude to the risk of being misunderstood or judged. P05 shared,

Honestly, most of the time I just carry it silently. It’s not that I don’t want to talk about it, but it’s really hard for people who don’t have PCOS to understand what it feels like. And then sometimes if I do bring it up, I get comments like just exercise more or don’t overthink it, which makes me feel even more isolated.

P04 similarly reflected, “Sometimes, when you have, like, a mood swing...you really don’t feel like you want to go somewhere. You just want to be, like, isolated inside the room and just sleep, like...don’t really want to speak with anyone.” P02 also mentioned that “I feel it is actually very personal...I try not to share too much with friends...and just feel very reluctant sharing that with friends.”

These reflections reveal that emotional isolation was less about the absence of support and more about a protective withdrawal, which we could consider as a coping mechanism to manage vulnerability, shame, and fatigue. Participants described feeling safer in silence than in explaining their experiences repeatedly or confronting others’ reactions. Over time, this pattern of self-isolation intensified emotional loneliness and internalized distress. From an interpretative perspective, this withdrawal signified more than social avoidance as it reflected an emotional detachment from the external world,

mirroring a deeper disconnection from one's own body and sense of identity. This self-imposed isolation, while protective, contributed to a cycle of solitude and self-criticism that further diminished participants' health-related quality of life.

Theme 4: Physical Appearance and Self-Confidence

This theme explores how the visible symptoms of PCOS such as acne, weight gain or fluctuations, hair loss, and excessive hair growth affected participants' self-perception and social confidence. These physical manifestations were often the most confronting aspects of the condition because they were visible reminders of difference and lack of control. For many, bodily appearance became closely tied to self-worth and emotional well-being, shaping how they engaged with others and evaluated their quality of life (e.g., Dewani et al., 2023). Key topics related to this theme included body image dissatisfaction, embarrassment and social withdrawal and loss and rebuilding of self-esteem. Collectively, these subthemes illustrated how appearance-related concerns influenced participants' emotional resilience and social engagement, highlighting the inseparable link between body image and health-related quality of life.

Body Image Dissatisfaction and Low Self-Esteem

Participants frequently described deep dissatisfaction with their bodies, expressing frustration over changes in weight, skin condition, or hair growth that they felt unable to control. These visible signs of PCOS often clashed with cultural ideals of femininity, attractiveness, and self-discipline leading to heightened self-consciousness and emotional strain. P03 reflected,

At I think at times, I feel very agitated or stressed, especially when I have to deal with irregular period cycles, acne breakout and definitely weight issues... My main concerns, yeah, I will say definitely irregular, irregular periods, and then excess hair growth on my face, especially on upper lip and middle cheek areas... And then break acne breakout, quite, very frequent. And, and also, another big major concern is definitely my weight, which doesn't, it's just been stagnant for so many years.

Similarly, P05 shared that "there are some days I have no confidence with my weight and hair, like I'm so thin that I look like I have a health problem" while P07 echoed this sentiment mentioning that "my weight made me feel unattractive and unsexy." In addition, P04 also expressed a cyclical struggle between attempts at control and feelings of futility:

I gained a lot of weight. And then I have, like, I tried to cut down on carbs and try to increase other I tried so many methods until I couldn't really lose my weight until one period. And then at one period, I lose my weight, but it's just that I doesn't look healthy. I look tired... then after I tried, I lost weight. My hair doesn't really healthy. It started to lose a lot. And after certain length of it, it really doesn't really grow.

These accounts revealed how physical appearance was deeply entangled with self-worth and social identity. The women's sense of attractiveness and femininity was often measured against internalized societal standards of being "healthy" or "normal." The visible symptoms of PCOS such as weight fluctuations, acne, and hair growth served as

persistent reminders of bodily difference, reinforcing feelings of inadequacy and shame. Over time, negative body image eroded self-confidence and motivation, extending beyond personal distress to affect participants' social engagement and professional self-presentation. This struggle to reconcile their physical reality with idealized expectations contributed to an ongoing sense of vulnerability and loss of control, illustrating how PCOS not only altered the body but also the meaning of self in everyday life.

Embarrassment and Social Withdrawal

The visibility of PCOS symptoms often led to embarrassment and avoidance of social interactions. Many participants spoke about retreating from social or family gatherings or even public spaces due to fear of being judged or stared at. P03 shared,

I don't think I have very high confidence, especially in attending events, when, at the same time, I have a lot of hair growth on my face, or a lot of acne breakout, I don't feel confident in meeting other people.

Similarly, P04 expressed that

You really don't feel like you want to go somewhere. You just want to be, like, isolated inside the room and just sleep, like, don't want to see like your doesn't want, really want to speak with anyone... So the hair loss, yes, will make them low self-esteem, and then it's like, make them low their self-confidence. So they just want to, like...they have to isolate. And then, like, doesn't want to go in public... So I like, very sad, cry. Always want to be alone, and then see other people very like, I'm out from social media. I doesn't really post anything.

For some participants such as P05, having to cope with the symptoms of PCOS contributed to her overall outlook that “at work, my confidence takes a hit. The fatigue and mood swings make me worry people see me as unreliable.” Just like most of the other participants, P07 also shared the same sentiments that “I mostly kept to myself and avoided social situations. Umm I didn’t want people to notice or judge me, and that made me feel even more isolated.”

These accounts reflected the social cost of visible symptoms such as embarrassment, avoidance, and heightened self-awareness in public settings. For several participants, this withdrawal was not merely about appearance but about control, i.e., avoiding situations where they might feel exposed or vulnerable. Over time, this avoidance reduced social engagement and reinforced feelings of isolation, demonstrating how physical appearance directly shaped the psychosocial dimensions of quality of life.

Loss and Rebuilding of Self-Esteem

Many participants described an evolving relationship with their self-esteem, initially marked by loss and self-doubt, but gradually transforming into cautious self-acceptance. The physical symptoms of PCOS, especially those affecting appearance, had deeply eroded their confidence. Yet over time, several women began to rebuild their sense of self by reframing beauty, health, and self-worth on their own terms. P03 reflected,

After getting to know about PCOS, after understanding it, and then I will say it’s something that you have to travel with it. So no point of me stressing too much or putting too much of stress on that when you know it just you can just help to

make it better. Yeah, can't really let like, you know, like, let go of it. So then I try to focus more other things in life.

P04 mentioned that "And finally, I learned to accept that I need to face this and and then I start to Google and everything is very common out there."

These accounts illustrated that self-esteem among participants was not static but dynamic as it is shaped by cycles of loss, reflection, and renewal. The process of rebuilding confidence required emotional resilience and a redefinition of femininity and self-worth beyond physical appearance. For many, this internal reconstruction became a turning point in their lived experience of PCOS, contributing to an improved sense of control and emotional balance. From an interpretative standpoint, the participants' narratives reveal that health-related quality of life involved not only managing symptoms but also reconstructing self-identity after the psychological disruption of altered appearance. For example, P07 shared that "For me, I focused on changing my diet, improving my lifestyle, and educating myself about women's reproductive health." This rebuilding of self-esteem represented an act of reclaiming agency which can be considered as an effort to reconcile the body's changes with a renewed sense of personal worth and acceptance.

Theme 5: Role Strain and Relationships (Family/Society)

This theme captures how participants negotiated their roles and identities within family, romantic, and societal contexts while living with PCOS. These women's accounts revealed that PCOS influenced not only their health but also their ability to fulfil culturally shaped expectations of womanhood. The expectations surrounding fertility,

appearance, and caregiving often conflicted with their own physical and emotional limitations, creating tension between self-care and social responsibility. Two subthemes emerged from these findings: societal and familial expectations of womanhood, and relational and role strain: negotiating care, conflict, and self-prioritization. Together, they highlight how social and cultural pressures intensified participants' emotional burden, shaping their perceptions of adequacy, belonging, and overall quality of life.

Societal and Familial Expectations of Womanhood

Participants described feeling pressure to conform to traditional expectations of femininity to appear attractive, maintain a healthy body, and, most importantly, bear children. These expectations came from family, social norms, and internalized cultural ideals. For example, P02 reflected that "It did not actually affect me as to how I look physically, but it did affect the way I thought of my body internally, and how it, how it would be able to cope as a married woman." Similarly, P04 expressed,

At the first point, they [her other family members] wasn't really supportive, aside from my husband and my mom, but I won't blame them, because they also doesn't really know what women go through in every single thing, because for my mom, she's normal. She never had this problem. And people surrounding very rarely, everyone can conceive normally, never had miscarriage or this thing. They only have hair losses after delivery, so it's like normal process. Suddenly, when I have this, they couldn't accept this.

Relational and Role Strain: Negotiating Care, Conflict, and Self-Prioritization

Beyond societal expectations, participants also described the strain that PCOS placed on their close relationships and daily roles. Emotional fluctuations, fatigue, and mood instability often created tension within families and intimate relationships, leading to feelings of guilt and frustration. The women spoke of how these interpersonal challenges were closely tied to the difficulty of fulfilling their responsibilities while managing their own health. P05 reflected, “Also earlier on, due to these emotional roller coaster rides, it caused friction with my family and close ones.”

For many, emotional volatility was both a personal struggle and a relational burden. Participants expressed distress about how their mood swings or physical exhaustion affected others, fearing they might be perceived as irritable or distant. This awareness added another layer of emotional strain, as they tried to maintain harmony within their relationships despite internal instability. P04 shared,

The mood swing thing so when I have the mood swing, I started to show with anger to my husband, with my son, everyone, which is I actually spoiling my family life. I shouldn't do that. So, but, but there's one point my husband really doesn't know why I'm doing that. Because it's not their fault.

Her reflection captures the guilt and helplessness that accompanied moments of emotional loss of control. Such episodes were described as damaging not only to self-esteem but to family cohesion, intensifying the sense of isolation many women felt within their closest relationships.

