School of Nursing and Midwifery
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An exploration of Western Australian women's experience of receiving a diagnosis of Polycystic Ovary Syndrome

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This thesis is presented for the Degree of
Master of Philosophy (Nursing and Midwifery)
Curtin University

August 2024

Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007), updated March 2014. The proposed research study received human research ethics approval from Curtin University Haman Research Ethics Committee. Approval number #HRE2019-0026

Signed:

Sara Veness

Date: August 2024

Abstract

This qualitative study explored the Polycystic Ovary Syndrome (PCOS) diagnosis experiences of 20 women in Western Australia (WA). PCOS diagnosis experiences of women have not been previously qualitatively well researched, and this is the first WA study known, to date, exploring women's diagnosis experiences of the condition. PCOS is commonly undiagnosed and therefore true representation of the number of women affected by the condition is unknown. It is a multisystem condition that can cause issues with reproductive, endocrine and menstrual health, impacting women in a multitude of ways. Few comprehensive studies focusing on PCOS diagnosis exist, and while they have pointed to issues with diagnosis, resources, education and support they have not provided adequate details around these to allow for improvements. Hence, the study aimed to explore the PCOS diagnosis experiences of Western Australian women to identify their support and education needs and improve the diagnosis process.

The study used a qualitative descriptive exploratory approach. Twenty participants were asked a series of five semi-structured questions through face-to-face and telephone interviews, exploring their experiences with obtaining a PCOS diagnosis in WA. Transcribed interviews were analysed using a process of thematic analysis, revealing four themes, with fourteen linked sub-themes. The four main themes were: 'lead up to diagnosis', 'diagnosis of PCOS', 'life after diagnosis' and 'listening to women'. Key findings included women experiencing a lengthy and frustrating process to get a PCOS diagnosis, women feeling dissatisfied with healthcare providers' interaction and knowledge, a reported lack of resource provision by healthcare providers to support health literacy and empower women and, a lack of community awareness and support related to PCOS. Additionally, participants highlighted the impact PCOS had on their mental health and emotional wellbeing.

In summary findings from this study support existing literature, indicating the need for improvements to the diagnosis process, how the diagnosis is communicated and subsequent care for the woman and strongly demonstrates the importance of providing adequate and appropriate support to women at diagnosis. Findings highlight the need for a more collaborative approach with women and the importance of the healthcare provider-patient rapport in developing this partnership. The myriad of comorbidities linked to PCOS point strongly to utilising a multidisciplinary team approach, with a focus on early preventative management and referral. Further research is needed to explore how healthcare provider knowledge of PCOS can be enhanced; to identify strategies to manage PCOS associated weight gain, through appropriate diet, lifestyle management and exercise; to develop appropriate health literacy resources to support women; and to implement nurse/midwife-led models of care to increase support to women during and after PCOS diagnosis. The current study has contributed to the growing body of knowledge surrounding PCOS by providing a voice for WA women, enabling their experiences of receiving a PCOS diagnosis to be used to help improve current practice and care.

Acknowledgement of country

We acknowledge that Curtin University works across hundreds of traditional lands and custodial groups in Australia, and with First Nations people around the globe. We wish to pay our deepest respects to their ancestors and members of their communities, past, present, and to their emerging leaders. Our passion and commitment to work with all Australians and peoples from across the world, including our First Nations peoples are at the core of the work we do, reflective of our institutions' values and commitment to our role as leaders in the Reconciliation space in Australia.

Acknowledgement

I would like to acknowledge the 20 women who participated in this study and shared their PCOS diagnosis experiences with me. A heartfelt thanks to each of you for providing me with your valuable time and information that has formed this research. Thank you for inviting me into your homes, and lives to hear your journeys and for entrusting me to share them. You all showed such strength and vulnerability sharing your experiences, that brought a myriad of emotions as you retold them, some of you for the first time. Together I hope to improve healthcare for women and increase the focus on PCOS. I have the highest admiration for you all, thank you ‘cysters’.

I cannot thank my two supervisors enough, Associate Professor Ravani Duggan and Doctor Lesley Kuliukas who have supported me through writing my thesis. Thank you for sharing your wisdom and knowledge and always pointing me in the right direction. I am grateful for your supervision and expertise over the past 6 years.

To my loyal dachshund dogs Charlie and Alice who sat with me in my home office, day and night while I wrote. The early mornings and late nights were made easier, having you by my side. If only you both knew how much it meant to me.

Finally, to my husband Arron Veness, who has been my constant, who stood by me when I doubted myself and who kept me grounded while I continued to work full time as a midwife, through many roles and varying hours. Thank you for always being there for me and for everything you did. I could not have done this without you and all of the love you gave me. Thank you for supporting me endlessly and always encouraging me to achieve my best. It is your unwavering support that ultimately helped me to finish this thesis.

This thesis is dedicated to, and in in loving memory of, my Nana, Pamela Joan Zimdahl, 6th of June 1933 – 8th of February 2023. A woman who taught me more than she will ever know and who always gave me her time, love and kindness.

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Glossary of Abbreviations

For the purposes of this study the following abbreviations and definitions have been listed as terms that may not be universally understood.

Abbreviation	Term
AAP	American Academy of Paediatrics
AES	Androgen Excess Society
NIH	National Institutes of Health
AMA	Australian medical association
BMI	Body mass index
GDM	Gestational diabetes mellitus
GP	General practitioner
HCP	Healthcare professional
IUD	Intrauterine device
NHMRC	Australian National Health and Medical Research Council
NP	Nurse Practitioner
OCP	Oral contraceptive pill
PATS	Patient-assisted travel scheme
PCOS	Polycystic ovary syndrome
PMS	Western Australia
QOL	Premenstrual stress
RA	Remoteness area
RACGP	Australian College of General Practitioners
RFDS	Royal Flying Doctors Service
WA	Western Australia
WACHS	Western Australian Country Health Service

Chapter One

Introduction

Polycystic Ovary Syndrome (PCOS) is a commonly underdiagnosed multisystem condition that affects the health of 8 – 13% of women of reproductive age worldwide (Gibson-Helm et al., 2017; Monash University, 2018). Management of the condition is dependent on symptoms and can range from changes to lifestyle, such as diet and exercise to medical intervention (Cowan et al., 2023). PCOS can cause reproductive, endocrine and menstrual health issues and may lead to greater health concerns for affected individuals (Boyle et al., 2012). This thesis reports on a study that explored the behaviours, feelings and lived experiences of Western Australian (WA) women who had received a diagnosis of PCOS prior to the study's commencement. A review of the existing literature revealed this study to be the first known qualitative study in WA to explore women's diagnosis experiences of PCOS, adding to and expanding on findings from prior qualitative and quantitative studies within Australia (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014). This study presented women with PCOS, who met the study criteria, the opportunity to share their experiences through an in-depth interview with the researcher, revealing new information pertinent to the delivery of the PCOS diagnosis and the on-going management of the condition.

A qualitative approach was best suited to the research problem as it allowed for the exploration of behaviour, feelings and lived experiences of women who had received a diagnosis of PCOS. It enabled the researcher, as the research instrument, to be immersed in the setting and to collect rich data from the participants, highlighting the depth and fullness of the experiences of women with this common endocrine condition (Holloway & Wheeler, 2010). According to Streubert and Carpenter (2011) qualitative research should encompass the participant's viewpoint which must be the central focus and the researcher must provide an accurate representation of the experiences shared by the participants. The need to present study findings in a narrative style capturing the participants' real-life accounts offers depth and richness in describing participants' experiences and is an important component of qualitative study. To understand the participants' perspective it is important to understand their circumstances and experience of the phenomenon under study; this has been demonstrated through the use of purposive sampling and semi-structured interviews, helping the researcher to understand the lived experience of the study participants (Streubert & Carpenter, 2011). The chosen methodological approach aligned with the aim of the study, which was to capture a clear, rich and full description of WA women's experience of receiving a diagnosis of PCOS.

Chapter One of this thesis includes a background to the research problem, the problem statement, study aim and objectives, study significance and a researcher positionality statement. The chapter will also provide a brief overview of the whole thesis and then finally conclude with a summary of key points and an introduction to Chapter Two, the literature review.

1.1 Background to the research problem

1.1.1 Definition of PCOS

PCOS is a common endocrine condition that can affect a woman's reproductive, metabolic, and psychological health. The cause of PCOS remains unknown, it is noted that due to a wide variation in the clinical features of the condition and the availability and use of different diagnostic criteria, diagnosis can be a lengthy and frustrating process for women with the condition (Dennett & Simon, 2015). PCOS has been recognised as a major public health issue with many women remaining largely undiagnosed (Monash University, 2018). Characteristic reproductive features include infertility (with anovulation reported to be the most common cause of infertility), hormonal imbalances leading to hair and skin issues, a greater risk for gestational diabetes mellitus (GDM) and first trimester miscarriages. Metabolic influences result in impaired glucose tolerance and a greater risk of developing Type 2 Diabetes. Women are also susceptible to early menopause, cardiovascular disease risk factors, including hypertension, impaired blood vessel function and hyperlipidaemia. Psychological outcomes include increased dissatisfaction with body image and increased risk of anxiety, mood and eating disorders (Dennett & Simon, 2015). Women with PCOS are at greater risk of developing other comorbidities; it has been identified that women would benefit from this information and also that healthcare professionals (HCPs) may be required to increase their knowledge of PCOS and associated co-morbidities to better support women following diagnosis (Tomlinson et al., 2013; Weiss & Bulmer, 2011). The compounding effect on risk factors associated with PCOS highlights the complexity and significance of the condition and the need to further develop the care provided to women living with PCOS. More detailed information on the associated health issues will be presented later in the chapter as a separate section.

Women being diagnosed with PCOS have described a variety of issues regarding self-image and self-esteem, as found by Snyder (2006). In the American qualitative study of 12 women, aged 21 – 48 years, the lived experience of women diagnosed with PCOS was explored and participants reported having increased weight gain, unwanted hair growth and severe mood swings compared to women without PCOS. The participants highlighted the importance of sourcing a healthcare provider who help them gain control of their condition, manage their feelings of guilt in relation to their increased weight and provide strategies to help deal with living with PCOS (Snyder, 2006). Similarly, another American qualitative study by Weiss and Bulmer (2011), with 12 young participants (18 – 23 years) diagnosed with PCOS, found that the women reported feelings of physical inferiority and concerns regarding long term health complications. Another frustration experienced by their participants was the perceived gaps in healthcare providers' knowledge, resulting in delayed diagnosis and poor delivery of information (Weiss & Bulmer, 2011). These two American studies highlight some of the difficulties faced by women with PCOS and emphasise the need for further exploration to improve the current understanding of PCOS diagnosis experiences.

1.1.2 Incidence and financial burden of PCOS

The incidence of PCOS is reported to be 8 – 13% of women of reproductive age worldwide (Monash University, 2018). From a worldwide perspective, the ability to diagnose PCOS has been recognised as one that comes with great difficulty, not only due to the variation in clinical features but due to the use of different diagnostic criteria (Deeks et al., 2011; March et al., 2010; Shannon & Wang, 2012; Snyder, 2006; Tomlinson et al., 2013). The three criteria being used to diagnose PCOS include the National Institutes of Health (NIH) criteria, the Rotterdam Criteria and the Androgen Excess Society (AES) criteria (March et al., 2010). Confusion over diagnosis was highlighted in a quantitative Australian study of 728 women born at a single maternity hospital in South Australia over a 2-year period (between 1973 – 1975). The women were traced and interviewed in adulthood, aged 27 – 34 years, in order to compare the three PCOS diagnostic criteria to create a representative prevalence of PCOS in the community. It was found that there was an increase in the number of women who met diagnosis of the condition under the Rotterdam criteria and AES criteria compared to a lower prevalence when the NIH criteria was applied, in fact estimates were up to two times higher with the Rotterdam criteria and AES criteria compared with the NIH criteria. Shannon and Wang (2012), acknowledge challenges with the availability of multiple criteria used in diagnoses of the common condition (Shannon & Wang, 2012). This Australian study highlighted that the use of different diagnostic tools could result in variances in the incidence of the condition which is dependent on the criteria used by HCPs (March et al., 2010). Having multiple criteria available results in differences with diagnosis. These studies highlight disparities in diagnoses due to the use of different criteria, leading to inaccurate incidences of

PCOS which presents further confusion for HCPs who need to have an awareness of the multitude of different presenting features of the condition.

A review of the literature did not reveal a reported incidence of PCOS in Australia; no current statistics were found. Published information on the prevalence of PCOS is reported as ‘women of reproductive age’ not specific to individual countries, such as Australia (March et al., 2010; Shannon & Wang, 2012; Spritzer, 2014). However, studies have been conducted with groups within the population including Indigenous women from Darwin, Australia, investigating the prevalence of PCOS among a sample of urban Indigenous women (Boyle et al., 2012). The International Evidence-Based Guideline for the Assessment and Management of PCOS 2018, reports the condition as affecting 8-13% of women of reproductive age with up to 70% of women remaining undiagnosed (Monash University, 2018). The guideline (Monash University, 2018) also highlights that incidences vary depending on the woman’s ethnicity, with Indigenous women having a higher prevalence when compared to non-Indigenous women and also suffering from more complications of the condition than non-Indigenous women.