In some cases, relational strain surfaced through repeated comments or misunderstandings about appearance or weight. P03 described how her family's conversations about her body became a persistent source of discomfort before eventually subsiding:

And then, I think, and then they used to talk a lot about my maybe, used to have a lot of conversation, but, you know, the weight issues and sometimes, I think, now not that much of on that anymore, because they know it's not something that can be easily fixed.

This statement reflects a gradual transition from criticism to cautious empathy. What initially felt like judgment evolved into understanding as her family learned that weight changes were not simply matters of willpower. The account highlights the emotional labor required to educate loved ones about PCOS, as participants often found themselves mediating between self-acceptance and others' expectations.

For others, the tension lay not in conflict, but in silence, as if a sense that PCOS was a private matter seldom discussed, even with family. P06 reflected on her personal growth and gradual openness in sharing her experience:

I was a little big growing up but after a point in time, I realized, I'm living my life for me, not for anyone else. PCOS is just a condition, it doesn't mean that my life has to pause as a result of it... You know someone asked me recently if I could share my story about PCOS and I feel like, after so many years, I get to openly talk about this condition even though it didn't affect me at all. So you asked me if I shared with my family or close friends, I feel it's not something we openly talk

about, maybe because of my relationship with my family, unless it came up as a topic of conversation.

Her words revealed a more reflective dimension of relational strain, not conflict, but distance. The hesitation to discuss PCOS openly suggests underlying cultural or emotional boundaries that limited dialogue. Yet her statement also carries a sense of empowerment and acceptance, as she reframes PCOS as a part of her life rather than a defining feature. This duality between silence and self-affirmation illustrates how relationships shaped both the burden and the resilience of living with the condition.

These accounts also revealed that the participants' struggles were not confined to physical symptoms but extended into the emotional and relational fabric of their lives. The dual burden of managing interpersonal expectations and personal well-being created a cycle of guilt and emotional fatigue, while the silence surrounding PCOS further complicated women's ability to seek understanding or support.

From an interpretative perspective, this relational and role strain illustrates how the women's health-related quality of life was shaped not only by the medical challenges of PCOS but also by the invisible psychological effort of sustaining relationships and fulfilling social roles while coping with chronic uncertainty. Their experiences underscore the complexity of living within interconnected social systems where emotional stability, family harmony, and self-care are in constant negotiation.

While this theme illustrated how PCOS strained women's interpersonal relationships and roles within family and social settings, participants also located their experiences within a broader cultural and societal context. Beyond the private sphere,

they encountered social stigma and misunderstanding that reinforced feelings of inadequacy and isolation. These perceptions extended beyond individual relationships, reflecting collective attitudes toward womanhood, fertility, and body image in Malaysian society. The following theme, Cultural Stigma and Social Misunderstanding, explores how participants navigated these wider cultural narratives, often negotiating between silence, self-protection, and education in their efforts to make sense of living with PCOS.

Theme 6: Cultural Stigma and Social Misunderstanding

This sixth theme was developed around how participants experienced PCOS within the broader sociocultural context of Malaysia, where women's reproductive health, appearance, and fertility remain sensitive and often misunderstood topics. Across accounts, participants revealed how stigma, misinformation, and traditional expectations surrounding womanhood shaped not only public perceptions but also their own self-understanding. Living with PCOS was not only a medical experience but a socially negotiated identity, deeply influenced by the silence, misconceptions, and moral undertones that surround women's health. The key topics informing this theme includes cultural blame and stigma, societal misconceptions, and navigating judgement through silence or education. Together, these subthemes illustrate how participants made sense of PCOS amid cultural silence and gradual social change.

Cultural Blame and Stigma

Participants described how PCOS carried implicit stigma within their cultural and community settings, where fertility and reproductive "normalcy" are often tied to moral worth and social acceptance. The inability to conceive or meet idealized standards of

womanhood was seen as a personal shortcoming, reflecting how gender expectations are deeply embedded within collective cultural identities. P02 reflected on this cultural weight within Chinese families: “A lot of women I’ve actually spoken with and share the same fear I had, they won’t be able to get pregnant. And that pressure, especially in our culture, you know, Chinese, yeah, having children is very, very important.” Similarly, P04 highlighted how fertility problems are viewed as a “big issue” within her Indian community, describing the heavy social judgement directed toward women with gynecological conditions:

Because as Indian, I would just say, for Indian society, Indians, if a woman have a gynae problem, it’s like very, very big issue. For Indian, if they, if the female have any gynae issue, they’ll just blame the female for until the end, the female to get more extra pressure and add up some of them, like until suicide, and they start to isolate because they just doesn’t want to be supportive, they said, and doesn’t really want to hear what they actually go through.

Her account reveals the intensity of stigma tied to reproductive health, where blame and isolation can become mechanisms of social exclusion. Even within her own family, she initially sensed disbelief and lack of support, before they slowly came to understand her condition:

At the first point, they wasn’t really supportive... because they also doesn’t really know what women go through... Suddenly, when I have this, they couldn’t accept this, but later on, they didn’t blame me for what I’m going through. They start to understand.

These reflections demonstrate how fertility stigma intersects with cultural values and generational differences. The inability to meet reproductive expectations often translated into social shame, misunderstanding, and emotional withdrawal. Yet, for some participants, gradual awareness and education within their families led to a slow redefinition of what “normal” womanhood could mean.

Societal Misconceptions

Beyond familial contexts, participants expressed frustration at the lack of public understanding and visibility surrounding PCOS. Many described encountering dismissive attitudes, where symptoms were trivialized or attributed to lifestyle choices rather than hormonal imbalance. P05 reflected on this limited awareness: “However, our community may not be readily to accept hormones as part of a contributing factor to a disease as we were constantly told that hormones are just hormones and they do not play a huge role.” Similarly, P03 discussed how broader societal stigma around women’s health issues and body image perpetuated misunderstandings:

Probably because of the stigma around women health issues and then lack of awareness, and I think body image pressure especially, yeah, as women are always judged by how they look, from their appearance to their body weight. So I think that makes it difficult for certain women to actually voice out, because they’re, they’re mostly, you know, judged or teased by how they look, how they Yeah, so they and you also maybe not aware of what they’re going through.....I probably it’s an also Asian thing, because I’ll say, like, not only in Malaysia, other Asian countries also.

These insights show that PCOS is often viewed through narrow biomedical or aesthetic lenses, rather than as a chronic condition with psychosocial implications. P04 described avoiding social situations because of others' curiosity and judgment:

I doesn't have confidence in meeting public because of because I doesn't know really how to, like, make up and all these to go outside. So I'm just like, who I am. So when I get people like, why you are like this? Why your face, like this is anything problems. So I does not really want to meet with public and then a part of that is like, always, like frustration and stress. So this thing really affect my daily life.

Such experiences underscore the embodied stigma of PCOS where visible symptoms like acne, hair loss, or weight gain become public markers of difference. The lack of social understanding reinforces isolation, forcing women to navigate their identities between visibility and concealment. From an interpretative standpoint, this invisibility reflects not only gaps in public knowledge but also structural silence around women's reproductive health in Malaysia's cultural discourse.

Navigating Judgment through Silence or Education

Faced with pervasive misunderstanding, participants adopted varied strategies to navigate judgment and stigma often oscillating between silence as protection and education as empowerment. Several participants described how silence served as a shield from gossip or discomfort. P01 expressed,

Yeah, I don't think it's easy to talk openly about the PCOS actually in Malaysia, because I think women feel a bit shy or uncomfortable talking about their health

like this. Yeah, yeah. It's not easy for people, especially in Malaysia, to talk openly about that.

Similarly, P07 echoed this sentiment, pointing to how social shame and taboo continue to silence conversations about reproductive health: "Exactly. In some families or communities, it's still a quiet topic. There's a lot of shame or misunderstanding around women's reproductive health, and that can make umm people feel isolated."

Yet, amidst this silence, some women chose to reclaim their voices through advocacy or awareness. P06 reflected on her own experience:

I think for some, it can be really tough, I mean not everyone may be blessed like me to have found a good doctor especially when it affects things like weight, skin, or fertility. The emotional part can be harder than the physical sometimes. But I also think with more awareness now, women are starting to take charge and not let it control them as much...Yup but I know that in more traditional or conservative families, it's still a quiet topic because people don't always feel comfortable discussing it. Hopefully that's changing with more conversations like this.

These statements revealed the emotional complexity of managing stigma within a cultural context that often silences women's health experiences. Participants carefully weighed the consequences of disclosure, oscillating between silence as a form of self-protection and selective openness as a way to correct misunderstanding. Choosing to speak or remain silent thus became a deeply personal and contextual act, one that is shaped by cultural expectations and emotional vulnerability. From an interpretative

perspective, their accounts illustrate how living with PCOS involved continual negotiation between concealment and self-expression, revealing the psychological toll of navigating societal judgment.

Theme 7: Coping and Acceptance

Moving beyond the constraints of social judgment, the participants appeared to have engaged in personal strategies of acceptance, adaptation, and self-care. Their narratives revealed a process of meaning-making, learning to coexist with the condition, redefine their identity, and regain agency amid physical and emotional uncertainty. As participants navigated the ongoing emotional and social challenges of PCOS, many described a gradual movement from resistance to acceptance. While early experiences were characterized by confusion, shame, or frustration, over time they learned to reframe the condition as a part of life that could be managed rather than an obstacle that defined them. For most women, coping was not a single moment of change but a continuous process of adaptation, self-reflection, and inner growth. The three subthemes that emerged from this are shifting mindset towards acceptance, lifestyle adaptation and drawing strength from faith or support networks.

Shifting Mindset Towards Acceptance

Participants described how, over time, they consciously worked to change how they thought about their condition. Acceptance was framed as an intentional act of letting go of self-blame and regaining emotional control. For example, P02 expressed how reframing her thoughts became essential to maintaining balance: “I wanted to hug someone when I got home. So, yeah, I convinced myself that it’s not a big deal of it’s not

that a big deal that I didn't want it to control my life." For her, acceptance involved acknowledging emotional vulnerability while choosing not to let the diagnosis dominate her sense of self. Similarly, P04 described the gradual realization that she was not alone and that learning about PCOS helped her cope better:

I try to Google a lot. I try to ask whatever question I have in my mind. I try to search online and ask myself, I have to realize this thing is, is I'm not alone, yeah. And then people with other, other symptoms, which can be some of it cured. And I shouldn't, like give up with this, that I should start finding with the treatment, anything. So I need to accept this.

These reflections suggest that acceptance was not passive surrender but a cognitive and emotional reframing, which can be considered an active process of choosing peace over frustration. From an interpretative standpoint, this shift marked a significant transformation in their health-related quality of life, as participants redefined control and well-being in psychological rather than purely medical terms.

Lifestyle Adaptation

For many participants, coping also took the form of practical adjustments that allowed them to better manage their symptoms and daily routines. These adaptations reflected both self-awareness and collective family support, highlighting a shift from helplessness to proactive self-care. P03 explained how her family's involvement, particularly her mother, became part of her coping process:

So she yeah, so she [mom] doesn't, she doesn't cook certain food that can, can trigger my bloataion, or, yeah, or some of the sometimes she even go for the

traditional way, which is Indians, we have some traditional way of boiling certain things, you know, to drink it, or what to like regulate back my hormones.

This account reflects both individual and relational adaptation, where coping extended beyond personal effort into shared family care. Rather than relying solely on medical advice, participants combined practical self-care with traditional approaches, reflecting both personal agency and social support. Similarly, P02 shared how she too adopted a proactive form of adaptation, where connecting with others helped her develop practical strategies for managing her symptoms:

I didn't actually share it with many of my friends, so I only shared with my husband, and I also joining online support groups. And then I realized that I wasn't alone. And then hearing other experiences give me hope. And also, you know, like, also get some practical tips as well...But after blaming myself and not really doing the sensible thing to overcome this right away, I decided that I should actually look for groups or communities to understand if other women are feeling the same way as I do.

Her experience demonstrates how lifestyle adaptation was not limited to physical practices but extended to informational and social learning, where online communities became spaces for both emotional reassurance and practical guidance. P04 too described how self-education and consistent effort toward treatment became part of her coping practice: "I try to Google a lot. I try to ask whatever questions I have in my mind. I have to realize this thing... I'm not alone, and I shouldn't give up with this. I should start finding treatment."

From an interpretative perspective, these lifestyle adaptations revealed that coping was not merely behavioral but existential, signifying a way for participants to regain agency over their bodies and restore a sense of control amid ongoing uncertainty. By aligning their daily routines, beliefs, and health practices, they cultivated a more balanced and empowered sense of living with PCOS.

Drawing Strength from Support Networks and Meaning-Making

Social and emotional support played a critical role in helping participants maintain resilience and acceptance while living with PCOS. Many women described drawing strength from close relationships, shared experiences with others, and personal meaning-making practices such as gratitude or faith when navigating periods of uncertainty. For example, P04 emphasized her husband's unwavering presence as a major source of strength, particularly when facing external judgement and emotional vulnerability:

I start to get my husband's support first, I'm having this problem... So he actually become a supportive for me. And then he listen, and I had whatever question was in my mind, I started asking. And it was like, someone is with me... He was there all the time for me. And whenever people ask me the negative question. I think he was the one answered.

This showed that his support functioned as an emotional buffer, enabling her to persist with treatment and maintain hope rather than withdraw or surrender to distress. For other participants, acceptance was strengthened through connecting with peers or support groups who shared similar experiences of PCOS. P07 described how peer

engagement reduced fear and restored a sense of control “Being able to talk about it and learn from others helped me feel less afraid and more in control.” Similarly, P02 mentioned “kept all the real emotions and feelings bottled up and pushed my husband away. But ever since opening up and seeking advice from others, I was able to make new friends and help each other on this journey.”

Together, these narratives illustrate how relational and meaning-based resources fostered emotional grounding and collective resilience. This further shows that support and meaning-making enabled participants to integrate PCOS into a broader sense of self, transforming isolation into connection and vulnerability into reassurance rather than erasure.

Additionally, as some participants grew more confident in managing their condition, their coping further evolved into self-advocacy. Rather than relying solely on medical professionals, they began seeking knowledge and community independently. As P05 reflected, she had “started looking for answers elsewhere, like online groups or other women going through the same thing,” which later inspired her to “become [her] own advocate.” This transition from self-care to self-advocacy signified an emerging form of empowerment that extended beyond personal coping which is a process explored further in the following section on Education, Awareness, and Advocacy.

Theme 8: Education, Awareness and Advocacy

As participants gained greater understanding of PCOS and confidence in managing their symptoms, their coping gradually evolved into a deeper sense of empowerment and purpose. For many, learning about the condition became not only a

personal necessity but also a form of agency, enabling them to challenge misinformation, seek appropriate care, and support others facing similar struggles.

This theme explores how participants' lived experiences inspired them to engage with knowledge, advocacy, and awareness as ways to reclaim control over their health and contribute to broader conversations about PCOS. Three interrelated subthemes emerged from the data which includes seeking knowledge and self-advocacy, raising awareness through shared experiences, and hope for social change and empowerment.

Seeking Knowledge and Self-Advocacy

For many participants, self-education became a crucial turning point in reclaiming agency. Having initially felt dismissed or misunderstood in medical consultations, several women described a shift toward questioning, researching, and advocating for themselves. For example, P02 shared how this awareness developed over time:

After consulting and exchanging information with a few others, I think I would have wished to have seen a different doctor earlier. I know that the importance of advocating myself for myself in doctor's office, so for a long time, I accepted surface level answer. But PCOS is complex, and everyone experience is different. I guess if I could go back, I think I'll ask more questions, connect support communities, and I also wish that I had been kinder to myself so, because in the beginning, I blame myself for my body and not working the way I thought it should. If I could go back. I think I will remind myself that PCOS is not my fault.

Her reflection captures both the frustration of earlier uncertainty and the empowerment that came from taking ownership of her care. Similarly, P01 emphasized the value of openness and seeking help as an empowering step:

I think it's important to know that you are not alone because outside of the world, I think many women we have the PCOS, but yeah, so I think it's okay to ask for help or maybe talk about what you have gone through to your friends or doctors.

P05 also explained how she took initiative to find her own answers: "I started looking for answers elsewhere, like online groups or other women going through the same thing if you know what I mean. In a way, I've had to become my own advocate." Her reflection captures a pivotal moment of transformation, from passively receiving care to actively shaping her understanding and decisions. Similarly, P06 shared how she recognized, in hindsight, the importance of being informed:

Ummm maybe I would've taken the time to understand my body better from the start. Back then, I didn't think much of it because I didn't feel any symptoms, but looking back, I realize that knowing more could have helped me make better lifestyle choices earlier on. Not out of fear, but just awareness. It's always good to be informed and proactive about our own health you know what I mean.

Such statements highlight the shift from dependency to self-advocacy, where participants assumed responsibility for learning and decision-making and moved from passively receiving medical information to critically seeking and integrating it into their own understanding. From an interpretative standpoint, this process reflects how education

became empowerment, a means of mitigating uncertainty and reinforcing control over one's health trajectory.

Raising Awareness Through Shared Experiences

For several participants, gaining awareness also brought a desire to share their experiences and help others who might be struggling silently. Their involvement in online groups or peer spaces became a form of informal advocacy, reflecting a growing awareness of the need for collective understanding. P02 described how she overcame her initial hesitation to open up publicly:

I would not consider myself as someone that would actually talk openly about problems and well, let alone personal issues or health conditions, right? But after blaming myself and not really doing the sensible thing to overcome this right away, I decided that I should actually look for groups or communities to understand if other women are feeling the same way as I do. So I think that the lack of awareness and the stigma behind this makes it harder for some of the ethnic group... It seems that for the urban population, as long as there is a safe space for them to come together, this women can openly share their experiences, as I did with them. I felt this was actually the first time the introvert in me was not afraid to speak up.

Similarly, P07 reflected on how open dialogue helped her and others feel more supported:

Yes I was lucky because I had access to it [support] but many do not...I mean I know many women don't. Some don't even know where to start or who to talk to about it...Exactly. In some families or communities, it's still a quiet topic. There's

a lot of shame or misunderstanding around women's reproductive health, and that can make umm people feel isolated... [having that support made a big difference for her] Oh yes, definitely. Being able to talk about it and learn from others helped me feel less afraid and more in control.

These accounts illustrate how awareness-raising operated as both a personal healing process and a collective act of empowerment. Through storytelling and community engagement, participants reclaimed their voices and challenged the silence that often surrounds women's reproductive health in Malaysian society.

Hope for Social Change and Empowerment

Beyond individual empowerment, participants expressed hope for broader societal change, envisioning a future where PCOS is better understood and discussed without stigma. Many viewed awareness as a pathway towards compassion, inclusivity, and early diagnosis for others. P06 expressed,

I think for some, it can be really tough, I mean not everyone may be blessed like me to have found a good doctor especially when it affects things like weight, skin, or fertility. The emotional part can be harder than the physical sometimes. But I also think with more awareness now, women are starting to take charge and not let it control them as much.

Her words captured a generational and cultural shift, where open conversation begins to replace silence and shame. Similarly, P04 passionately articulated the courage and purpose to speak up:

I would just say, as a woman, you should be bold and brave. Whatever you work through. You just accept it, you're just not alone, and there's nothing you need to be afraid of. You Your voice, your your voice has the power to raise awareness, you need to inspire other women, so you can create a change for the coming generation.

Her statement reflects the transition from private acceptance to public empowerment. P03 also highlighted the importance of awareness and open dialogue:

I think there should be more awareness and open discussion so women can actually have a better understanding of their health and know that this condition can be helped, so at least that way they can, they can feel more confident and talk about it and hopefully live a better and healthier life. Yeah, dealing with this instead of going into depression and all.