The financial implications of PCOS for women and the healthcare systems worldwide have been considered by many authors, for example an American study (Marin et al., 2005), using a systematic literature review of published medical literature from almost four decades, provided estimated costs of PCOS on the healthcare system (adjusted using inflation measurements at the time). The costs were calculated using lower than current estimations of PCOS prevalence and found anticipated healthcare related economic costs of PCOS to be $4.36 billion (USD) annually. The total amount could be broken down into three main categories; anovulation (31%), infertility (12%) and PCOS associated diabetes (40%). In 2006 this calculation equated to an estimated annual economic cost of $400 million (AUD) in Australia and was considered a “major health and economic burden” (Teede et al., 2010, p. 2). These estimations give some insights into the present-day financial impact PCOS has on the

Australian healthcare economy. In light of the findings by Teede et al. (2010), this new WA study may help to reduce the current associated costs of PCOS through expanding current knowledge surrounding diagnosis delivery and management of the condition. The present study has added to the evidence of understanding current practices and provision of care for women with PCOS. If women are satisfied with the care, information and support they receive at diagnosis, they may not need to seek further consultation from other HCPs or make multiple visits to the same HCP. It is known from previous research that many women see more than three HCPs before a diagnosis of the condition is confirmed (Gibson-Helm et al., 2017). The study reported in this thesis provides an understanding from the women's perspective of the diagnosis experience; this knowledge may contribute to reducing the current cost burden to the Australian healthcare system. Additionally, it has the potential to assist with decreasing the financial and emotional cost surrounding diagnosis of PCOS that women are reported to experience (Gibson-Helm et al., 2017; Marin et al., 2005; Teede et al., 2010).

1.1.3 PCOS diagnosis

As previously mentioned in this chapter there are three criteria used to diagnose PCOS (March et al., 2010). The NIH criteria (1990) require both of the following symptoms to be present: clinical and/or biochemical signs of hyperandrogenism and chronic menstrual irregularity due to oligomenorrhea and/or anovulation. The Rotterdam criteria (2003) require any two of the following three symptoms to be present: clinical and/or biochemical hyperandrogenism, oligomenorrhea and/or anovulation and polycystic ovaries detected on ultrasound scan (Tomlinson et al., 2013). The AES (2006) criteria require presence of hyperandrogenism clinical or biochemical in combination with ovarian dysfunction; oligomenorrhea and/or anovulation, and/or polycystic ovaries (PCO) detected on ultrasound scan, with a central feature of androgen excess and after exclusion of other possible causes (Azziz et al., 2009; March et al., 2010). The main diagnostic tool used for PCOS detection in

Australia, is the Rotterdam diagnostic criteria (Boyle & Teede, 2012; Monash University, 2018), which is recommended for use by the International Evidence-Based Guideline for the Assessment and Management of PCOS (Monash University, 2018), with further detail provided later in the chapter.

An Australian quantitative study from 2014 on PCOS diagnosis experiences, involving 210 women who completed online or paper-based questionnaires, highlighted some of the issues surrounding PCOS diagnosis. The issues included inadequate provision of information at time of diagnosis, a lengthy diagnosis period (>2 years for one quarter of the women) and reported dissatisfaction with diagnosis delivery. These findings suggesting areas for improvement in the provision of care for women with the common condition (Gibson-Helm et al., 2014). While this provided insight into the experience of Australian women, it was limited in that it captured a broad snapshot using a quantitative descriptive survey and that further in-depth study using a qualitative approach was needed. Following this study a larger quantitative study was conducted with 1385 women (53% North America, 42.2% Europe and 4.9% living in other world regions), aged 18 – 35 years linking delayed diagnosis and a lack of information with dissatisfaction in women with PCOS (Gibson-Helm et al., 2017). This international study found that more than one third of women reported that on average it took longer than two years and included more than three HCPs to reach a diagnosis of PCOS. In studies focusing on PCOS diagnosis women reported poor satisfaction with their diagnosis experience and the information given to them, which further supported the need to understand women's PCOS diagnosis experiences and improve the way that it is managed (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017). Both of these studies were quantitative studies using questionnaires to obtain information about women's diagnosis of PCOS, an in-depth exploration was not carried out as there was no qualitative component to the studies, which further supported the need for a qualitative study to expand and provide depth of knowledge surrounding PCOS diagnosis. Recommendations from the quantitative study by Gibson-Helm et al. (2014) on women’s diagnosis experiences of PCOS concluded with a recommendation for a qualitative study that would complement quantitative findings and add richness to prior studies. Studies focusing on PCOS diagnosis (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014; Gibson-Helm et al., 2017) have focused on issues such as diagnosis, resources, education and support; this WA study aimed to provide further detailed information to inform HCPs and help improve the experience of women diagnosed with PCOS.

Geographical location of women with PCOS may also impact their diagnosis experiences. Western Australia has the largest land area by square kilometre compared with any other state and territory in Australia (Commonwealth of Australia, 2019). Although it does not have the largest population compared with the other states or territories, the vastness of the state creates further problems for women with PCOS including access to medical services. The ‘National Strategic Framework for Rural and Remote Health’ (NSFRRH) document assigns each state and territory a code, graded according to remoteness area (RA), using the Australian geographic classification system (The Department of Health, 2016). The grades range from RA1 to RA5 with 5 being the highest area of remoteness according to the classification scale. The majority of WA was classified as RA5; very remote Australia. The NSFRRH states that “the health of Australians in rural and remote areas is generally poorer than that of people who live in major cities and towns” (The Department of Health, 2016, p. 14).

The NSFRRH document highlighted the differences in health care provision with healthcare services in rural and remote areas not providing the same level of care as metropolitan city services. There is a dependence on primary healthcare services, specifically GPs and consequently patients have to travel further to access specialised medical care. According to a Royal Australian College of General Practitioners (RACGP) report on the ‘Health of the Nation’ published in 2018 there were 61.5 GPs per 100,000 population in very remote areas of Australia in comparison to 101.3 per 100,000 in major cities. In the entirety of WA there were 78.9 General Practitioners (GPs) per 100,000 equating to the third lowest prevalence of GPs compared to all other jurisdictions (The Royal Australian College of General Practitioners [RACGP], 2018). This highlights the inequality in medical services and availability of healthcare providers and further supported the need for women to describe their experiences in the study reported in this thesis.

A South Australian study focused on information needs of women diagnosed with PCOS (Avery & Braunack-Mayer, 2007) and included 10 women, however the study did not specify where the women were located, such as metropolitan or rural areas within SA. It was therefore difficult to evaluate whether the findings would be transferable to the unique WA context. Another Australian study that used a quantitative approach (Banting et al., 2014), focused on PCOS diagnosis experiences of women, and included 210 participants with 27% from rural areas. While this provides some insight into the experience of women living in rural areas, the data was collected using a questionnaire only, with no qualitative component, therefore in-depth exploration of women's diagnosis experiences did not occur. Additionally, this study did not specify the specific geographical location of the women; the state or territory within Australia was unknown making it difficult to ascertain whether the findings were generalisable to women living with PCOS in WA. Further exploration of women's experiences of receiving a PCOS diagnosis in different settings was required to establish whether they faced similar or different issues. The WA study reported in this thesis included women from metropolitan and rural areas of the state.

1.1.4 Guidelines and management options

The requirement for an international guideline for PCOS has been long awaited, with several studies over the last 10 years recognising the difficulties women with PCOS faced due to conflicting opinions and advice. In 2011, the Australian National Guidelines for PCOS were published, titled ‘Evidence-based Guideline for the Assessment and Management of Polycystic Ovary Syndrome’, with the aim of assisting clinical decision-making and supporting women with the condition. Establishment of the Australian National Guideline followed a meeting of PCOS leaders from research, clinical areas and the community in 2008, facilitated by the Jean Hailes Foundation for Women’s Health by the PCOS Australian Alliance. There was acknowledgement that the development of such a guideline was overdue as there were no international guidelines for PCOS at the time (Alliance, 2011) and was needed to support management of the condition in Australia. Later, in 2018, the Australian National Health and Medical Research Council (NHMRC) approved publication of the ‘International Evidence-Based Guideline for the Assessment and Management of Polycystic Ovary Syndrome’, published by Monash University, Melbourne. The guideline was developed with assistance from the Centre for Research Excellence in Polycystic Ovary Syndrome, the European Society of Human Reproduction and Embryology, the American Society of Reproductive Medicine, professional societies and international consumer advocacy groups. The International Guideline replaced previous publications, including the original 2011 National Guideline (Monash University, 2018). The new International Guideline supports the use of the Rotterdam PCOS diagnostic criteria with the aim “to develop and translate rigorous, comprehensive evidence-based diagnosis, assessment and treatment guidelines, to improve the lives of women with polycystic ovary syndrome (PCOS) worldwide” (Monash University, 2018, p. 5) and is the main guideline still in use in Australia today.

With International guidelines now available for practitioners, PCOS management and treatment options for women suffering from the condition can be followed to suit individual need. Similarly in a study by Teede et al. (2010), medical therapy for PCOS was recommended to be targeted to PCOS symptoms and individual need including oligomenorrhoea/ amenorrhoea, hirsutism, pharmacological treatment, infertility and metabolic issues. Symptom management of PCOS is recognised as being difficult for women with the condition and also for the clinicians providing treatment options (Teede et al., 2010). Support, education, a healthy lifestyle and psychological wellbeing are all important in the treatment of PCOS (Teede et al., 2010). It has been established that screening for PCOS should encompass detailed history taking and physical examination, as it is known that the condition may affect metabolic, reproductive and endocrine systems (Lucid, 2017). The recommendation for management of PCOS to include early diagnosis, intervention and collaborative care by a multidisciplinary team was also confirmed by Gibson-Helm et al. (2014) in their world-wide cross-sectional study of 1385 women. More information on these recommendations is provided in chapter two of this thesis.

1.1.5 Awareness of PCOS associated comorbidities

As mentioned earlier, PCOS has many associated health issues, some of these include, however not limited to; a greater risk of type 2 diabetes mellitus, infertility, endometrial cancer, and mental health conditions such as depression (Shannon & Wang, 2012). Comorbidities associated with PCOS are discussed in detail throughout chapter two of this thesis. In a study by Tomlinson et al. (2013) it was acknowledged that women with PCOS have a general awareness of the comorbidities associated with the condition, however they had difficulties obtaining helpful information following initial diagnosis. Tomlinson et al. (2013) highlighted the need for women with PCOS to be provided with information on potential comorbidities including cardiovascular risks and type 2 diabetes and highlighted the importance of screening for PCOS related comorbidities. Studies (Lamvu et al., 2020; Tomlinson et al., 2013; Tomlinson et al., 2017) have indicated that healthcare professionals lack awareness of PCOS associated comorbidities and the screening for these risks should be part of the diagnosis process. There is a need to understand women's experiences of the dialogue between themselves and the health practitioner at the point of diagnosis to develop improved understanding of what would help women move forward with the condition. This new WA study aims to implement findings to further support and improve the PCOS diagnosis experiences for women.

As noted earlier, Indigenous women have a higher prevalence of PCOS, and experience more complications of the condition compared to non-Indigenous women (Monash University, 2018). Existing data on the prevalence of PCOS in Australian Indigenous populations is limited and not current, hence supporting the need for further research in this area (Boyle et al., 2012; Davis et al., 2002). In an Australian study by Boyle et al. (2012) on the prevalence of the condition in a sample group of Indigenous women in Darwin, Australia (n=248), it was reported that 15.3% of those sampled had PCOS. This incidence is higher when compared to the global reported incidence of 8 – 13% of women of reproductive age (Monash University, 2018). Screening for comorbidities associated with PCOS is inconsistent in Indigenous women. Regular screening for diabetes is especially important due to the increased risk of type 2 diabetes in both women with PCOS and First Nations people (Ellis et al., 2018). The implementation of evidence-based multidisciplinary clinical services that improves healthcare for Indigenous women with PCOS in remote areas was evaluated by Boyle et al. (2017) where, women were offered cardiometabolic screening, emotional screening and lifestyle management with a high response rate from the participants. Recommendations from Boyle et al. (2017) included further exploration of multidisciplinary team services for PCOS at a national level. These findings highlight the importance of the role of the nurse and midwife in ongoing support and management for women following the diagnosis of PCOS.