Echoing this optimism, P07 connected awareness with compassion and community:

For some, it can be really tough like they might feel isolated or frustrated. But I also think with umm more awareness and community support, many women are learning to manage it and feel less alone. For some, it can be really tough like they might feel isolated or frustrated. But I also think with umm more awareness and community support, many women are learning to manage it and feel less alone...Listen to your body. PCOS is like an alarm bell telling you something needs to change. Make time for yourself, eat well, move your body, and never feel ashamed of your condition.

As several participants highlighted, mental health emerged as an inseparable part of living well with PCOS. Awareness was not only about physical symptoms or medical management but also about creating emotional safety and reducing psychological distress. For these women, social change and empowerment represented a hope for a world where mental well-being is recognized as central to women's health. These accounts revealed how hope, education, and solidarity were intertwined in the women's sense of purpose. From an interpretative perspective, this represented an existential reframing, that is, a movement from enduring PCOS to transforming it into a platform for empathy, advocacy, and generational change. For many, empowerment extended beyond personal well-being toward envisioning a more informed, compassionate, and inclusive society.

Addressing the Research Question

This study aimed to explore the health-related quality of life of women with PCOS in Malaysia. Across all seven participants, PCOS emerged not merely as a medical diagnosis but as a pervasive life condition that shaped physical well-being, emotional resilience, social participation, and sense of identity. The findings illustrated that quality of life for these women is profoundly interwoven with how they make sense of, cope with, and navigate their bodies, relationships, and social environments.

The first three themes of diagnostic and medical uncertainty, physical symptoms and psychological disruptions, and emotional burden and psychological strain, revealed how ambiguity, chronic discomfort, and emotional distress intersected to disrupt daily functioning and self-perception. These experiences underscored that diminished quality

of life often stemmed as much from uncertainty and invisibility as from physical symptoms themselves.

Themes on physical appearance and self-confidence and role strain within family and society further highlighted how the women's self-image and social identities were tested by cultural expectations surrounding femininity, fertility, and productivity. These relational pressures magnified the psychological toll of PCOS, situating individual suffering within a broader sociocultural context. Lastly, subsequent themes on social and cultural judgement, coping and acceptance, and education, awareness, and advocacy illuminated a gradual shift from distress to empowerment. Through processes of self-reflection, lifestyle adaptation, and seeking supportive communities, participants redefined their quality of life not as the absence of symptoms but as the ability to live meaningfully with PCOS. In doing so, they moved from silence and stigma toward voice and agency, transforming personal struggle into social contribution.

Collectively, the themes demonstrated that the health-related quality of life of Malaysian women with PCOS is a multidimensional and dynamic construct, shaped by interactions between medical experiences, emotional wellbeing, cultural norms, and evolving self-understanding. The women's narratives reflected both the challenges of living with an unpredictable body and the resilience that emerges through self-knowledge, social connection, and advocacy.

Summary

This chapter presented the results of the study and outlined the analytic process undertaken to explore the lived experiences of Malaysian women with PCOS. It included

details of the data collection procedures, analytic methods, and evidence of trustworthiness that supported the credibility and rigor of the findings. Semi-structured interviews were conducted with seven participants who met the inclusion criteria for this study. Each interview was analyzed using IPA, leading to the identification of eight interconnected themes that reflected the participants' perceptions of their health-related quality of life.

The analysis revealed that living with PCOS was experienced as an ongoing negotiation between physical realities and the psychological, relational, and cultural meanings attached to the condition. At the core of the participants' experiences was a sense of uncertainty and disruption, both diagnostic and emotional that challenged their sense of bodily normalcy and self-control. The early stages of their journeys were often marked by confusion, inconsistent medical information, and physical distress. Over time, these experiences were internalized, giving rise to feelings of frustration, sadness, and diminished self-worth, particularly as participants struggled to meet personal and societal expectations of womanhood. Despite these difficulties, the women's narratives also reflected resilience and transformation. Through lifestyle adaptation, faith, and the pursuit of knowledge, they gradually reconstructed their identities and developed coping strategies that balanced self-acceptance with self-advocacy. Support from family, partners, and online communities played a pivotal role in helping them manage the emotional and practical challenges of PCOS.

This study also highlighted the sociocultural dimensions of quality of life in the Malaysian context. Participants' experiences were influenced by cultural scripts

surrounding femininity, fertility, and body image, as well as by prevailing silence and stigma related to reproductive health. Yet, through advocacy, self-education, and collective dialogue, many participants began to reframe PCOS not as a source of shame but as an opportunity for empowerment and awareness-raising. In essence, the findings demonstrated that the health-related quality of life of Malaysian women with PCOS is a dynamic, multidimensional construct, one that extends beyond medical symptom management to encompass emotional well-being, self-perception, and social connectedness. The women's journeys actually reflected a movement from uncertainty and distress towards understanding and empowerment, illustrating how meaning-making and resilience become central to living well with PCOS. In Chapter 5, the findings will be further discussed in relation to existing literature and theoretical perspectives, moving beyond description to offer interpretation, connecting the participants' lived experiences to the broader context of women's health and quality of life.

Chapter 5: Discussion, Conclusions and Recommendations

The purpose of this study was to explore the health-related quality of life of women with PCOS in Malaysia through their lived experiences. Studies have consistently demonstrated that PCOS affects multiple domains of health-related quality of life, including emotional well-being, body image, social functioning, and psychological health (e.g., Barnard et al., 2007; Coffey & Mason, 2003; Jones et al., 2004; Li et al., 2011;). Beyond physical symptoms, women with PCOS experience elevated levels of anxiety, depression, and emotional distress, often linked to uncertainty surrounding diagnosis, treatment, and societal expectations (Elsenbruch et al., 2003; Gibson-Helm et al., 2017; Hollinrake et al., 2007). This chapter presents findings drawn from in-depth, semi-structured interviews with seven women who met the study's inclusion criteria and were purposively recruited to ensure experiential relevance.

Guided by IPA, the analysis revealed how these women made sense of their condition, managed their physical and emotional challenges, and reconstructed meaning and identity over time. The eight themes identified in Chapter 4 reflect a unique interplay between the biological, psychological, social, and cultural dimensions of PCOS, highlighting health-related quality of life as a lived and contextual experience rather than a purely clinical outcome. This chapter will interpret these findings in relation to existing literature on PCOS and women's health, highlighting areas of convergence and divergence with previous studies. The analysis pays particular attention to how experiences of medical uncertainty, embodied distress, stigma, coping, and empowerment shape quality of life within the Malaysian sociocultural context. It will also discuss the

implications of the findings for clinical practice, patient education, and social awareness within the Malaysian context. The chapter concludes by reflecting on the study's contributions, limitations, and directions for future research.

Interpretation of the Findings

The findings of this study contribute to the growing body of literature on the lived experiences and health-related quality of life of women with PCOS. Through in-depth IPA, participants described how they made sense of living with a chronic and often misunderstood condition, negotiated physical and emotional disruptions, and reconstructed meaning and identity over time. In doing so, they revealed how PCOS shaped not only their bodily experiences but also their self-worth, relationships, and perceptions of womanhood within a Malaysian sociocultural context.

These findings align with and extend previous research that has documented the multidimensional impact of PCOS on women's quality of life, particularly in relation to psychological distress, body image concerns, and social functioning (Coffey & Mason, 2003; Jones et al., 2004; Li et al., 2011). The nine themes identified in this study reflect recurring patterns of meaning-making that both support existing literature and offer new insights into how cultural expectations, healthcare encounters, and personal coping strategies intersect to shape women's lived experiences.

By centering the voices of Malaysian women with PCOS, this study addresses an underexplored population and provides contextually grounded insights that can inform future research, culturally sensitive healthcare practices, and patient-centered

interventions. The following sections discuss these findings in relation to existing literature, organized around key experiential domains that emerged from the analysis.

Theme 1: Diagnostic and Medical Uncertainty

Participants' accounts of diagnostic and medical uncertainty emerged as a foundational aspect of their lived experiences with PCOS and a significant contributor to diminished health-related quality of life. In this study, uncertainty was not confined to the moment of diagnosis but extended across repeated healthcare encounters characterized by inconsistent explanations, delayed confirmation, and limited emotional validation. These experiences shaped how participants made sense of their condition and influenced their trust in the medical system.

These findings align with existing research indicating that women with PCOS frequently experienced delayed diagnosis and dissatisfaction with the information provided by healthcare professionals (Gibson-Helm et al., 2014, 2017; Hillman et al., 2020; Soucie et al., 2021). Similar to participants in the present study, women in prior qualitative research have reported confusion, frustration, and a sense of being dismissed during clinical consultations (Ismayilova & Yaya, 2022; Soucie et al., 2021). However, the current findings extend this literature by illustrating how diagnostic ambiguity was internalized, leading participants to question their own bodily knowledge and credibility as patients. It also appeared that medical uncertainty functioned as an existential disruption, destabilizing participants' sense of control and coherence. Rather than offering reassurance, repeated encounters with fragmented care contributed to self-doubt, emotional exhaustion, and a growing sense of invisibility. Participants described feeling

caught between clinical measurements and lived suffering, highlighting a disconnection between biomedical priorities and experiential realities. This resonates with earlier phenomenological work describing PCOS as a condition that threatens women's sense of bodily legitimacy and identity (Kitzinger & Willmott, 2002).