1.2 Research problem

As highlighted earlier in this chapter, the incidence of PCOS is reported to be 8 – 13% of women of reproductive age worldwide (Monash University, 2018). PCOS is known to affect metabolic, reproductive and endocrine systems within the body and has a profound impact on women’s lives with many associated comorbidities. Published literature on women’s diagnosis experiences of PCOS highlighted the need for further information at the time of diagnosis, the impact of delayed diagnosis on women with the condition, the need for consultation with multiple HCPs before reaching a diagnosis and dissatisfaction with how the diagnosis was delivered. Key gaps in knowledge include no existing literature focusing on WA women’s experiences of receiving a diagnosis of PCOS, a lack of understanding of women’s information and support needs at the time of diagnosis, inadequate exploration of women’s diagnosis experiences of the condition and capturing of their suggestions and recommendations to improve the process of PCOS diagnosis. Hence, it was necessary to explore WA women’s experience of receiving a diagnosis of PCOS.

1.3 Study aim & objectives

The aim of the study reported in this thesis was to explore the PCOS diagnosis experiences of Western Australian women. The study hoped to address the following specific research objectives:

1. To explore women’s experiences of receiving a diagnosis of PCOS.
2. To identify women’s perceptions of supportive care during the process of diagnosis.
3. To identify from women’s experiences their resource and education needs related to the diagnosis of PCOS.
4. To describe women’s suggestions for how the PCOS diagnosis process could be improved.

1.4 Study significance

In the interest of developing literature, which is specific to the profession of nursing, midwifery and other relevant HCPs, this research allowed women to share their PCOS diagnosis experiences revealing issues specific to WA women. This research offers HCPs insight into how to provide women with a diagnosis of PCOS in the most supportive way. The findings from this will help HCPs in developing current approaches to and management of the condition and in the on-going support of women with the condition through an understanding of women’s experiences and information needs at the time of diagnosis. Study findings may help women by reducing the time taken to diagnose the condition and alleviating the need to seek consultation with multiple HCPs for PCOS related symptoms prior to diagnosis. The evidence produced may improve women’s experiences of diagnosis and assist to empower women by improved information provision and diagnosis processes. A broader understanding of women’s experiences may strengthen diagnosis delivery and improve the education, care and advice offered by HCPs across wider contexts.

As the life expectancy for women continues to rise in Australia and around the world there is a continued need for planning and improvement to health outcomes (Australian Institute of Health and Welfare, 2019). This study is congruent with the National Women’s Health Strategy 2020-2030, which has five policy principles, specifically this study supports principle 5: a strong and emerging evidence base, with the strategy objective to: “support effective and collaborative research, data collection, monitoring, evaluation and knowledge transfer to advance the evidence base on women’s health” (Australian Government, 2018, p. 7). This study allowed women with PCOS the opportunity to share their experience of diagnosis and has provided recommendations for HCPs in acknowledging the needs of women with the condition surrounding the time of diagnosis. Recommendations are expanded upon in Chapter Five, Discussion.

1.5 Researcher positionality

This positionality statement is provided to assist with understanding the researcher in the context of this study and as a research instrument within a qualitative research approach. The researcher completed a Bachelor of Nursing in 2009, followed by the completion of a Graduate Diploma of Midwifery in 2011. Through her work as a registered nurse and midwife, the researcher has had exposure and experience caring for and meeting women with PCOS and was enlightened by some of the experiences and issues women shared. Some women had been told they could not conceive but had gone on to conceive naturally and others had received fertility treatment. Some women were prescribed medication and others were advised to manage their condition with diet and exercise. The researcher's interest in PCOS developed over time and evolved into the study reported in this thesis.

Parallel to this professional exposure to and interest in PCOS the researcher also experienced her own health journey that led to a diagnosis of PCOS. This experience further developed and strengthened this research interest. A statement from the researcher's own HCP, who was providing ongoing PCOS treatment and management, alerted the researcher to the difficult path women may face when exploring options following their diagnosis. Additionally, the general information given by the researcher's own HCPs was limited, and she consequently felt that there was a need to explore women's experiences surrounding their diagnoses of PCOS in depth. The researcher saw a need to determine women's perceived level of support and care provided by their HCP at the time of diagnosis. A review of the literature indicated that this was not a well understood area and supported the need for further study.

Prior to commencement of the study the researcher attempted to identify any preconceived ideas and assumptions she may have had going into the study, recognising that it was important to do this in qualitative research to ensure quality, trustworthiness and to illustrate credibility of the study (Colorafi & Evans, 2016). As a woman with PCOS herself she acknowledged and carefully considered her own experience of receiving a diagnosis of the condition and how it had been a frustrating journey, presenting to multiple GPs for many years before a diagnosis was confirmed. The researcher also reflected on the advice she had been given over the years from a variety of HCPs and how her emotions had been affected. The long journey leading up to diagnosis included receiving much varied and sometimes conflicting advice and information, which was often inadequate and at times upsetting. The researcher acknowledged other preconceived ideas including all other women with PCOS must be having difficult diagnosis experiences; women require further support at the time of diagnosis; ideas of how the condition should be managed; GPs do not have a good understanding of the condition and so are unable to provide satisfactory care for women suffering with PCOS. These four points were recognised as possible biases.

The researcher also discussed her own confirmed diagnosis of the condition with her supervisors prior to data collection. It was decided after discussion with supervisors to disclose this information to the participants prior to the interviews taking place to assist with ensuring that the researcher did not project her own experience of PCOS diagnosis onto the participants. This disclosure proved to be helpful and aided the researcher in developing rapport with the participants, prior to commencing the interviews. The researcher found that open discussion was easily facilitated as the interviewees perceived that the researcher could relate to their experiences having been diagnosed with PCOS herself. The researcher and the supervision team were mindful of the need to be vigilant across the data collection and analysis process to avoid researcher personal bias influencing the emerging understanding of the phenomenon under study. Study supervisors, therefore, reviewed interview transcripts to ensure that the researcher's own experiences did not drive data collection and to independently discover and confirm emergent themes within the data.

Regular supervision meetings with the research team helped to ensure the researcher's own biases were not entering the data. This thesis was continuously reviewed by the study supervisors to ensure conclusions were trustworthy. Preconceived assumptions either evolved, were confirmed or refuted across the conduct of this study. Being aware of personal bias that the researcher had demonstrated reflexivity (Polit & Beck, 2017). The researcher's preconceived idea of 'all other women with PCOS must be having difficult diagnosis experiences’ evolved as the women interviewed in this study described their experience of diagnosis, including lengthy diagnosis period, visits to multiple HCP’s and challenges they faced. It was apparent that each woman with the condition had her own experience and journey leading to diagnosis of PCOS and that it could not be assumed that all women had difficult diagnosis experiences. Another preconceived idea was ‘women require further support at the time of diagnosis’, this was confirmed throughout this study as the women interviewed shared their needs surrounding diagnosis of the condition including the provision of PCOS resources, HCPs to discuss associated comorbidities, HCPs to be sensitive with women’s journey to PCOS and longer appointment times. The preconceived idea of ‘how the condition should be managed’ was refuted, as it became apparent throughout the study reported in this thesis that each woman diagnosed with PCOS had different needs relating to the condition. Management of PCOS was depend on the women’s symptoms and concerns, for some women their focus was around fertility and for others it was around associated comorbidities, symptoms including acne or mental health issues. The final preconceived idea acknowledged by the researcher prior to conducting this research was ‘GPs do not have a good understanding of the condition and so are unable to provide satisfactory care for women suffering with PCOS’ this assumption was refuted. While some study participants reported that their HCP/GP did not have the knowledge or understanding around PCOS, the knowledge of HCPs managing and treating women with the condition was not assessed and therefore cannot be confirmed as it was an assumption made by some of the women in this study based on their experiences. Disclosing assumptions and preconceived ideas allowed the researcher to demonstrate reflexivity by discussing how these developed over the course of the research being conducted and is an important aspect of any research being conducted.

1.6 Thesis Organisation

This thesis is presented through five chapters. Chapter One has provided a background to PCOS, including its incidence globally (national statistics were not available), diagnosis of the condition, diagnostic criteria and guidelines for management and awareness surrounding PCOS associated comorbidities. Chapter One also described the research problem statement and provided the study aims and objectives, its significance and the researcher positionality.

Chapter Two contains a review of the relevant literature on the topic of the study and provides evidence for the need for the qualitative research study reported in this thesis. It includes a description of the search strategy used to explore existing PCOS literature with a focus on diagnosis experiences of women with the condition. This study builds on previous findings through an in-depth exploration of WA women's experiences of receiving a diagnosis of PCOS using a qualitative approach. The themes identified in the literature are expanded on throughout this chapter.

Chapter Three describes the use of a descriptive exploratory approach as the chosen methodology used in this qualitative study. Twenty women's experiences of being diagnosed with PCOS in Western Australia (WA) were explored, guided by the aim and objectives of the study. A broad overview of the paradigms of quantitative (positivist) and qualitative (constructivist/interpretive) research and a brief description of mixed methods approaches are provided. Following this overview, the methodological aspects of the study are described and include research design, sampling and recruitment, data collection and analysis, trustworthiness, ethical considerations, and data storage and management.

Chapter Four presents the study findings and includes demographic details of participants. Data analysis revealed four themes, with fourteen linked sub-themes. The four main themes were: 'lead up to diagnosis', 'diagnosis of PCOS', 'life after diagnosis' and 'listening to women'.

Chapter Five presents a discussion of study findings against the existing body of knowledge. This is the first WA study known, to date, exploring women's diagnosis experiences of the condition and therefore it was important to explore the implications of findings in the context of what is already known. Chapter Five includes study limitations, implications for clinical practice and recommendations under the categories of education, service, policy and research.

Finally, the participant information sheets and consent forms, the semi-structured interview question guide and other relevant study documents are available to the reader as appendices at the end of the thesis.

1.7 Conclusion

PCOS is a common endocrine condition experienced by approximately 8 – 13% of women of reproductive age. Diagnosis of the condition has been reported to be a lengthy and difficult process for women, due to variation in presenting symptoms and different diagnostic criteria being used by HCPs. PCOS can affect metabolic, psychological and reproductive health with increased risk of developing cardiovascular disease and its associated risk factors, non-alcohol fatty liver disease, mental health conditions including depression and anxiety, thyroid disorders, type 2 diabetes mellitus including insulin resistance, endometrial cancer, hypertension and high body mass index and obesity. Evidence indicated that women may benefit from individualised treatment and management options based on presenting symptoms. A review of existing literature had not identified any studies exploring women's PCOS diagnosis experiences in WA. It was, therefore, important to understand the experience of WA women diagnosed with PCOS from both metropolitan and rural areas to produce contextually relevant information. The findings of this study may help to improve diagnosis experiences for women with this common condition and will add to existing knowledge of PCOS. Chapter One has provided an overview of the study, background to the research problem, problem statement, aims and objectives, study significance and researcher positionality. Chapter Two will provide a comprehensive literature review on PCOS, focusing on prior research relevant to this WA study.

Chapter Two

Literature Review

This thesis reports on a study exploring the initial diagnosis experience of twenty women living with PCOS in Western Australia and includes their behaviours, feelings and lived experiences. The reviewing of literature is an important step in the research process as it aids in identifying findings of prior research to determine what is already known and highlights gaps in knowledge used to guide further investigation. Such a review assists with synthesising evidence on a topic, which in this thesis was PCOS, allowing the researcher to critically evaluate and summarise the available evidence. The review should be objective and summarised in the researcher's own words to demonstrate that the literature has been interpreted and understood by the researcher, providing current evidence and identifying gaps in knowledge (Polit & Beck, 2017). Evidence presented should be clear and concise, with a logical structure allowing the reader to comprehend the points being made by the researcher (Hart, 1998). A review of the literature around PCOS identified no existing qualitative studies exploring women's diagnosis experiences of PCOS in WA and inadequate deep and rich exploration of women's diagnosis experiences of the condition. Other gaps in knowledge that were identified include a lack of understanding of women's information and support needs at the time of diagnosis.

This chapter (Chapter Two) presents an evaluation of current literature through the critical analysis of individual studies, collating and summarising findings from previous studies, demonstrating the synthesis of the evidence surrounding PCOS concisely and objectively (Polit & Tatano Beck, 2012) and providing evidence for the need for the qualitative research study reported in this thesis. It includes a description of the search strategy used to explore existing PCOS literature with a focus on diagnosis experiences of women with the condition. This study builds on previous findings through an in-depth exploration of WA women’s experiences of receiving a diagnosis of PCOS using a qualitative approach. The themes identified in the literature will be expanded on throughout this chapter.

2.1 Literature search strategy

A review of existing literature was conducted initially during the proposal development phase and specifically examined the diagnosis experiences of women with PCOS. A second literature review was undertaken during the write-up of the thesis and explored relevant literature more broadly. Hence, the literature presented in this chapter builds on that which was presented in chapter one of this thesis and was conducted using the ‘PubMed’, ‘ProQuest’, ‘Medline’ and ‘CINAHL’ databases. These databases were chosen for their coverage of medical, nursing and health journals and as suggested databases for nurses (Polit & Tatano Beck, 2012). The terms used in the search were ‘polycystic’, ‘PCOS, ‘living with PCOS’, ‘diagnosis’ and ‘experience’. The Boolean operators, ‘AND’, ‘NOT’ and ‘OR’ were used in the literature search to expand and limit the exploration. The relevance and quality of articles were determined by recency, type of study, location of study setting, sample size and findings. Obtaining primary sources of evidence was important in providing a comprehensive and up to date literature review for the period from 1995 to 2023. This period was chosen as the National Institute of Health (NIH) diagnostic criteria were introduced in 1990 and allowed for the inclusion of literature following the introduction of the NIH criteria. Themes identified through the literature review have been used to structure the subsequent sections of this chapter. These themes highlight major findings of previous studies, with sub-headings exploring literature specific to; limitations in the use of different PCOS diagnostic criteria, diagnosis experiences of women with PCOS and various PCOS associated comorbidities.