Importantly, the erosion of trust in healthcare was not merely a reaction to poor communication but became a pivotal influence on how women evaluated their overall quality of life. Consistent with research linking illness perceptions to psychological outcomes in PCOS (Fossey et al., 2023; Light et al., 2021), participants' uncertainty about diagnosis and management shaped emotional responses, coping behaviors, and engagement with care. In this way, medical encounters themselves became part of the illness experience, reinforcing distress rather than alleviating it. Taken together, these findings underscore that diagnostic and medical uncertainty is not a peripheral issue but a central determinant of health-related quality of life for women with PCOS. The present study contributes to the literature by demonstrating how uncertainty extends beyond clinical timelines to influence self-trust, emotional well-being, and meaning-making over time. Addressing this uncertainty through clearer communication, continuity of care, and validation of women's lived experiences may therefore play a critical role in improving both psychological outcomes and overall quality of life.

Theme 2: Physical Symptoms and Psychological Disruption

Following experiences of diagnostic and medical uncertainty, participants described PCOS as a condition that was lived primarily through the body, with physical symptoms exerting a profound influence on psychological well-being. In this study,

fatigue, pain, hormonal instability, and visible bodily changes were not experienced as isolated symptoms but as ongoing disruptions that shaped mood, motivation, and daily functioning. These embodied experiences played a central role in how participants evaluated their health-related quality of life.

Consistent with previous research, women with PCOS in this study reported a range of physical symptoms, including chronic fatigue, weight fluctuation, menstrual irregularities, acne, and excessive hair growth (Barnard et al., 2007; Chaudhari et al., 2018; Coffey & Mason, 2003; McCook et al., 2005). Quantitative studies have long demonstrated that such symptoms are associated with reduced quality of life and increased psychological distress (Li et al., 2011; Tabassum et al., 2021). However, the present findings extend this literature by indicating how participants made sense of these symptoms as signs of bodily unpredictability and loss of control. Participants frequently described a cyclical relationship between physical discomfort and emotional disturbance, whereby fatigue and hormonal changes intensified irritability, anxiety, and low mood. This reciprocal pattern aligns with studies documenting elevated rates of anxiety and depression among women with PCOS (Almeshari et al., 2021; Chaudhari et al., 2018; Elsenbruch et al., 2003; Habib et al., 2021; Hollinrake et al., 2007;).

These emotional responses extended beyond reactions to symptoms, reflecting instead the lived experience of bodily unpredictability and loss of control. Physical strain became intertwined with psychological vulnerability, reinforcing an embodied sense of distress. More importantly, participants' narratives suggested that hormonal instability was experienced not only as a biochemical phenomenon but as an existential challenge

that disrupted emotional confidence and self-trust. This finding reinforces with research highlighting the role of illness perceptions in shaping emotional outcomes among women with PCOS (Fossey et al., 2023; Light et al., 2021). As symptoms fluctuated unpredictably, participants described heightened vigilance toward their bodies, increased self-monitoring, and feelings of helplessness, all of which contributed to psychological exhaustion.

The present findings suggest that the physical and psychological experiences of PCOS are closely interrelated. Participants did not describe bodily symptoms and emotional responses as separate processes, rather, they spoke of an embodied experience in which physical discomfort, hormonal fluctuations, and emotional distress shaped their everyday lives. These accounts align with research demonstrating how women's illness perceptions in PCOS influence emotional well-being and psychological outcomes (Alur-Gupta et al., 2019; Fossey et al., 2023; Light et al., 2021). They also reinforce evidence that the physical manifestations of PCOS contribute to reduced quality of life, reflecting the interconnected relationship between symptom experience and emotional well-being described within the health-related quality of life model. More broadly, these narratives resonate with phenomenological perspectives on chronic illness, which understand distress as lived through the body and embedded within daily experience rather than confined to either physical or psychological domains (Kitzinger & Willmott, 2002).

Theme 3: Emotional Burden and Psychological Strain

Building on the embodied disruptions described in the previous section, participants' accounts revealed a substantial emotional burden associated with living with

PCOS. Women spoke of persistent feelings of frustration, sadness, anxiety, and hopelessness that extended beyond isolated emotional reactions. These experiences were closely connected to a perceived loss of control, uncertainty about the future, and difficulties reconciling who they felt they were with how they now experienced their bodies and lives. For many participants, emotional distress became central to how they understood their health and evaluated their overall quality of life.

Consistent with existing literature, women in this study described emotional distress that went beyond transient mood changes, reflecting a more sustained psychological strain associated with PCOS (Chaudhari et al., 2018; Elsenbruch et al., 2003; Hollinrake et al., 2007). Previous research has similarly documented higher prevalence rates of anxiety and depressive symptoms among women with PCOS compared to those without the condition (Almeshari et al., 2021; Bazarganipour et al., 2013; Douglas et al., 2021; Gnawali et al., 2021; Rasgon et al., 2003). While these studies highlight the psychological burden of PCOS, the present findings further illustrated how distress was experienced as something that accumulated and unfolded over time, rather than as a discrete mental health outcome. Distress was not described solely in terms of emotional symptoms but was deeply intertwined with changes in how participants understood themselves and their perceived sense of agency. Several women reflected on an internal conflict between who they believed themselves to be prior to diagnosis and how they experienced themselves while living with PCOS. This sense of dissonance often gave rise to self-blame, feelings of inadequacy, and heightened emotional vulnerability. Such accounts echo earlier qualitative and phenomenologically informed

research describing PCOS as a condition that can disrupt women's sense of self and undermine personal coherence (Alur-Gupta et al., 2019; Kitzinger & Willmott, 2002; Wang et al., 2023).

Participants also described a tendency toward emotional withdrawal, not due to a lack of social support, but as a protective response to internal distress and self-consciousness. Women spoke of turning inward through rumination, overthinking, or becoming emotionally sensitive as a way of containing overwhelming feelings. Similar patterns have been reported in studies highlighting the role of illness perceptions and internalized stigma in shaping psychological outcomes among women with PCOS (Dewani et al., 2023; Light et al., 2021). In this sense, emotional isolation functioned less as social exclusion and more as a strategy for coping with emotional overload. The emotional burden described by participants aligns with a substantial body of literature indicating elevated levels of anxiety, stress, and depressive symptoms among women with PCOS, reinforcing the psychological dimension of health-related quality of life and highlighting emotional well-being as a central component of living with the condition.

Importantly, emotional burden did not emerge in isolation from physical symptoms or social expectations. Instead, it was shaped at the intersection of bodily disruption, cultural norms, and personal meaning-making. The participants' accounts also suggested that unpredictability, perceived inadequacy, and uncertainty about the future, particularly in relation to fertility, relationships, and long-term health, often intensified emotional distress. These experiences blurred the boundary between emotional strain and everyday functioning, reinforcing the sense that distress was embedded in daily life rather

than confined to emotional states alone. This interpretation is consistent with existing evidence that health-related quality of life in PCOS is influenced by complex psychosocial processes rather than symptom severity alone (Barnard et al., 2007; Li et al., 2011).

Taken together, the findings position emotional burden and psychological strain as central dimensions of health-related quality of life for women living with PCOS. By attending to how distress is experienced, made sense of, and worked through over time, this study contributes to a more refined understanding of PCOS as a condition that shapes emotional resilience, identity, and everyday well-being in enduring ways.

Theme 4: Physical Appearance, Self-Confidence, and Identity

The participants' narratives highlighted physical appearance as a salient and emotionally charged aspect of living with PCOS, closely tied to self-confidence and identity. Changes in weight, skin condition, hair growth, and hair loss were not experienced merely as physical symptoms but as visible markers of difference that shaped how women understood themselves and anticipated being perceived by others. These embodied changes had a profound influence on participants' sense of femininity, attractiveness, and self-worth, and were central to how they evaluated their health-related quality of life. This finding is consistent with existing literature demonstrating that body image dissatisfaction is a key contributor to psychological distress among women with PCOS (Alur-Gupta et al., 2019; Barnard et al., 2007; Coffey & Mason, 2003). Quantitative studies have shown that concerns related to weight, hirsutism, and acne are associated with lower self-esteem and increased anxiety and depressive symptoms

(Benetti-Pinto et al., 2015; Panico et al., 2017). The present study supports these findings while offering deeper insight into how appearance-related concerns were interpreted, monitored, and internalized within participants' everyday lives.

In their accounts, participants often spoke of their bodies as sites of ongoing negotiation. Efforts to manage, conceal, or compensate for visible changes were intertwined with heightened self-awareness, emotional vulnerability, and constant self-surveillance. Visible symptoms became recurring reminders of bodily unpredictability and loss of control, reinforcing feelings of inadequacy and self-consciousness. Similar embodied disruptions have been described in qualitative and phenomenologically informed accounts of PCOS, where bodily changes alter how women inhabit and relate to their bodies in daily life (Kitzinger & Willmott, 2002; Wang et al., 2023). From this perspective, distress was not simply about appearance dissatisfaction but about a disrupted relationship with one's own body.

Importantly, participants' experiences were shaped not only by personal evaluations of appearance but also by internalized sociocultural expectations surrounding femininity, health, and self-discipline. Cultural narratives that equate womanhood with physical attractiveness, reproductive capability, and bodily control heightened participants' sensitivity to bodily changes and social comparison. Similar dynamics have been reported in studies examining the social construction of PCOS and its impact on women's identities, particularly within collectivist or appearance-conscious contexts (Batoool & de Visser, 2014; Dewani et al., 2023; Pathak & Nichter, 2015). Diminished self-confidence extended beyond private self-perception to shape social engagement and

professional self-presentation. Participants described withdrawing from social situations, feeling hesitant in public spaces, or questioning their competence and desirability. In this way, appearance-related concerns became a bridge between embodied distress and social participation, further influencing how women evaluated their quality of life. Similar links between appearance concerns, social confidence, and health-related quality of life have been documented in both qualitative and health-related quality of life-focused research in PCOS (McCook et al., 2005; Soucie et al., 2021).

Overall, the findings underscore that body image dissatisfaction in PCOS is not a superficial concern but a deeply embodied and identity-related experience. By situating appearance-related distress within broader cultural, psychological, and social contexts, this study highlights how self-confidence and identity reconstruction are central to understanding health-related quality of life among women living with PCOS.

Theme 5: Role Strain and Relationships (Family/Society)

Participants' experiences of PCOS extended beyond individual bodily and emotional challenges to shape their relationships and social roles. In this study, role strain emerged as a salient aspect of lived experience, as women described tensions between managing their health and meeting expectations within family, intimate partnerships, and broader society. These relational challenges contributed meaningfully to how participants evaluated their health-related quality of life, particularly in relation to emotional functioning, social participation, and perceived adequacy in everyday roles. Consistent with previous research, women described strain within close relationships that was often linked to emotional volatility, fatigue, and difficulties maintaining consistency in daily

functioning (Batool & de Visser, 2014; Coffey & Mason, 2003; Kitzinger & Willmott, 2002). Participants spoke of how mood fluctuations and physical exhaustion sometimes led to misunderstandings, conflict, or feelings of guilt toward family members and partners. Rather than reflecting a lack of care or commitment, these tensions were experienced as distressing consequences of living with a condition that disrupted emotional regulation and energy levels.

Based on their accounts, participants frequently framed role strain in relation to a strong sense of responsibility and self-expectation. Many women expressed distress about their perceived inability to fulfil relational roles “properly,” whether as partners, daughters, or family members. This internalized pressure intensified feelings of inadequacy and emotional burden, reinforcing earlier themes of self-blame and diminished control. Similar challenges to relational identity and interpersonal harmony have been documented in studies examining chronic health conditions within cultural contexts that emphasize familial responsibility, reciprocity, and cohesion (Pathak & Nichter, 2015). Participants’ narratives also reflected considerable variability in relational experiences. Some women in fact described supportive partners or family members who acted as buffers against distress, offering understanding, reassurance, and practical support. Others, however, spoke of emotional friction arising from misunderstanding, minimization, or limited awareness of PCOS. These mixed experiences underscored how the quality of close relationships can either mitigate or exacerbate the psychological impact of the condition. Comparable patterns have been reported in research examining

psychosocial coping among women living with reproductive or chronic health challenges (Fido & Zahid, 2004; Soucie et al., 2021).

Role strain also extended beyond the family to encompass broader social expectations surrounding womanhood, emotional composure, and productivity. Participants described feeling pressure to remain emotionally stable, socially engaged, and consistently functional despite ongoing symptoms. When unable to meet these expectations, women reported feelings of guilt, frustration, and withdrawal. In this way, relational strain became intertwined with wider identity concerns, further shaping participants' perceptions of their quality of life. These findings align with health-related quality of life research highlighting the importance of social and role functioning as key dimensions of well-being in women with PCOS (Hillman et al., 2020; McCook et al., 2005).

These findings suggest that PCOS affects not only how women experience themselves but also how they relate to others and navigate social expectations. Role strain within family and societal contexts emerged as a significant dimension of health-related quality of life, highlighting the functional status domain of the health-related quality of life model and illustrates the relational and contextual nature of living with PCOS. Addressing these challenges may therefore require not only individual-focused interventions but also greater relational understanding, communication, and social support.

Theme 6: Cultural Stigma and Social Misunderstanding

Beyond relational and role-based challenges, participants' accounts made clear that living with PCOS was shaped not only by symptoms or healthcare experiences but also by broader cultural and social environments marked by silence, stigma, and misunderstanding. For many women, social judgement formed a persistent backdrop to everyday life, influencing how openly they spoke about their condition, how they sought support, and how they evaluated their quality of life. Reproductive and hormonal health were frequently described as sensitive or taboo topics, particularly within family-oriented and collectivist cultural contexts, where expectations surrounding womanhood, fertility, and emotional composure were strongly embedded (Batool & de Visser, 2014; Pathak & Nichter, 2015;).

Women described heightened awareness of how PCOS might be interpreted by others, especially in relation to fertility, physical appearance, and emotional stability. This awareness shaped patterns of self-presentation and disclosure. Some participants chose silence or selective sharing as a way of protecting themselves from judgement, gossip, or intrusive questioning, while others spoke of carefully managing how much of their condition was revealed in different social settings. Similar experiences have been documented in qualitative research highlighting how stigma surrounding women's reproductive health contributes to isolation and emotional distress (Dewani et al., 2023; Kitlinger & Willmott, 2002).

Notably, judgement was often experienced even in the absence of overt criticism. Participants spoke of anticipating blame or misunderstanding which influenced how they

interpreted social interactions and made sense of others' responses. In this way, cultural judgement became internalized, shaping emotional reactions, self-evaluation, and behavioral choices. This inward dimension of stigma aligns with past research showing that distorted illness perceptions and reduced perceived control are key contributors to psychological distress among women with PCOS (Fossey et al., 2023). In addition, these experiences were not static. Participants' narratives reflected ongoing negotiation between silence and disclosure. While some women remained guarded to preserve emotional safety, others gradually chose to speak more openly about PCOS, often framing disclosure as a way to educate others, challenge misconceptions, or reclaim a sense of agency. Similar patterns have been reported in studies examining how women navigate stigma and legitimacy in healthcare and social contexts related to PCOS (Ismayilova & Yaya, 2022). This movement between concealment and openness highlights stigma as a dynamic process rather than a fixed social condition.

The emotional consequences of cultural judgement were closely tied to participants' assessments of their well-being. Feelings of shame, frustration, and emotional exhaustion were common, particularly when cultural expectations surrounding fertility, appearance, or emotional restraint were perceived as unattainable. Recent empirical evidence supports this connection, showing that women facing stronger cultural pressure related to reproductive roles experience higher levels of psychological distress (Hassan et al., 2025; Ligoeka et al., 2024). In participants' accounts, social judgement intensified existing emotional strain and reinforced earlier themes of identity disruption and self-doubt.

Living with PCOS therefore involved more than managing physical symptoms or emotional responses; it required navigating cultural meanings about womanhood, legitimacy, and belonging. Social and cultural judgement shaped how women understood themselves, how they related to others, and how they evaluated their place within family and society. From a health-related quality-of-life perspective, these sociocultural dynamics emerged as emotionally consequential aspects of everyday life rather than distant background factors. Addressing stigma through culturally sensitive education, open dialogue, and broader social awareness may therefore be essential for supporting psychological well-being and social participation among women living with PCOS.

Theme 7: Coping and Acceptance

Alongside earlier themes of emotional strain, relational tension, and cultural judgement, participants' accounts also revealed gradual processes of coping and acceptance that shaped how they learned to live with PCOS over time. Coping was not described as a single response or endpoint but as an evolving process through which women renegotiated expectations, adjusted priorities, and sought to regain a sense of agency in their everyday lives. These processes were central to how participants evaluated their health-related quality of life, particularly in relation to emotional stability, self-efficacy, and perceived control.

Many participants described a psychological shift towards acceptance that marked a turning point in their experiences. Moving away from persistent self-blame, frustration, or resistance, women spoke of acknowledging PCOS as part of their lived reality rather than something to be constantly fought against. This shift did not imply resignation but

allowed participants to reframe the condition as manageable, reducing emotional distress and restoring a sense of internal balance. Similar associations between adaptive illness perceptions, acceptance, and improved emotional well-being have been documented among women with PCOS (Light et al., 2021; Fossey et al., 2023). The participants' accounts suggested that acceptance involved a reorientation of meaning rather than a loss of hope. Women described learning to integrate PCOS into their sense of self without allowing it to dominate their identity. In this way, acceptance functioned as an anchor that supported emotional resilience amid ongoing uncertainty. This process aligns with qualitative research highlighting how individuals with chronic health conditions reconstruct identity and regain coherence through meaning-making and self-compassion (Batool & de Visser, 2014).

Coping also took embodied and practical forms through lifestyle adaptation. Participants described adjusting diet, physical activity, rest, and daily pacing in response to bodily unpredictability and fatigue. These adaptations were framed not as rigid health regimens but as flexible responses to bodily signals, reflecting growing attentiveness to physical limits and needs. Consistent with studies emphasizing the role of health-related knowledge, self-efficacy, and behavioral adaptation in PCOS management, such changes were often experienced as empowering rather than restrictive (Lin et al., 2018; Moran et al., 2017). For many women, these practical adjustments supported a renewed sense of agency in daily life. By aligning routines with physical realities, participants described feeling more capable of managing symptoms and maintaining participation in work,

family, and social roles. These adaptations enhanced not only physical functioning but also emotional confidence and perceived competence in everyday activities.

Beyond individual acceptance and self-management, participants also drew strength from relational and spiritual resources. Supportive relationships with partners, family members, and peers provided reassurance, validation, and a sense of shared understanding. For some participants, faith or spiritual beliefs offered additional comfort, helping them contextualize their experiences within a broader life narrative and cope with uncertainty. The protective role of social and emotional support in mitigating psychological distress has been widely documented among women facing reproductive or chronic health challenges (Batool & de Visser, 2014; Fido & Zahid, 2004). As participants became more confident in managing their condition, coping gradually extended into self-advocacy. Women described seeking information, engaging with others who shared similar experiences, and speaking more openly about PCOS. This shift from internal adjustment to outward engagement reflected an emerging sense of empowerment and ownership over their health. Similar trajectories have been observed in qualitative studies examining how women navigate chronic conditions through knowledge-seeking, communication, and advocacy (Ismayilova & Yaya, 2022; Soucie et al., 2021;).

Living with PCOS therefore involved an ongoing process of adjustment rather than a fixed outcome. Through acceptance, lifestyle adaptation, relational support, and self-advocacy, participants worked toward reclaiming a sense of agency and stability in their lives. In the participants' accounts, coping and acceptance emerged not as passive

responses to illness but as active, meaning-driven processes that supported emotional resilience, identity integration, and sustained participation in everyday life.