2.2 Limitations in the use of different diagnostic criteria

In 1935 Stein and Leventhal provided the first description of the gynaecological condition that was later called PCOS (Stein & Leventhal, 1935). Since the discovery of PCOS, what is known about the condition including how it is diagnosed has developed greatly. Initially, PCOS was described as the presence of ovarian cysts with anovulation (Stein & Leventhal, 1935), it is now diagnosed based on the key features of oligo or amenorrhea, androgen excess and PCOS morphology (Rodgers et al., 2019). Further progress around understanding the condition also included the development of the three different PCOS diagnostic criteria, as outlined in chapter one of this thesis, namely the National Institute of Health (1990), the Rotterdam (2003) and the Androgen Excess Society (2006) sets of criteria.

The Rotterdam criteria (2003) remains the most widely accepted diagnostic tool used in Australia (Boyle & Teede, 2012), with the diagnostic criteria endorsed in the International evidence-based guideline for the assessment and management of PCOS (Monash University, 2018). Further updates were made to the Rotterdam criteria which expanded their use to include the diagnosis of PCOS in adolescent girls (Monash University, 2018). The Rotterdam criteria is recommended for PCOS diagnosis due to encompassing a broader spectrum of ovarian dysfunction and inclusion of the NIH and AES criteria (National Institutes of Health, 2012). Application of the Rotterdam criteria to studies has seen an increase in the prevalence of PCOS compared to the NIH and AES criteria (Christ & Cedars, 2023; Deswal et al., 2020). It is recommended that other possible causes for PCOS symptoms experienced should be excluded, prior to diagnosis of this chronic condition (Monash University, 2018). Chapter one provided a description of the available diagnostic criteria used for PCOS and information on how PCOS is diagnosed. The following section of chapter two will explore the limitations surrounding the use of different diagnostic criteria and the impact this has on women with the condition as well as the subsequent under-diagnosis of women and over-diagnosis of adolescent girls.

2.2.1 PCOS phenotypes

In 2012 the National Institute of Health extended the 2003 Rotterdam diagnosis criteria for PCOS and recommended the use of four PCOS phenotypes (National Institutes of Health, 2012). The phenotypes initially introduced by Azziz et al. (2009) are classified based on clinical features including hyperandrogenism, ovulatory dysfunction, and polycystic ovarian morphology. The four phenotypes are: phenotype A, phenotype B, phenotype C and phenotype D (Azziz et al., 2009; Lizneva et al., 2016; Monash University, 2018; National Institutes of Health, 2012). Table 3 below, provides for a visual representation of the PCOS phenotypes with linked clinical features.

Table 3
PCOS phenotype classification

	Phenotype A	**Phenotype B**	**Phenotype C**	**Phenotype D**
Features				
Hyperandrogenism	✓	✓	✓	✗
Ovulatory dysfunction	✓	✓	✗	✓
Polycystic ovarian morphology	✓	✗	✓	✓

Women experiencing PCOS are classified into the four phenotypes according to the presence or absence of the three key features, namely hyperandrogenism, ovulatory dysfunction and polycystic ovarian morphology (Azziz et al., 2009; Lizneva et al., 2016; National Institutes of Health, 2012). Women with phenotypes A and B, also referred to as having ‘classic PCOS’, are at the highest risk of metabolic dysfunction, ovulatory dysfunction and obesity, this is important to identify at diagnosis to ensure correct management of the condition (Dietz de Loos et al., 2021; Kim et al., 2014; Lizneva et al., 2016; Mehrabian et al., 2011; Moran & Teede, 2009). Phenotype C, also referred to as ‘ovulatory PCOS’, includes the prevalence of metabolic syndrome and intermediate levels of serum androgens (Carmina et al., 2005; Dietz de Loos et al., 2021; Jamil et al., 2016; Lizneva et al., 2016). Women with phenotype D have the mildest form of endocrine dysfunction and lowest incidence of metabolic dysfunction, compared to the other phenotypes (Dewailly et al., 2006; Dietz de Loos et al., 2021; Lizneva et al., 2016). The phenotypes are also further subdivided into hyperandrogenic (phenotypes A, B, C) and normoandrogenic (phenotype D), this separation can be useful in further investigation into the condition, such as the link between comorbidities and PCOS phenotypes (Daan et al., 2014; Dietz de Loos et al., 2021; Lizneva et al., 2016).

Building on existing PCOS definitions, the phenotypes are useful in clinical practice to identify women with the condition who are high risk of metabolic dysfunction (Lizneva et al., 2016). PCOS phenotypes are also useful in epidemiology research, allowing researchers to compare findings within the PCOS populations based on phenotypes which can be useful in research conducted on the condition (Lizneva et al., 2016). These phenotypes are used to further understand the complexity of PCOS by linking symptoms of the condition together, such as metabolic comorbidities and cardiovascular risk factors (Azziz et al., 2009; Dewailly, 2016; Fauser et al., 2012; Lizneva et al., 2016; Marchesan & Spritzer, 2019). According to Dennett and Simon (2015), healthcare professionals need to familiarise themselves with the variety of PCOS phenotypes to improve PCOS awareness. The Rotterdam criteria (2003) is recommended in the diagnosis of PCOS, as it uses a phenotypic approach that is beneficial in clinical and non-clinical settings including research (Monash University, 2018). Other diagnostic criteria are also used by healthcare professionals to diagnose PCOS. The following section will expand on the limitations of the use of the different diagnostic criteria.

2.2.2 Diagnostic criteria

The use of different diagnostic criteria for PCOS remains controversial. As mentioned previously, in 2018 the International Guidelines for the Assessment and Management of PCOS endorsed the use of the Rotterdam criteria for the diagnosis of PCOS. The guidelines were designed to improve the lives of women with PCOS worldwide, by reducing conflicting information and advice (Monash University, 2018). Prior to these guidelines, there were many limitations in Australia in diagnosing the condition due to poor universal guidance, leading to the use of different tools by individual HCPs. As outlined in chapter one, diagnosis by the NIH criteria (1990) requires both of the following symptoms to be present: clinical and/or biochemical signs of hyperandrogenism and chronic menstrual irregularity due to oligomenorrhea and/or anovulation. The Rotterdam criteria (2003) requires any two of the following three symptoms to be present: clinical and/or biochemical hyperandrogenism, oligomenorrhea and/or anovulation and polycystic ovaries diagnosed by ultrasound scan (Tomlinson et al., 2013). The AES criteria (2008) require the presence of hyperandrogenism clinical or biochemical in combination with ovarian dysfunction; oligomenorrhea, anovulation and/or polycystic ovaries (PCO). Additionally, it includes a central feature of androgen excess, after exclusion of other possible causes (Azziz et al., 2009; March et al., 2010). See table 4 below, for a visual representation of the PCOS diagnostic criteria.

Table 4

PCOS diagnostic criteria

NIH 1990 **Requires both**	**Rotterdam 2003** **Requires two out of three**	**AES 2006** **Requires both**
1. Clinical and/or biochemical signs of hyperandrogenism	1. Clinical and/or biochemical signs of hyperandrogenism	1. Clinical and/or biochemical signs of hyperandrogenism
2. Oligomenorrhea and/or anovulation	2. Oligomenorrhea and/or anovulation	2. Oligomenorrhea, anovulation ***and/or*** Polycystic ovaries on ultrasound scan
	3. Polycystic ovaries on ultrasound scan	

Note. All criteria require exclusion of other androgen excess related disorders and investigation of possible causes for reported symptoms.

It has been recognised that limitations in diagnosing PCOS due to the use of different diagnostic tools by HCPs, lack of HCP awareness around the condition and the diversity of presenting symptoms have resulted in difficulty diagnosing the condition (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Tomlinson et al., 2013). The use of the three different diagnostic criteria has impacted women's diagnosis experiences, resulting in delays in diagnosis, over-diagnosis of adolescent girls and under-diagnosis of women (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; March et al., 2010; Tomlinson et al., 2013; Tomlinson et al., 2017). The true prevalence of PCOS is also difficult to determine due to the different diagnostic criteria used (March et al., 2010). The limitations of different diagnostic criteria are further expanded upon in this chapter and include the impact on women with PCOS.

In summary, the Rotterdam criteria (2003) diagnostic tool is favoured internationally as it has been shown to reduce underdiagnosis of the condition. Higher rates of PCOS are found when using the Rotterdam criteria due to the requirement that any two of the three clinical features must be present, in comparison to the NIH (1990) and AES (2006) which require all features of their criteria to confirm a diagnosis of PCOS (Monash University, 2018; Tay et al., 2020; Teede et al., 2010; Tomlinson et al., 2017; Witchel et al., 2019). However, the Rotterdam diagnostic criteria are not always the diagnostic criteria of choice by HCPs (Dewailly, 2016). Due to the use of different diagnostic criteria (NIH/ Rotterdam/ AES) diagnosis of PCOS is not consistent which may lead to overdiagnosis in one context and delayed diagnosis in another context, based on tool preference. As Avery and Braunack-Mayer (2007) highlighted, diagnosis of PCOS may provide relief from and recognition of the symptoms experienced by women with the condition. It is therefore important that symptoms of PCOS are recognised by women and identified by HCPs through increasing awareness and education around PCOS to minimise a delay in diagnosis and treatment of the condition. Delayed diagnosis related to diagnosis experiences will be discussed later in this chapter.

2.2.3 Underdiagnosis of PCOS

The prevalence of PCOS varies within the literature and is influenced by the diagnostic criteria used by HCPs, with many studies reporting underdiagnosis of women with the condition (Boyle & Teede, 2012; March et al., 2010; Tay et al., 2020). Up to 70-75% of women with the condition remain undiagnosed (Boyle & Teede, 2012; March et al., 2010; Teede et al., 2010; Wolf et al., 2018b). PCOS remains an under-recognised condition with one in 10 women not receiving adequate treatment due to underdiagnosis (Dennett & Simon, 2015) and subsequently the estimated rates of PCOS in the community compared to women presenting with PCOS are low (Ding et al., 2016). According to Dennett and Simon (2015) and Ding et al. (2016), women and healthcare professionals need to be better informed about PCOS to improve recognition, management and treatment of the condition. The Rotterdam criteria (2003) has led to a reduction in the under diagnosis of PCOS (Deswal et al., 2020; March et al., 2010). An Australian retrospective birth cohort of women were interviewed and comparisons were made using the three PCOS diagnostic criteria to create a representative prevalence of PCOS in the community (March et al., 2010). They found that the Rotterdam and AES PCOS diagnostic criteria demonstrate prevalence estimates twice than that obtained with the NIH criteria. Findings from March et al. (2010) were used in the International Guidelines, providing recommendations for the assessment and management of PCOS. The use of these guidelines may help to address the gap in the under-diagnosis of the condition (Monash University, 2018).

2.2.4 Overdiagnosis of adolescent girls

While adult women are being under-diagnosed, adolescent girls are being over-diagnosed (Monash University, 2018; Peña et al., 2022; Tay et al., 2020; Witchel et al., 2015). This remains challenging, due to similarities between the symptoms of PCOS and early features of puberty (Dokras & Witchel, 2014; Lizneva et al., 2016; Weiss & Bulmer, 2011; Witchel et al., 2015).

Overdiagnosis of adolescent girls was reported in a study by Tay et al. (2020), comparing the prevalence of PCOS in a post-menarchal adolescent cohort (n=227). A comparison was made between the updated (2018) and original (2003) Rotterdam criteria, with PCOS being diagnosed in 66 (29.1%) adolescent girls using the original criteria compared to 37 (16.3%) with the updated Rotterdam criteria. Another difference found between adolescent girls and adult women was that the adolescents were diagnosed sooner, with fewer HCP visits required before a diagnosis was confirmed (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Peña et al., 2022). A recent quantitative study by Peña et al. (2022) involving 86 adolescents (13-19 years) using an online questionnaire, found that, unlike adult women, the majority (78%, n=67) of the adolescents were diagnosed with PCOS in less than 1 year from the initial HCP visit, with 66% seeing only 1-2 HCPs before diagnosis was confirmed. The recommended criteria used to diagnose adolescent girls with PCOS has changed over the last decade, (Fauser et al., 2012; Legro et al., 2013; Lizneva et al., 2016) with the 2018 International guidelines being the most recent update, endorsing the use of the Rotterdam criteria for the diagnosis of PCOS in both adult women and adolescents (Monash University, 2018). The criteria, stricter than previously existing diagnostic criteria and guidelines, require both hyperandrogenism and oligo-anovulation to be evident and exclude the use of pelvic ultrasound scans in adolescents, aiming to reduce overdiagnosis (Monash University, 2018; Peña et al., 2022; Tay et al., 2020). Changes to diagnosing guidelines in adolescent girls includes specific recommendations, such as ultrasound not recommended within 8 years of menarche due to normal reproductive physiology mirroring symptoms, thus leading to overdiagnosis (Monash University, 2018). The literature surrounding the diagnosis of adolescents with PCOS remains limited, however the use of the updated 2018 Rotterdam criteria is aimed at minimising overdiagnosis in adolescent girls.

In summary, the variation in the use of the three different diagnostic tools: NIH, Rotterdam and AES criteria and the four PCOS phenotypes have contributed to issues with the diagnosis of the condition. Diagnosis of the condition can be difficult as there is not a single test available to confirm PCOS. The difficulties in diagnosing the condition have been highlighted, including early pubescent symptoms having similarities to PCOS and the need to exclude other possible causes of presenting symptoms first. The 2018 International Evidence-Based Guideline for the Assessment and Management of PCOS recommends the use of the updated Rotterdam criteria in the diagnosis of the condition for both adolescent girls and women. These recommendations were in response to evidence highlighting delayed PCOS diagnosis, underdiagnosis of PCOS/undiagnosed women and overdiagnosis in adolescent girls. Diagnosis experiences including delayed diagnosis will be explored in the following section of this chapter.

2.3 Diagnosis experiences

While diagnosis experiences vary and individual experiences may be influenced by many factors, commonalities exist surrounding the diagnosis experiences of PCOS and other health conditions, such as endometriosis. These include but are not limited to length to diagnosis, consulting multiple HCPs, lack of information provision by HCP and women’s dissatisfaction with the diagnosis experience. Like women with PCOS, women living with endometriosis are reported to experience a long and difficult journey to obtain a diagnosis and receive appropriate treatment for the condition, resulting in symptoms worsening and increasing (Lamvu et al., 2020). The following sections will explore PCOS diagnosis experiences, highlighting issues such as lengthy diagnosis, consulting multiple HCPs, lack of information provision and dissatisfaction with the diagnosis process, and will close with the role of nurses in the diagnosis process.

2.3.1 Length to diagnosis

Delayed diagnosis can occur with PCOS due to symptoms being linked or explained by other causes, including increased levels of stress, poor diet resulting in weight gain, lack of exercise and hormonal imbalances. As mentioned earlier in this chapter, diagnosis of PCOS in adolescent girls can be difficult due to similarities between the symptoms of PCOS and early features of puberty (Dokras & Witchel, 2014; Weiss & Bulmer, 2011; Witchel et al., 2015). Delayed diagnosis can impact physical and reproductive health, with an increased risk of mental health problems linked to longer diagnoses. Screening for PCOS co-morbidities, such as cardiovascular disease, non-alcohol fatty liver disease, mental health conditions including depression and anxiety, thyroid disorders, type 2 diabetes mellitus including insulin resistance, endometrial cancer, hypertension and high body mass index and obesity, does not occur without a diagnosis of the condition first. If the PCOS diagnosis is delayed, related co-morbidities may not be detected until later, causing exacerbation of these linked conditions.

Another important consideration is that because the diagnosis of PCOS helps clinicians link the condition to known co-morbidities, these connections are often not made until the initial PCOS diagnosis is confirmed (Brady et al., 2009), consequently demonstrating the importance of early diagnosis. The quantitative study by Gibson-Helm et al. (2017), included women from different regions of the world and used a self-report questionnaire to investigate PCOS diagnosis experiences. They found that women with PCOS experienced delayed diagnosis, resulting in dissatisfaction. The study highlighted that delayed diagnosis, inadequate, education and lack of support need to be improved for women being diagnosed with PCOS (Gibson-Helm et al., 2017). Unfortunately, the study did not explore in-depth the experiences of these women due to its quantitative method. It has, however, identified gaps in knowledge and the need for qualitative studies exploring women’s diagnosis experiences.

Findings from the study reported in this thesis address this gap in knowledge and assist to improve women's diagnosis experiences.

For some women the delay in diagnosis of PCOS can be very long, in fact it can take several years (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Kitzinger & Willmott, 2002; Weiss & Bulmer, 2011). Awareness of the delay in diagnosis resulted from early work by Kitzinger and Willmott (2002), and was still highlighted by Avery and Braunack-Mayer (2007) and again by Gibson-Helm et al. (2014) and Gibson-Helm et al. (2017). Despite the issue being consistently highlighted over time this remains a continuing trend 21 years later, with women reporting delay in PCOS diagnosis. Studies by Gibson-Helm et al. (2014) and Gibson-Helm et al. (2017) report a consistent picture of delay in diagnosis of PCOS, indicating that there have been no changes in practice despite the literature. In a quantitative study Gibson-Helm et al. (2014) found that 24% (n=50) of women were diagnosed two or more years after initially presenting to an HCP with symptoms of the condition. Delay of diagnosis for women in the Gibson-Helm et al. (2014) study was universal, there was no reported association with any demographic details, including age, BMI and educational status of the women; all women were uniformly affected. The study did not explore reasons for lengthy diagnosis as it was a quantitative study and surveys may fail to capture in-depth perceptions, however, this knowledge gap further supported the need for qualitative research exploring women's diagnosis experiences of PCOS. Limitations of the study (Gibson-Helm et al., 2014) included potential recall bias as the median time since diagnosis was 5 years. In the study reported in this thesis, inclusion criteria included diagnosis within the last 2 years to optimise recency of the diagnosis experience and improve recall. In a follow up study on delayed diagnosis of PCOS, Gibson-Helm et al. (2017) found that 33.6% (n=461) of women were diagnosed two or more years after initial presentation. Hence, there had been no improvement in the length of time to diagnosis.

In a smaller qualitative study, Avery and Braunack-Mayer (2007) reported that 70% (n=7) of women received a delay in diagnosis of two or more years. Similarly, and to make a comparison with the management of another gynaecological condition, studies on endometriosis also found an increased length of time to obtain a diagnosis with women experiencing symptoms over several years (Ballard et al., 2006; Cromeens et al., 2021; Lamvu et al., 2020; Parasar et al., 2017; Surrey et al., 2020). In a study by Ballard et al. (2006), the median time from symptoms to diagnosis was 8.5 years and Lamvu et al. (2020) found that more than 50% of women (total study n=451) waited 6 or more years to receive a diagnosis of endometriosis. Women reported 20 or more discussions with their HCP about symptoms experienced before receiving a diagnosis with 24% reporting it took 11 or more years to receive a diagnosis (Lamvu et al., 2020). The issues with multiple consultations that resulted in a delay in diagnosis included women being diagnosed with other conditions prior to receiving a diagnosis of endometriosis. Findings from the above studies highlight the importance of understanding the diagnosis experience of female specific conditions. The study reported in this thesis explores women's diagnosis experiences of PCOS, gaining insight into the needs of women with the condition specifically surrounding diagnosis.

Women with PCOS are sometimes prescribed the oral contraceptive pill for the management of their symptoms and have attributed this to the delay in their PCOS diagnosis (Fauser et al., 2012; Goodman et al., 2015; Vrbíková & Cibula, 2005; Yildiz, 2015). Delay to diagnosis is an issue for women with PCOS, confirmed by Tomlinson et al. (2017), attributed to a lack of referral for investigations and perceived lack of understanding of PCOS by HCPs. Similarly, adolescent girls have been identified as a group that experience an increased delay in diagnosis of endometriosis (≥11 years) compared to other women (≥6 years), which in some cases has been linked to referral to paediatricians who may not be as familiar with the condition (Lamvu et al., 2020). Reasons for the possible delay in the diagnosis of endometriosis include reported normalisation of symptoms by HCPs and intermittent suppression of hormones from the use of the oral contraceptive pill, prescribed to women sometimes prior to diagnosis. Our WA study addressed the gap in knowledge surrounding delayed diagnosis of PCOS, through in-depth exploration of women's diagnosis experiences of PCOS and has highlighted concerns of participants including reasons for lengthy diagnosis.

Delayed diagnosis not only impacts physical and reproductive health, it also impacts mental health, with increasing risk as time to diagnosis increases. Mental health issues related to PCOS can be further compounded by negative diagnosis experiences (Avery & Braunack-Mayer, 2007; Deeks et al., 2011; Gibson-Helm et al., 2014). Delayed diagnosis has been linked to anxiety and depression and dissatisfaction with the length of time to diagnosis (Gibson-Helm et al., 2017; Hoeger et al., 2021). Mental health issues in relation to PCOS will be discussed in detail in the co-morbidities section of this chapter.

2.3.2 Consulting multiple HCPs

While many women reported that the time to diagnosis of PCOS took several years, they also reported seeing multiple HCPs before receiving a diagnosis of the condition (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017). More than one-third of women were seen by three or more HCPs before a diagnosis of PCOS was reached (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017). A diagnosis of endometriosis has had similar issues for women, with them also requiring multiple visits to HCPs and multiple discussions, before receiving a reason for the symptoms they had experienced for many years (Ballard et al., 2006; Lamvu et al., 2020). In a study by Ballard et al. (2006) adult women reported multiple visits to HCPs and between 1 to 27 years to the diagnosis of endometriosis, with 46% of women experiencing symptoms for 10 years before receiving a diagnosis. Women with PCOS or endometriosis reporting multiple healthcare consultations prior to receiving a diagnosis of the condition highlights how integral HCPs are to the diagnosis process and to ensuring a timely diagnosis and a satisfactory diagnosis experience.

Lin et al. (2018) compared women's perceptions of trust in HCPs and their medical experiences in a quantitative, cross sectional study including women with PCOS (n=134) and without (n=198). The study found that women with PCOS perceived that HCPs appeared to spend "less effort" (Lin et al., 2018, p. 1005) and were "less qualified" (Lin et al., 2018, p. 1001) to deal with PCOS compared to other general health concerns. Women reported receiving general health information from HCPs which often was not specific to their needs and PCOS. In comparison to general health concerns, it was reported that HCPs only sometimes comprehended the women's PCOS related health concerns. Women felt healthcare providers were "well qualified" (Lin et al., 2018, p. 1004) to treat general health concerns but not PCOS and that general health was given priority over PCOS with women perceiving a lack of emotional support from healthcare providers (Lin et al., 2018). Increasing HCP awareness around specific women's health conditions may improve diagnosis experiences for women (Lamvu et al., 2020). A search of the literature identified that further exploration was needed of women's experiences of their interactions with HCPs during the process of obtaining a PCOS diagnosis. This WA qualitative study has helped fill this gap by giving voice to women's perspectives, helping HCPs to understand women's diagnosis experiences and proactively mitigating potential negative aspects of care.

2.3.3 Lack of information

Women have found that when diagnosed with PCOS, information provided by the HCP often did not meet their needs (Avery & Braunack-Mayer, 2007). Women who received PCOS information reported a focus on fertility, irrespective of whether women were actually trying to conceive or not, while general health risks associated with the condition were not highlighted (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014). Women expected to receive

PCOS information from their primary healthcare contact which was commonly their GP. According to Avery and Braunack-Mayer (2007) women reported feeling powerless to do anything until trying to conceive and reported they felt unless they had visible symptoms such as unwanted hair growth, worsening symptoms or were planning a pregnancy, there were no PCOS treatment options available to them. It has been 17 years since these findings (Avery & Braunack-Mayer, 2007) were published with changes to diagnosis and care approaches that support the need for new research exploring women's diagnosis experiences of PCOS.

Insufficient information provision and perceived dissatisfaction with the information provided at the time of diagnosis has been described in existing literature, with women reporting they were neither given nor referred to information sources at diagnosis (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Tomlinson et al., 2017). It appears from the available literature that the information needs of women diagnosed with PCOS continue to be unmet and the provision of PCOS information to women at diagnosis has not improved over the decade, between 2007 and 2017 (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014; Gibson-Helm et al., 2017). Women have reported they were unsatisfied with PCOS related information at diagnosis on lifestyle management, medical therapy, long-term PCOS complications and information on emotional support and counselling (Gibson-Helm et al., 2017). It was therefore necessary to understand the information needs of women at the time of diagnosis to identify their resources and educational needs, related to the diagnosis of PCOS.