Theme 8: Education, Awareness and Advocacy

Beyond the processes of coping and personal adjustment, the participants' accounts from the study also reflected a growing emphasis on education, awareness, and advocacy as important aspects of living with PCOS. Many women described an increasing desire to better understand their condition over time, particularly in response to earlier experiences of confusion, uncertainty, or perceived gaps in information following diagnosis. Seeking knowledge was often framed as a way to regain a sense of control and make more informed decisions about managing symptoms, lifestyle changes, and future health considerations. These experiences highlight how access to information and understanding can shape how women evaluate their health-related quality of life.

Participants described actively searching for information through healthcare providers, online resources, support groups, and conversations with others living with PCOS. For some, learning more about the condition helped reduce anxiety and self-blame by normalizing their experiences and clarifying misconceptions. This process of acquiring new knowledge was not only informational but also interpretative, as women described making sense of their symptoms and experiences within a broader framework of understanding. Similar findings have been reported in research highlighting how improved knowledge and health literacy can enhance self-efficacy and support more effective self-management among women with PCOS (Gibson-Helm et al., 2017; Lin et al., 2018).

Alongside increased awareness, few of the participants described a gradual shift toward advocacy, both for themselves and for others. Women spoke about becoming more confident in asking questions during medical consultations, seeking second opinions, or communicating their needs more clearly to family members and partners. This emerging sense of self-advocacy reflected a growing confidence in managing their condition and navigating healthcare interactions. In some cases, participants expressed a desire to share their experiences more openly in order to raise awareness and reduce stigma surrounding PCOS, particularly among younger women or those newly diagnosed. These experiences align with qualitative research indicating that women often engage in knowledge-sharing and advocacy as part of adapting to chronic conditions and reconstructing a sense of empowerment (Ismayilova & Yaya, 2022; Soucie et al., 2021).

Participants also highlighted perceived gaps in public awareness and understanding of PCOS, noting that misconceptions about the condition contributed to feelings of isolation and misunderstanding. Most of the women expressed hope that greater education among healthcare providers, families, and communities could improve support and reduce stigma. From a health-related quality of life perspective, these accounts suggest that education and awareness extend beyond information provision, shaping emotional well-being, social understanding, and perceived legitimacy of women's experiences. This theme therefore underscores how access to information and opportunities for dialogue can support women in making sense of their condition, fostering confidence, and fostering a greater sense of personal control while living with a chronic condition.

Overall Interpretation

Taken together, the themes identified in this study provide insight into how Malaysian women experience and interpret living with PCOS and how these experiences shape their health-related quality of life. Although many of the physical and psychological challenges described by participants are consistent with findings reported in previous PCOS research, the present study offers a deeper understanding of how these experiences are situated within the Malaysian sociocultural context. While existing studies in Malaysia have largely focused on prevalence, diagnosis, and biomedical aspects of the condition, far less attention has been given to how women themselves make sense of living with PCOS and the ways in which the condition affects their daily lives differently.

The findings of this study therefore contribute to the existing literature by highlighting the complex interplay between physical symptoms, emotional well-being, and social expectations in shaping women's experiences of PCOS. Participants described how symptoms such as irregular menstruation, infertility concerns, and changes in physical appearance affected not only their physical health but also their sense of identity, relationships, and confidence. In several accounts, these experiences were further influenced by cultural expectations surrounding femininity, fertility, and family roles. By exploring these lived experiences through IPA, this study provides a more refined understanding of health-related quality of life among Malaysian women with PCOS and adds context-specific insight to the broader body of PCOS research.

Theoretical Framework

This study was guided by Wilson and Cleary's (1995) health-related quality of life model, which conceptualises quality of life as the outcome of dynamic interactions between biological and physiological variables, symptom experience, functional status, general health perceptions, and overall well-being. The framework was chosen because it extends beyond traditional population health indicators and instead focuses on how health conditions are experienced and interpreted in everyday life. This orientation was particularly relevant for understanding PCOS that is often clinically assessed through biomedical markers but lived in ways that extend far beyond physiological symptoms. Across participants' accounts, physical manifestations of PCOS were rarely described in isolation. Instead, bodily symptoms were consistently linked to emotional responses, reduced functioning, and shifts in self-perception, reinforcing the interconnected domains proposed within the model.

Participants frequently described how fatigue, pain, and hormonal fluctuations affected their ability to function at work, regulate emotions, and engage socially, shaping their overall sense of quality of life. For example, P4 articulated this interconnection clearly when describing the cumulative impact of symptoms on daily functioning and emotional well-being which illustrated how symptom burden influenced not only physical comfort but also motivation, emotional regulation, work functioning, and social engagement. In line with Wilson and Cleary's model, quality of life emerged as a product of how symptoms were experienced and carried into everyday roles, rather than as a direct reflection of clinical severity alone. Beyond functional limitations, participants also

emphasized the psychological dimension of living with PCOS, particularly in relation to perceived control and emotional vulnerability. Even when symptoms were described as manageable, participants spoke of an underlying sense of emotional instability and reduced control that shaped how they evaluated their health and daily functioning. Women such as P5 described becoming more easily overwhelmed by minor stressors, accompanied by difficulty regulating emotions and articulating these experiences to others. This sense of diminished control was experienced as particularly distressing, as it affected not only emotional well-being but also participants' confidence in navigating everyday demands and relationships.

This pattern closely aligns with the model's emphasis on psychological processes and general health perceptions as central components of health-related quality of life. Importantly, these experiences were not isolated emotional reactions but were embedded within broader processes of self-evaluation, relational strain, and uncertainty about the future, all of which were reflected across the study's themes. While Wilson and Cleary's framework provide a robust structure for understanding these multidimensional experiences, the present findings also extend the model by highlighting the central role of meaning-making and identity. Participants' narratives demonstrated that quality of life was shaped not only by symptom presence or functional limitations, but by how PCOS disrupted their sense of self, coherence, and agency over time. In this way, the model offered a valuable foundation for interpretation, while the lived accounts captured in this study added depth to understanding how health-related quality of life is experienced, negotiated, and reconstructed among women living with PCOS.

Limitations of the Study

The present study explored the lived experiences of women diagnosed with PCOS, with a particular focus on how the condition influenced emotional well-being, identity, relationships, and health-related quality of life. Participants' accounts provided rich and meaningful insights into the multidimensional impact of PCOS and contributed to a deeper understanding of the condition beyond its biomedical features. Reasonable efforts were made throughout the research process to ensure methodological rigor, credibility, and ethical integrity. However, several limitations should be acknowledged.

The current study employed IPA with a small, purposively selected sample of seven participants. Although the initial recruitment plan aimed for a larger sample, the final number reflects participant availability, withdrawal, and non-attendance, which are common challenges in qualitative research involving sensitive health topics. In line with IPA methodology, this sample size remains appropriate for in-depth, idiographic analysis and allowed for a detailed exploration of participants' lived experiences.

Second, while the original inclusion criteria specified women aged 18 to 45 years, the final sample included participants aged between 29 and 50 years. This occurred as recruitment progressed and reflects the realities of purposive and snowball sampling in qualitative research. Although the inclusion of participants above the initially defined age range may limit strict comparability with the original sampling frame, it also introduced perspectives from women with longer illness trajectories and extended experience managing PCOS. Nevertheless, this variation should be considered when interpreting the findings.

The current study's participation was limited to Malaysian women who were fluent or able to converse in English. While this criterion facilitated in-depth interviews and detailed expression of lived experience, it may have excluded women who were less comfortable communicating in English or who preferred to speak in other languages commonly used in Malaysia. As a result, the findings may not fully capture the experiences of women from different linguistic or educational backgrounds. Additionally, participants were recruited using a purposive snowball sampling method, which was considered appropriate given the private and often stigmatized nature of PCOS. However, this approach may have resulted in a sample with shared social or informational characteristics, as women who were more open about their diagnosis or connected to existing networks may have been more likely to participate. Consequently, the range of perspectives represented in the study may have been limited, which may also affect the transferability of the findings to women with PCOS in other social, cultural, or linguistic contexts within Malaysia or beyond. However, consistent with qualitative research principles, the detailed descriptions of participants' experiences provided in this study allow readers to determine the extent to which the findings may be applicable to other settings.

As data were collected through semi-structured interviews conducted via the Zoom platform, this approach offered practical advantages and allowed participants to engage from familiar and comfortable environments. However, the absence of face-to-face interaction may have limited the observation of non-verbal cues and more subtle interpersonal dynamics. In addition, reliance on stable internet connectivity and digital

access may have influenced participants' level of comfort or engagement during the interviews. The findings also reflect the interpretative nature of phenomenological analysis. In keeping with the principles of IPA, the study involved a double hermeneutic process in which participants made sense of their experiences and the researcher, in turn, interpreted these accounts. Although reflexive practices, bracketing, and peer debriefing were employed to enhance transparency and credibility, complete objectivity is neither possible nor intended within this methodological framework.

In conclusion, these limitations helped to clarify the scope and contextual boundaries of the study while reinforcing the value of its contribution. By situating the findings within clearly defined methodological constraints, the study offered a refined and contextually grounded understanding of how Malaysian women experienced and interpreted the impact of PCOS on their health-related quality of life.

Recommendations

The findings of this study highlighted the multidimensional impact of PCOS on women's health-related quality of life, extending beyond physical symptoms to encompass emotional well-being, identity, relationships, and sociocultural context. During the interviews, many participants spoke not only about managing symptoms, but also about the emotional and relational challenges of living with PCOS, often describing unmet needs in communication, support, and understanding. In light of these accounts, several recommendations are proposed for clinical practice, patient education and support, healthcare systems, and future research.

Practice Implications for Healthcare Providers

Participants' accounts suggested that clinical encounters related to PCOS were often experienced as focusing primarily on physical symptoms, diagnostic criteria, or reproductive outcomes, with comparatively less attention given to emotional distress or broader quality-of-life concerns. Women described feeling that the psychological and relational impact of PCOS was not always acknowledged during consultations, despite these aspects significantly shaping their day-to-day experiences. Information from the data indicated that greater awareness of patients' emotional and psychosocial concerns during clinical interactions may support more person-centred and responsive care.

The findings also highlighted the importance of clear, empathetic communication at the point of diagnosis and during follow-up care. Participants frequently described confusion, emotional overwhelm, or lingering uncertainty after receiving a PCOS diagnosis, often linked to limited explanations or fragmented information. These experiences suggested that opportunities for clarification, reassurance, and ongoing dialogue may play a meaningful role in supporting women's adjustment to the condition and their engagement with care over time. More importantly, these experiences pointed to a potential need for greater sensitivity to how women interpreted and lived with PCOS beyond its biomedical presentation. Participants' narratives emphasized that feeling heard and understood was closely tied to their sense of trust, perceived control, and willingness to engage in health-related decision-making. From this perspective, attending to patients' lived experiences may enhance the therapeutic relationship and contribute positively to overall health-related quality of life.

Patient Education and Support

The majority of the participants spoke during the interviews about feeling isolated in their experiences, particularly when emotional distress, body image concerns, or uncertainty about the future were not openly discussed. These accounts highlighted the need for accessible and culturally sensitive education and support initiatives that addressed both the medical and psychosocial aspects of PCOS. Educational resources that normalize emotional responses and identity-related challenges may help reduce self-blame and foster greater self-understanding. Participants also described the value of feeling understood by others with similar experiences. In this context, peer support initiatives may offer meaningful opportunities for validation, shared learning, and emotional reassurance. Future support programs could explore formats that respect privacy and cultural sensitivities, particularly given the stigma surrounding reproductive and hormonal health in many settings.

Healthcare Systems and Policies

The participants' accounts pointed to gaps in coordinated care, particularly in relation to emotional and psychological support. These findings suggested that healthcare systems may benefit from greater integration of psychosocial services within PCOS management pathways. Interdisciplinary approaches that involve medical, psychological, and allied health professionals may help address the full spectrum of needs associated with PCOS. In addition, broader public health initiatives aimed at increasing awareness and understanding of PCOS may help reduce stigma and social misunderstanding. Educational efforts that present PCOS as a complex and legitimate health condition,

rather than a condition defined solely by fertility or appearance, may actually contribute to more supportive social and healthcare environments.

Recommendations for Future Research

Finally, future studies may build on the findings of this research by exploring the lived experiences of women with PCOS across a wider range of cultural, linguistic, and socioeconomic contexts. Including participants who are not fluent in English may offer further insight into how language, access to information, and healthcare navigation influence quality-of-life experiences. Future research should also consider longitudinal qualitative designs to examine how women's experiences of PCOS, coping strategies, and perceptions of quality of life evolve over time. Such studies may be particularly valuable in exploring transitions across different life stages, including diagnosis, relationship formation, fertility-related decision-making, and aging with PCOS. Additionally, future studies could also explore mixed-methods approaches that integrate qualitative accounts with validated health-related quality-of-life measures. This may help to further illuminate how the lived experiences of women align with, or diverge from, standardized clinical assessments.

Implications

The findings of this study have broader implications for how PCOS is understood and addressed beyond individual experiences of care. By highlighting women's lived accounts, the study underscored the importance of viewing health-related quality of life as a multidimensional and dynamic construct shaped not only by physical symptoms but also by emotional responses, relational contexts, and sociocultural expectations. Rather

than focusing solely on biomedical indicators, this perspective emphasizes the importance of recognizing women's lived experiences as central to how PCOS is understood and supported. At a broader level, the findings suggest that healthcare systems may benefit from greater integration of psychosocial considerations within PCOS care pathways. Participants' experiences pointed to gaps in continuity, coordination, and recognition of emotional and identity-related concerns, indicating that fragmented models of care may not fully reflect how PCOS is lived over time. Approaches that allow for ongoing engagement, flexibility, and attention to changing needs across the life course may better align with women's experiences and support more meaningful quality-of-life outcomes.

The study also has implications for education and awareness. Participants' accounts reflected persistent misunderstanding and stigma surrounding PCOS, particularly in relation to fertility, physical appearance, and emotional regulation. These experiences highlighted the need for broader educational efforts that present PCOS as a complex and legitimate health condition, rather than one narrowly defined by reproductive function or visible symptoms. Increased awareness may help foster more informed conversations within families, workplaces, and communities, potentially reducing isolation and self-blame among women living with PCOS.

In addition, the findings pointed to the importance of centering women's voices in future research. Qualitative approaches, including IPA, offer valuable insight into how health conditions are experienced, interpreted, and managed in everyday life. Future studies may build on this work by exploring diverse cultural, linguistic, and

socioeconomic contexts, as well as by adopting longitudinal designs to examine how perceptions of PCOS and quality of life evolve over time. Integrating qualitative insights with established quality of life frameworks may further strengthen understanding of PCOS as both a biomedical condition and a lived experience.

Together, these implications emphasized the value of adopting more holistic, context-sensitive approaches to understanding and supporting women with PCOS. By situating health-related quality of life within lived experiences, this study contributes to ongoing efforts to bridge the gap between clinical knowledge, social understanding, and women's everyday realities.

Conclusion

This study explored the health-related quality of life of Malaysian women living with PCOS, with a particular focus on how the condition is experienced and interpreted in everyday life. Through an interpretative phenomenological approach, the findings revealed that PCOS was not experienced as a collection of isolated symptoms, but as an ongoing and deeply personal condition that shaped emotional well-being, identity, relationships, and future expectations. Women's accounts highlighted how physical changes, uncertainty, and social and cultural pressures intersected to influence how they made sense of themselves and their health over time.

By drawing on Wilson and Cleary's health-related quality-of-life model, this study offered a structured yet flexible framework through which participants' experiences could be understood. The findings demonstrated how biological symptoms, emotional responses, general health perceptions, and social functioning were closely interconnected,

reinforcing the value of viewing quality of life as a dynamic and multidimensional process rather than a fixed outcome. Importantly, the study showed how women's lived experiences often extended beyond what is typically captured in clinical assessments, underscoring the relevance of experiential knowledge in understanding PCOS.

The study also contributed to the limited qualitative literature on PCOS within the Malaysian context. By centering women's voices, it provides insight into how cultural expectations, stigma, and relational dynamics shape the experience of living with PCOS. These findings highlighted the importance of attending to sociocultural context when considering health-related quality of life, particularly in settings where reproductive and hormonal health remain sensitive or misunderstood topics.

While the findings are grounded in a small and context-specific sample, they offer a rich and nuanced account of how PCOS is lived and managed over time. Rather than aiming for generalization, this study sought to deepen understanding of women's experiences, offering perspectives that may resonate with others facing similar challenges and inform future research and practice. In other words, this study underscored the value of listening to women's stories in making sense of PCOS as a lived condition. By foregrounding experience, meaning-making, and quality of life, this research highlights the importance of approaches that recognize women not only as patients, but as individuals navigating complex physical, emotional, and social realities. It is hoped that this work contributed to more compassionate, informed, and context-sensitive understandings of PCOS and its impact on women's lives.

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[x](#)

Appendix: Interview Questions

Demographic Questions:

1. How old are you?
2. Which state are you currently residing in?
3. What is your ethnic or cultural identity? (e.g., Malay, Chinese or Indian)
4. What is your current marital status?
5. Do you have any children? If yes, how many?
6. What is the highest level of education you have completed?
7. Are you currently working?
8. Is English your first language?
9. What is your weight (in kg)?
10. What is your height (in cm)?
11. When were you diagnosed with polycystic ovarian syndrome (PCOS)?
12. Do you currently have any of these medical conditions like
 - a. Diabetes
 - b. Hypertension
 - c. Heart disease
 - d. High cholesterol
 - e. Thyroid problems
 - f. Infertility
 - g. Endometriosis
 - h. Depression

- i. Migraines
- j. Anxiety

Probe: If yes to any of the above, do you have a primary care doctor? Were you informed if any of these conditions are related to your PCOS?

If no to any of the above, are you concerned or afraid of being diagnosed with any of these conditions/diseases?

Interview Questions:

1. Tell me about yourself – what are your hobbies?
2. How would you describe your health in general?
3. What does having PCOS mean to you?
4. What feelings did you encounter because of PCOS? Please explain them.
5. Can you also share any concerns you have of PCOS? Probe: talk about symptoms (e.g., growth of visible hair on face, overweight, weight loss, mood swings, irregular menstruation, self-conscious, infertility, low sex drive, constantly worried, lack of control of the situation)
6. Can you tell me about your experience(s) related to the diagnosis of your condition (PCOS)?
7. What feelings or emotions did you have when you found out you had PCOS? (Probe: what sort of emotions – positive or negative e.g. relief, sadness, embarrassment or neutral etc)
8. Does having PCOS affect your self-esteem in one way or another?

9. Have you ever felt like you don't know what to do to help yourself deal with PCOS?
10. What coping strategies did you adopt upon diagnosis?
11. Were these strategies self-taught or suggested by a medical practitioner?
12. In your opinion were any of these strategies effective – why or why not?
13. Tell me about any problems you have had with work or other regular activities as a result of any emotional problems? Were these emotional problems related to the PCOS? Or as a result of your physical health related to PCOS?
14. (If no to children, but married) Are you and your spouse trying for a baby?
15. (If answered yes to children) What was your pregnancy journey like?
16. How has having or knowing you have PCOS impacted your daily life?
17. Did you share your diagnosis with your family and/or close friends? (Probe: what were their response like?)
18. What would you consider the best thing that has happened to you since you had PCOS?
19. In your opinion, how do you think PCOS affects other women with the same condition?
20. Were you able to have access to support or reach out openly about your condition? i.e., do you feel that it's difficult for women in Malaysia to openly talk about PCOS or any of their issues?
21. Do you know anyone else with PCOS? How do you know them?

22. What would you like to have known or done differently if you could go back to the start of your diagnosis?
23. Are there any tips that you can offer to women out there experiencing the same or similar problems?