Women also indicated HCPs not meeting information needs related to medication as a treatment option, receiving alleged poor advice and that provision of information from HCPs surrounding exercise and dietary recommendations was vague (Gibson-Helm et al., 2017). This lack of information led to women sourcing their own information online (Tomlinson et al., 2013; Tomlinson et al., 2017). A British qualitative study, on the diagnosis and lived experience of PCOS, included 32 participants and reported that women with PCOS experienced a perceived lack of information provision, inconsistent experiences with medications prescribed in the management of PCOS, insufficient advice regarding fertility and lack of HCP awareness surrounding comorbidities (Tomlinson et al., 2017). Women in the study by Tomlinson et al. (2017) were recruited from primary and secondary care settings that provided them care for their PCOS and therefore may have different experiences to women who were recruited outside of healthcare settings. In addition, differences in the healthcare systems between Britain, where the study was conducted, and Australia could potentially result in findings not being transferable to the WA context. Hence, the study reported in this thesis provided further insight into the PCOS diagnosis experiences of Western Australian women not already engaged in hospital care or specialist clinics. This information is important in understanding women’s resource and education needs related to the diagnosis of PCOS and in improving their diagnosis experiences.

2.3.4 Dissatisfaction with the diagnosis process

Lengthy diagnosis, consultation by multiple HCPs and reported lack of information provision by HCPs were all reported by women during their diagnosis experience. It appears from the available literature that women with PCOS are dissatisfied with the diagnosis process (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Peña et al., 2022). Similar to adult women, adolescent girls also reported dissatisfaction with their diagnosis experience, in terms of lack of information provision on lifestyle management, long-term complications, emotional support and counselling after diagnosis (Peña et al., 2022). Similarly, women diagnosed with endometriosis also reported not being satisfied with their HCPs perceived lack of ability to listen to their concerns and women felt the treatment options provided by HCPs did not meet their needs (Ballard et al., 2006; Lamvu et al., 2020). Women diagnosed with PCOS have described commencing hormonal medication, prescribed by their HCP, as inappropriate and have reported to be unsatisfied with this form of management, (Tomlinson et al., 2017; Williams et al., 2015). Lack of satisfaction with the diagnosis process experienced by women was common, with Gibson-Helm et al. (2017) reporting that 42.4% (n=585) of the participants were dissatisfied with their diagnosis experience. In this study, in which the majority of participants were North American, there was dissatisfaction with information provision, medical treatment options, long term complications of PCOS and emotional support and counselling (Gibson-Helm et al., 2017). Findings from the study (Gibson-Helm et al., 2017) may not be transferable to the Australian setting due to the different cultural context and healthcare system in America, further supporting the need for the current study reported in this thesis. Existing quantitative studies fail to capture an in-depth understanding of women's PCOS diagnosis experience. This was addressed by the qualitative approach adopted in the study reported in this thesis, helping to build on existing literature, and expanding on our understanding of the PCOS diagnosis experience.

2.3.5 The role of nurses in the diagnosis process

PCOS is a confronting chronic condition, with the potential to affect many aspects of a woman's life including fertility, mental health and physical wellbeing. Providing a diagnosis or prognosis of any condition to a patient is a sensitive matter. Diagnosis provision should include the prognosis, management and treatment options available. Nurses are seen as advocates for patients in their care and play an integral role in the diagnosis process and have a large responsibility in healthcare delivery, offering support and understanding to patients (Abbasinia et al., 2020; Austad, 2006; Newman, 2016). However, it should be noted that the country of origin and inherent cultural norms of the healthcare professional can influence their ability to provide patients with a diagnosis. It can also influence the extent of disclosure, who provides the diagnosis and who the diagnosis is disclosed to, for example, disclosure and truth can be withheld in some countries where patients who have terminal illnesses are prevented by their families from being informed of their condition or prognosis (Huang et al., 2014; Ling et al., 2019; Repetto et al., 2009). It is therefore important that nurses are aware of and align the advice with the cultural and contextual norms of the women receiving the care and that the care is person-centred and provided in collaboration with the woman receiving it.

The American Academy of Paediatrics (AAP) recommend that adolescents have one to one time with HCPs from age 11, providing the opportunity to discuss concerns in an open manner and for HCPs to provide early education around sexual and mental health including anxiety and depression (Hagan et al., 2017). Similarly, within the Australian context, whilst the Australian Medical Association (AMA) does not specify an age, adolescents are encouraged to start attending appointments without their parents or guardians, where appropriate, to encourage independence in managing health and wellbeing. According to the AMA if a young person (age not specified) can make autonomous decisions, they can choose for their treatment to remain confidential (Australian Medical Association, [AMA], 2023). In such situation's nurses can be a source of support and advocacy, assisting the adolescent patient in understanding the information provided by their HCP. Nurses can assist with PCOS diagnosis for adolescent girls by providing support, understanding and education of the condition. The role of the nurse also includes patient advocacy, ensuring the patient is aware of the options available to them and is supported to make an informed decision around their care.

Doctors are primarily responsible for delivering diagnoses to patients in Western countries and nurses and midwives are not always present at the time a patient receives a diagnosis. However, nurses and midwives are involved in the care that follows diagnosis by providing support, management and treatment of a variety of conditions (Stan et al., 2023; Timm et al., 2021). Nurses and midwives may provide care for patients following diabetes diagnosis, prior and during fertility treatment, and through pregnancy loss (Fernández-Basanta et al., 2021). In a systemic review of nurse-led diabetes care, patients had better glycaemic control, care was more cost effective and greater patient satisfaction was reported compared to physician-led care (Crowe et al., 2019). Similar findings were reported in a quantitative study by Stan et al. (2023), highlighting that midwives and nurses have an integral role in providing care for patients in pregnancy, following diagnosis of conditions such as gestational diabetes mellitus (GDM) and pregnancy induced hypertension, including ongoing education to optimise best outcome. In a qualitative study by Timm et al. (2021), midwives described the need to support women in coping with GDM, following diagnosis. These studies (Crowe et al., 2019; Stan et al., 2023; Timm et al., 2021) highlight the importance of the role of the nurse and midwife in providing patient care, especially support and education for patients following diagnosis of various conditions.

In summary, while diagnosis experiences varied there were common themes experienced by women with PCOS. Women went to their GP as their initial contact with a HCP, presenting with symptoms of the condition for investigation. Women reported lengthy diagnoses with consultation by multiple HCPs and resultant impacts on physical, reproductive and mental health. Existing evidence also indicated a lack of information and dissatisfaction with the overall PCOS diagnosis experience.

2.4 Associated comorbidities

As indicated in chapter one, PCOS has been shown to have multiple associated comorbidities. These include cardiovascular disease and its associated risk factors, non-alcohol fatty liver disease, mental health conditions including depression and anxiety, thyroid disorders, type 2 diabetes mellitus including insulin resistance, endometrial cancer, infertility, hypertension and high body mass index and obesity. The following sections explore these comorbidities associated with PCOS within the available literature.

2.4.1 Cardiovascular disease risk factors

Cardiovascular disease risk factors have been widely reported in women with PCOS (De Groot et al., 2011; Dokras, 2013; Fauser et al., 2012; Macut et al., 2015; Mani et al., 2013; Marchesan & Spritzer, 2019; Wild et al., 2010). Women living with the condition have been found to have an increased risk of cardiovascular disease as they age, with Mani et al. (2013) suggesting an increased incidence of myocardial infarction and angina. According to Macut et al. (2015) increased cardiovascular disease risk is linked to women with androgen excess, with PCOS being the most common androgen excess disorder. The study highlighted that from the age of 40 years women with PCOS are at a higher risk for early cardiovascular disease (Macut et al., 2015). The 20-year British retrospective cohort study (Mani et al., 2013) included women diagnosed with PCOS between 1998 and 2008 and found that over 25% of women over the age of 65 with PCOS had experienced myocardial infarction or angina. The study (n=2301) concluded that clinical diagnosis of PCOS in younger women suggests a future risk of cardiovascular disease. Findings highlight the correlation between PCOS and cardiovascular disease risk factors; this is of importance as having a more efficient and timely diagnosis will enable women and their HCPs to mitigate and proactively manage risk for comorbidities.

Multiple PCOS risk factors including insulin resistance, hypertension, obesity and type 2 diabetes mellitus led to a higher risk for cardiovascular disease for women with the condition (Daan et al., 2014; Dokras, 2013). Women with PCOS are twice as likely to have an increased risk of arterial disease regardless of body mass index compared to the healthy population of women and have double the risk of cardiovascular disease and stroke compared to the general population of healthy women (Calderon-Margalit et al., 2014; De Groot et al., 2011; Dokras, 2013; Fauser et al., 2012; Macut et al., 2015; Mani et al., 2013). Similarly, Calderon-Margalit et al. (2014) reported an increase in cardiovascular disease risk for women with PCOS, however, their study suggested that both anovulation and hyperandrogenism needed to be present for women to have an increased risk of cardiovascular disease. Anovulation or hyperandrogenism alone was found to not cause an increased risk of cardiovascular disease (Calderon-Margalit et al., 2014).

The Androgen Excess and PCOS Society identified that women with PCOS who have increased adipose tissue are at a greater risk of stroke and cardiovascular disease. Due to the evidence surrounding cardiovascular disease risk being greater for women with PCOS, cardiovascular disease prevention should be a vital part of managing the condition. In addition, all women with PCOS should be assessed for individual cardiovascular disease risk (Wild et al., 2010). Evidence of cardiovascular disease-related morbidity and mortality in women with PCOS remains limited and further studies investigating this are required (Dokras, 2013). The link between the risk of cardiovascular disease and PCOS has been highlighted in the literature and it was, therefore, important to understand what information women receive at diagnosis about the potential comorbidities of PCOS.

2.4.2 Oral contraceptives and cardiovascular disease risk

Oral contraceptives are commonly used to manage PCOS symptoms (Fauser et al., 2012; Goodman et al., 2015; Vrbíková & Cibula, 2005; Yildiz, 2015). According to Carmina (2013) and Wang et al. (2016) metabolic disturbances are a potential complication of oral contraceptives and individual cardiovascular disease risk should be assessed prior to their recommendation and commencement. Combined hormonal contraceptives remain the first-line pharmacological treatment option for women with PCOS who are experiencing menstrual irregularities and hyperandrogenism (Monash University, 2018). According to De Melo et al. (2017) many clinical guidelines recommending hormonal contraceptives as first line treatment for women with PCOS, are based on studies of efficacy in women without PCOS. The risk of cardiovascular disease and potential metabolic disturbances caused by hormonal contraceptives are important for HCPs to consider, particularly when providing treatment options for women with PCOS. Understanding women's diagnosis experience of PCOS was therefore, important in understanding what information is given to women at the time of diagnosis to ensure that treatment follow up is appropriate.

2.4.3 Non-alcoholic fatty liver disease

Non-alcoholic fatty liver disease refers to a build-up of fat in the body's liver cells that is not caused by alcohol. The condition is defined when greater than 5-10% of the weight of the liver is comprised of fat (American Liver Foundation, 2021). In an American cross-sectional study assessing the relationship between PCOS and non-alcoholic fatty liver disease, it was reported that women with PCOS are at 4 times higher risk of developing non-alcoholic fatty liver disease compared to women without PCOS. The study involved data from 50,785,354 women, including 77,415 who were confirmed to have PCOS. Risk factors for non-alcoholic fatty liver disease include obesity, diabetes, dyslipidaemia and metabolic syndromes, features commonly present in women with PCOS (Asfari et al., 2020). Unlike the study by Asfari et al. (2020) where the cohort of women with PCOS had a high incidence of obesity compared to the control group, Kim et al. (2017) and Kumarendran et al. (2018) both reported an increase in non-alcoholic fatty liver disease in non-obese women with PCOS. This supports findings that while obesity was a risk factor for non-alcoholic fatty liver disease, it also exists independent of obesity (Kim et al., 2017). Due to these findings, the recommendation of non-alcoholic fatty liver disease screening for women with PCOS has been suggested (Kumarendran et al., 2018; Sarkar et al., 2020).

2.4.4 Depression and anxiety

Another comorbidity linked to PCOS is mood disorders, including depression, depressive disorders, anxiety and other forms of psychological distress (Damone et al., 2019; Elsenbruch et al., 2006; Hollinrake et al., 2007). Although the exact link between depression and anxiety in PCOS remains unclear, symptoms of PCOS, including changes to physical appearance, menstrual abnormalities and difficulty conceiving, have all been associated with a lower degree of satisfaction with sex, self and overall health (Damone et al., 2019; Elsenbruch et al., 2006). Women with PCOS have demonstrated low scores in health-related quality of life (QOL) questionnaires, and it has been found that psychological effects of the condition remain underestimated and psychiatric illness may be undiagnosed in women with PCOS (Elsenbruch et al., 2006; McCook et al., 2005). Women who consult healthcare practitioners and attend for a diagnosis might already be experiencing issues with their mental health and the diagnosis process could exacerbate these or, if managed appropriately, could help to diminish mental health issues.

Depression in women with PCOS is found to be higher compared to women without the condition (Damone et al., 2019; Hollinrake et al., 2007; Jedel et al., 2009; Sirmans et al., 2014). A cohort study by Hollinrake et al. (2007) investigating the risk of major depressive disorders or other depressive syndromes in women with PCOS found depressive disorders were higher (35%) in the PCOS group (n=103) compared to the control group (10.7%) (n=103). Similarly, Damone et al. (2019) found higher findings of self-reported depression in women with PCOS (27.3%) compared to women without the condition (18.8%) and Sirmans et al. (2014) reported a 25.9% rate of women with depression in PCOS compared to 13.6% in those without PCOS. In the study by Hollinrake et al. (2007) almost half (47%) of the PCOS group were currently trying to conceive compared with 6% of the control group. The added issue of trying to conceive and fertility problems associated with PCOS may influence the incidence of increased depressive disorders for women with the condition. The difference in reported rates of depression between the two groups (PCOS group versus control group) should be noted, due to the significantly higher rate in the PCOS group. Fatigue and sleep disturbances followed by appetite changes and lack of interest in daily activities were the most common symptoms reported in the diagnosis of depressive disorders. Existing literature provides a clear link between depression, including depressive disorders and PCOS.

Anxiety is also linked to PCOS, with a higher rate of anxiety and increased levels of perceived stress reported in women with the condition. Anxiety and anxiety-related symptoms (reduced sleep, worries, phobias and pain) and anxiety disorders including panic disorder were higher in women with PCOS compared to women without the condition (Damone et al., 2019; Hollinrake et al., 2007; Jedel et al., 2009; Sirmans et al., 2014). Due to an increase in the prevalence of anxiety, depression and mood disorders in women with PCOS, screening of anxiety, depression and QOL has been recommended (Wild et al., 2010). Clinicians need to understand the possibility of anxiety in women with PCOS and give consideration when managing the diagnosis experience for such women. Understanding the diagnosis experience of women with PCOS will highlight how to provide a diagnosis in a way that is mindful of the possibility of depression and anxiety and the screening needed for these conditions.

2.4.5 Thyroid disorders

Adult women with undiagnosed PCOS are often referred for thyroid examination, due to hypothyroidism and hyperthyroidism being underlying causes of menstrual disorders and subsequently decreased fertility. Although decreased fertility is associated with both Hashimoto’s thyroiditis and PCOS, it appears that in patients with both conditions, fertility disorders appear more frequently and are more pronounced (Kowalczyk et al., 2017). It has been established through the literature that there is a common prevalence between thyroid disorders, such as Hashimoto’s thyroiditis and, PCOS (Du & Li, 2013; Gaberšček et al., 2015; Garelli et al., 2013; Kowalczyk et al., 2017; Romitti et al., 2018). A study including 113 women diagnosed with PCOS and 100 women in the control group found that women with PCOS had an increased rate of Hashimoto’s or autoimmune thyroiditis (27%) compared to those without PCOS (8%). The reason for the joint prevalence remains unclear, however, there is evidence to support a link between the two conditions (Garelli et al., 2013) as body mass index and insulin resistance have been reported as the common connection between PCOS and thyroid disease (Romitti et al., 2018). Given these findings and the link between thyroid disorders and PCOS, diagnosis of PCOS provides HCPs with an opportunity to offer investigative options in the detection of thyroid disorders.

2.4.6 Type 2 Diabetes Mellitus

Women with PCOS are at a higher risk of developing type 2 diabetes mellitus and impaired glucose tolerance, therefore oral glucose tolerance testing is recommended to assess insulin resistance in women with the condition (Dokras, 2013; Fauser et al., 2012; Kakoly et al., 2018; Wekker et al., 2020). It has been acknowledged that women with PCOS who are obese are generally insulin resistant and at an increased risk of type 2 diabetes mellitus and impaired glucose tolerance (Bednarska & Siejka, 2017; Cassar et al., 2016; Kakoly et al., 2018; Wild et al., 2010) which is a known feature of type 2 diabetes mellitus. According to Azziz et al. (2009), 50-70% of women with PCOS have insulin resistance and hyperinsulinism. The risk of impaired glucose and type 2 diabetes mellitus was further increased with nationality; women from Europe had a 3-fold risk, those from America had a 4-fold risk, while women from Asia had a 5-fold risk. Similarly, in another systematic review and meta-analysis by Cassar et al. (2016) insulin sensitivity was reduced in women with PCOS and of those women who were also obese, insulin sensitivity was reduced by a further 15%. The link between PCOS and impaired glucose tolerance, reduced insulin sensitivity or insulin resistance highlights the importance of HCPs discussing the risk of type 2 diabetes mellitus with women diagnosed with PCOS.

2.4.7 Endometrial cancer

The association between PCOS and endometrial cancer can be difficult to assess due to an overlap in PCOS comorbidities and endometrial cancer risk factors. Recognised endometrial cancer risk factors include nulliparity, infertility, hypertension, type 2 diabetes mellitus, anovulation and obesity, which are also commonly present in women with PCOS (Chittenden et al., 2009; Fauser et al., 2012). Difficulty in assessing endometrial cancer risk due to the possible confounding effects of obesity and diabetes have been highlighted in the literature, with both being recognised risk factors of endometrial cancer and also known comorbidities of PCOS (Barry et al., 2014; Harris & Terry, 2016). Oestrogen dominance causing a progesterone deficiency is believed to be the main contributor, increasing the risk of endometrial cancer for women. The disruption of the reproductive system that occurs due to PCOS may be the cause of an increased risk of endometrial cancer (Chittenden et al., 2009; Schindler, 2009). Women with PCOS who experience prolonged exposure to oestrogen dominance caused by anovulation or amenorrhea are at greater risk for endometrial hyperplasia and cancer (Chittenden et al., 2009; Goodman et al., 2015; Lauretta et al., 2016). A meta-analysis by Barry et al. (2014) that included 11 studies, with 919 women with PCOS and 72,054 women without the condition, found women less than 54 years of age with PCOS were at an even higher risk of developing endometrial cancer. Women with PCOS have a significantly increased risk of developing endometrial cancer, with reports that women with the condition are 3 to 4 times more likely to develop endometrial cancer compared to the healthy population of women (Barry et al., 2014; Chittenden et al., 2009; Fearnley et al., 2010; Goodman et al., 2015; Gottschau et al., 2015; Haoula et al., 2012; Lauretta et al., 2016; Schindler, 2009).

Studies by Chittenden et al. (2009) and Haoula et al. (2012), recommended early detection measures, education, and the possible implementation of endometrial cancer screening of women with PCOS. It has been suggested by Chittenden et al. (2009) and Haoula et al. (2012) that HCPs should work collaboratively with patients to reduce the risk of endometrial cancer. Early detection of endometrial cancer has been associated with high survival rates, thus the implementation of screening programs for the early detection of endometrial cancer is important (Haoula et al., 2012). Together with screening programs, it is reported that exercise, weight loss and use of the oral contraceptive pill may help to reduce the risk of endometrial cancer (Chittenden et al., 2009). Given these findings and the link between endometrial cancer and PCOS, diagnosis of PCOS provides HCPs an opportunity to offer management options known to reduce the risk of developing endometrial cancer.

2.4.8 Infertility

PCOS is one of the most common causes of infertility, with treatment ranging from alternative options, such as supplements and acupuncture, to pharmacological and surgical intervention and in vitro fertilisation (Collée et al., 2021). Most commonly management of infertility is initially focused around lifestyle changes (Cunha & Póvoa, 2021). Infertility is commonly present with other PCOS comorbidities including thyroid disorders and endometrial cancer, there is also a reported increase in the incidence of depressive disorders for women with infertility and PCOS. According to Jannink et al. (2024) further support is required for women experiencing infertility, given the impact of infertility on mental well-being. Furthermore, findings from Hanson et al. (2017) highlight the need for HCPs to be aware of the broader health impact of infertility for women including mental health conditions and endometrial cancer to provide targeted counselling regarding associated risks. Women with infertility related to PCOS are more likely to develop cardiovascular disease and type 2 diabetes mellitus and the potential concerns for women beyond reproductive health should be discussed. Investigation of infertility is recommended after 12-months of trying to conceive, while PCOS is primarily the cause of infertility, other aetiologies should be excluded first (Collée et al., 2021). However, for women with PCOS it is recommended that investigation of infertility commences at 6 months of trying to conceive, where couples are having sexual intercourse 2-3 times a week (Melo et al., 2015). Infertility and PCOS have been discussed throughout Chapter Two of this thesis, including the relationship between infertility and other PCOS comorbidities. Given these findings and the link between infertility and PCOS, diagnosis of PCOS provides HCPs an opportunity to offer preconception counselling and investigation of infertility may lead to investigation and diagnosis of PCOS.

2.4.9 Hypertension

Women with PCOS are at an increased risk of hypertension, however, the rate of hypertension varies throughout the literature with multiple studies reporting higher rates of hypertension in women with PCOS compared to those without the condition (Joham et al., 2015; Marchesan & Spritzer, 2019; Wekker et al., 2020). According to Macut et al. (2015) hypertension occurs in about 10 - 40% of women with PCOS. The link between PCOS and hypertension remains unclear (Joham et al., 2015), however, it is suggested that the possible link is due to increased aldosterone concentration related to insulin resistance (Cascella et al., 2006; Teede et al., 2006). In an Australian cross-sectional study of 8,612 women, Joham et al. (2015) found that 5.5% of women with PCOS also had hypertension, compared to 2% in the control group. There were higher incidences of hypertension in women using the oral contraceptive pill (7.3%), compared to those who were not (4.9%) in the PCOS group, however, body mass index was not found to be associated with hypertension (Joham et al., 2015). Similarly, in a meta-analysis by Wekker et al. (2020) hypertension was higher in women with PCOS (13.1%) compared to women without the condition (6.6%). Marchesan and Spritzer (2019) also found that women with PCOS had an increased risk of hypertension with the incidence of reported rates varying between 26.6% and 65% depending on the criteria used to diagnose hypertension. The risk of cardiometabolic comorbidities was found to be higher in women with hypertension and the prevalence of dysglycemia and hypertriglyceridemia were 3 times higher in the group with hypertension and PCOS, providing evidence of a link between hypertension and PCOS and other comorbidities for these women.

2.4.10 High body mass index and obesity

According to the World Health Organisation (WHO), a body mass index greater than 25 is considered to be overweight and greater than 30 is obese (World Health Organisation, [WHO], 2021). An older study reported that the percentage of women who have PCOS and are obese or overweight varies (Lim et al., 2012). However, more recent literature has reported that as high as 50-80% of women with PCOS are obese, with ethnicity influencing rates of obesity (Hoeger et al., 2021; Lim et al., 2012; Lim et al., 2013). Central or abdominal obesity is higher in women with PCOS (Diamanti-Kandarakis, 2007; Lim et al., 2012). In a PCOS retrospective cohort study by Mani et al. (2013), of 1,810 patients who had body weight data available, 23.8% were overweight and 51.5% were classified as obese. Being overweight or obese is linked with increased risk of developing PCOS related comorbidities including type 2 diabetes mellitus and cardiovascular disease (De Groot et al., 2011; Mani et al., 2013). Many studies recommend weight loss in the treatment and management of PCOS to reduce the risk of associated comorbidities (Avery & Braunack-Mayer, 2007; De Groot et al., 2011; Wild et al., 2010). A Cochrane review (Lim et al., 2019) which included 15 studies and 498 participants concluded that lifestyle interventions including diet and exercise may help reduce weight and body mass index for women with PCOS.

In summary, many comorbidities are linked to PCOS and the condition is known to affect metabolic, reproductive and endocrine systems within the body. While evidence builds, existing studies have shown strong links between PCOS and cardiovascular disease, non-alcoholic fatty liver disease, mental health conditions including depression and anxiety, thyroid disorders, type 2 diabetes mellitus, endometrial cancer, infertility, hypertension, high body mass index and obesity. The study reported in this thesis explores women’s diagnosis experiences of PCOS and provides HCPs insight into the needs of women with the condition. Follow-up care after the diagnosis of PCOS may provide the opportunity for HCPs to perform screening for known comorbidities and to provide a comprehensive management plan based on individual needs.

2.5 Conclusion

Evidence from other cultural contexts has provided some insight into the PCOS diagnosis experience of women. It has highlighted issues including lengthy PCOS diagnosis with reported insufficient information provision. Women with PCOS also reported receiving care from multiple HCPs over a number of years before receiving a diagnosis. These experiences resulted in perceived dissatisfaction with the overall PCOS diagnosis experience. The varying PCOS diagnostic criteria influences the prevalence of PCOS and subsequently led to the development of the International evidence-based guideline for the assessment and management of PCOS (2018). The use of the Rotterdam criteria for the diagnosis of PCOS, is recommended in the guideline as the most efficient diagnostic criteria to date with consensus for its use nationally and internationally. The aim of the guidelines is to help reduce the overdiagnosis of PCOS in adolescent girls and the underdiagnosis in adult women. PCOS is known to have multiple associated comorbidities which include cardiovascular disease and its associated risk factors, non-alcohol fatty liver disease, mental health conditions including depression and anxiety, thyroid disorders, type 2 diabetes mellitus including insulin resistance, endometrial cancer, infertility, hypertension and high body mass index and obesity. A review of the literature prior to the conduct of the study reported in this thesis, indicated no available literature exploring women’s diagnosis experiences of PCOS in Western Australia, with scant qualitative findings from other contexts. To address the existing gap in knowledge, our study explored women’s diagnosis experiences of PCOS in Western Australia using a qualitative approach. Chapter three, which follows, provides an exploration of the methodology used in this study, with an explanation and justification for the related methods used to sample and recruit study participant, collect and analyse data, ensure study rigour, and adhere to ethical considerations.

Chapter Three

Methodology

Chapter Three of this thesis provides background to the use of a descriptive exploratory approach as the chosen methodology in this qualitative study. Twenty women's experiences of being diagnosed with PCOS in Western Australia (WA) were explored, guided by the aim and objectives of the study. The aim was to explore women's PCOS diagnosis experiences, specifically understanding the diagnostic processes, including the support given, education needs, and ways participants felt improvements could be made. A qualitative approach was considered best suited to address the research question as it allowed for the exploration of behaviours, feelings, and lived experiences of women who had received a PCOS diagnosis through semi-structured interviews. This chapter provides a broad overview of the paradigms of quantitative (positivist), and qualitative (constructivist/interpretive) research and a brief description of mixed methods approaches. Following this overview, the methodological aspects of the study are described and include research design, sampling and recruitment, data collection and analysis, trustworthiness, ethical considerations, and data storage and management.

3.1 Research paradigms

Research methodology refers to the framework used in undertaking a study, including the principles that guide the research process. Careful consideration of the selected design is important as it informs the overall structure of the study. Research methodology can be separated into two different paradigms, namely quantitative (or positivist) and qualitative (or constructivist/interpretive) (Polit & Beck, 2017). A mixed methods approach is used to describe research that uses a combination of the two paradigms (Ghiara, 2020).

According to Polit and Beck (2017), research paradigms are selected based on the ways they respond to basic philosophical questions. Research paradigms are built on ontological and epistemological perspectives. Ontology is the nature of being or reality (Blaikie & Priest, 2019) and epistemology is the theory of knowledge (O'Brien, 2022). The following is an example of an ontologic question, "What is the nature of reality" (Polit & Tatano Beck, 2012, p. 11) and an example of an epistemologic question is, “What is the relationship between the inquirer and those being studied?” (Polit & Tatano Beck, 2012, p. 11). The chosen approach and paradigm are influenced by the research question, aim, and objectives of the study. The exploratory descriptive design chosen for this study falls within the constructivist paradigm. The following sections will discuss quantitative, qualitative, and mixed methods approaches, presenting a justification for the constructivist approach.

3.1.1 Quantitative paradigm (positivist)

Philosophical stance (types of research questions and place of the researcher)

A quantitative or positivist paradigm is an approach that is rational and scientific (Richardson-Tench et al., 2018). Quantitative research relies on the collection of numerical data that can be measured or observed and is used to answer the research question, providing results that are generalisable to the wider population (Park et al., 2020). The philosophical stance of quantitative research (also referred to as modernism) is to remain neutral and assume that an objective reality independent of human observation exists (Polit & Beck, 2017). A positivist paradigm is aligned with being objective, following a scientific approach with controlled research conditions, aiming to prevent personal beliefs or biases from entering the data and impacting the findings. Thus, positivist methodologies aim to control any factors that may influence the study, outside the key variables of interest. Conditions for quantitative researchers involve testing already existing knowledge or hypotheses, within controlled environments in which the researcher is separate from the research processes, and a standardised, reliable, and valid tool or instrument is used to collect the data. Quantitative researchers strive to remove bias and tend to use closed-ended and multiple-choice questions for their inquiry. The data usually addresses questions that are descriptive, correlational, experimental, and quasi-experimental (Harris et al., 2006).

Research designs

Quantitative research uses research designs that include randomised controlled trials and experiments. A descriptive study explores patterns between one or more variables and can take various forms such as case reports, case series, cross-sectional studies, and ecological studies (Aggarwal & Ranganathan, 2019; Cathala & Moorley, 2018). Descriptive studies usually include large numbers of participants with data collection through surveys or questionnaires (Aggarwal & Ranganathan, 2019). Correlational studies are also referred to as observational studies, and examine the link between two or more variables and whether one variable will react to the change of another variable (Cathala & Moorley, 2018). Types of correlational studies include cohort, cross-sectional, and case-control (Lau & Kuziemsky, 2017). Correlational studies often compare exposed and unexposed subjects or participants, and data can be collected using postal questionnaires and interviews (Lau & Kuziemsky, 2017). The final approach used in quantitative studies is experimental, involving the manipulation of variables to observe the effect upon an outcome variable (Cathala & Moorley, 2018). Experimental studies may include randomised controlled trials where the researcher randomly allocates participants into control and comparison groups allowing them to isolate the observed effect of the intervention. This enables the researcher to identify links between interventions and outcomes (Munnangi & Boktor, 2022). Randomised controlled studies can have high associated costs, attrition, and non-compliance (Munnangi & Boktor, 2022). Due to the difficulties of experimental studies, ‘quasi-experimental’ studies are an alternative, using a non-randomised interventional approach when it is not ethical or logical to do an experimental study. However, the lack of random assignment is a reported weakness in quasi-experimental studies (Harris et al., 2006). A non-randomised interventional approach refers to the researcher controlling the allocation of participants using methods that are not random. In healthcare research, quasi-experimental approaches are used to evaluate treatment effects on outcomes (Schmidt, 2017).

Sampling techniques and sizes

Quantitative research places an emphasis on large sample sizes to strengthen the result generalisability of the target population and reduce uncertainty (Polit & Beck, 2017). Determining the appropriate sample size for a study is important in answering the research question. An inappropriate sample size may lead to the collection of insufficient or unsuitable information. In quantitative research, statistical software programs and techniques are used to conduct a power analysis calculation to generate an appropriate sample size (Kang, 2021). Generalisability is one of the concepts of external validity and refers to the extent to which the findings of a study or sample population can be applied to a wider population. External validity refers to the degree to which study findings can be applied outside of their original setting and be accurate or true (Murad et al., 2018).

Data collection (types of data collected and methods used)

Quantitative research involves measurement and quantification; data is usually collected in a numeric form (Cathala & Moorley, 2018). Data types in quantitative research include continuous and discrete (categorical) variables. A variable refers to participant information described in quantities. A continuous variable can take any value in an interval, therefore the value can include decimals, for example, body mass index (BMI). A discrete or categorical variable is reported in specific numeric values with a clear quantitative interpretation, using whole numbers, for example, the number of pregnancies (Vetter, 2017). As outlined previously in this chapter, the three main approaches in quantitative research used to answer research questions are descriptive, correlational, and experimental. The most appropriate approach is selected based on what variables are being focused on and the research question that the study is addressing (Cathala & Moorley, 2018). There are many types of data collection techniques in quantitative research such as using a questionnaire to survey a sample of elements from a target population (Aggarwal & Ranganathan, 2019; Lau & Kuziemsky, 2017).

Data analysis (descriptive and inferential statistics)

As discussed earlier in this chapter, statistics are used in quantitative research as a means of organising, interpreting, and communicating information in numeric form. Statistics in quantitative research are categorised as either descriptive or inferential and inform the statistical tests used by researchers. Descriptive statistics are used to summarise quantitative data to describe the characteristics of the sample population in numeric form. Inferential statistics in contrast are used to make inferences about group differences or changes related to the effect of variables (Polit & Beck, 2017). Types of descriptive statistics include the measure of central tendency and the measure of variability. Central tendency is displayed in a single number and represents the average of a set of scores, it includes mode, median, and mean. Variability is how diverse the data is and includes range, variance, and standard deviation (Polit & Tatano Beck, 2012). There are four levels used in measuring descriptive statistics, namely nominal, ordinal, interval, and ratio. The four levels form a range with ratio measures at the top, followed by interval, ordinal, and lastly nominal (Polit & Tatano Beck, 2012). Each level builds on the previous, adding precision through measurement and each level is important as it helps to determine the type of statistical analysis performed. Moving from a higher to a lower level of measurement represents information loss. Therefore, higher levels of measurement represent more information. The two key types of inferential statistics include estimation and hypothesis testing. Selection of the appropriate statistical method depends on the following; the aims and objectives of the study, the type and distribution of the data and if the observations were paired or unpaired (Mishra et al., 2019). Paired observation refers to the use of the same subjects under two different scenarios, such as different points in time or different methods. Unpaired observations refer to different subjects in each scenario or group (Mishra et al., 2019). It is important the researcher chooses the most appropriate form of data analysis in order to yield reliable results.

Rigour

In quantitative studies, rigour is determined through an evaluation of the validity and reliability of the instruments used. Validity is concerned with the ability of the instrument to measure what it was intended to do and reliability is the accuracy of the instrument used (Ahmed & Ishtiaq, 2021). Validity and reliability are therefore important in conducting or critiquing a study. As outlined by Heale and Twycross (2015), there are three major types of validity, namely content, construct, and criterion, and they are all used to evaluate the validity of a study. While it is not possible to calculate reliability, an estimate can be conducted using the three attributes of reliability, namely homogeneity or internal consistency, stability, and equivalence. The rigour of a quantitative study is assessed through an evaluation of the validity and reliability of a study, which will allow the reader to decide whether or not the findings of the study can be applied, for example to clinical nursing practice (Heale & Twycross, 2015).

Quantitative suitability for exploring the research question

The aim of the study reported in this thesis was to explore women's diagnosis experiences of PCOS. Little was known from the perspective of WA women living with PCOS, making the testing of pre-existing knowledge difficult. Hence, it was important to build the knowledge base related to this phenomenon of interest, using a qualitative approach to yield the rich data necessary. The following section will discuss the second paradigm in nursing and midwifery research, the qualitative or constructivist paradigm, presenting an evaluation of the suitability of the design approach of the study reported in this thesis.

3.1.2 Qualitative paradigm (constructivist)

Philosophical stance (types of research questions and place of the researcher)

There are two major branches of qualitative research, descriptive and interpretive. The qualitative or constructivist paradigm is also referred to as the naturalistic paradigm. Within the qualitative paradigm, reality is not viewed as being fixed, rather it is constructed by study participants. Naturalism extends from post-modernistic thinking, reconstructing old ideas and values and putting them into new ideas. Qualitative research is based on subjective and multiple realities. The interpretations of participants and their voices are essential to understanding the phenomenon under study (Polit & Beck, 2017).

Research designs

Research design in qualitative studies is flexible, meaning that through the simultaneous process of data collection and analysis, researchers may decide to collect further data that was not originally considered (Polit & Tatano Beck, 2012). Data collection using qualitative research designs occurs via researchers using subjective interactions to understand the phenomenon under study and collaboratively construct findings. This design comprises a wide range of methods, including but not limited to interviews (semi-structured and focus group), observations, self-reports, critical incidents and oral histories (Polit & Beck, 2017). Subjectivity in qualitative research is the understanding that both the researcher and the participant have their perspectives and that both are valuable. However, the researcher needs to be mindful of their positionality with interpretations and has a responsibility to ensure the participants' voices are heard by using the participants' own words (Bradshaw et al., 2017).

Sampling techniques and sizes

Sampling techniques in qualitative research are selected to achieve a deep understanding of the phenomenon under study and usually include selecting participants from a population using a non-random process (Richardson-Tench et al., 2018). The purpose of qualitative sampling is to find people who have experienced the phenomenon of interest, rather than attempting to make generalisations across large populations. The intent of qualitative studies is not to generalise to wider populations but rather to understand a phenomenon within a specific group at a specific point (Murad et al., 2018). Sample selection is therefore conducted purposefully to include participants who best represent the phenomenon of interest (Polit & Beck, 2017). Types of qualitative sampling may include convenience sampling, snowball sampling, and purposive techniques. Sample sizes are often small compared to quantitative studies and appropriate sample sizes are determined through data saturation (Whitehead et al., 2013).

Data collection (types of data collected and methods used)

Data collection in qualitative studies is often a long, intensive process for the researcher. Techniques may include observation, in-depth interviews, and other self-report data. The data collected may include life or oral histories, critical incidents, diaries and journals, photo-elicitation, and self-report narratives (Polit & Beck, 2017). Semi-structured interviews were chosen as the data collection method for the study reported in this thesis and an overview of the chosen method will be provided later in this chapter. In qualitative studies, the researcher is the research instrument and therefore the relationship between the researcher and study participants is of significant. Data collection approaches in constructivist research are less structured than in positivist research, facilitating new strategies to emerge during the process of data collection (Polit & Beck, 2017; Whitehead & Whitehead, 2014). In the constructivist paradigm, researcher and participant interaction is important as it facilitates and shapes the data gathered. Qualitative studies are usually conducted in a naturalistic setting, such as participants' homes or community environments. Participant and researcher safety and rapport building are prioritised to facilitate trust and subsequently, rich data is collected (Williamson & Burns, 2014).

Data analysis

In qualitative research, data collection and data analysis often occur simultaneously allowing the researcher to determine when data saturation occurs through constant comparison of the data (Maher et al., 2018; Polit & Beck, 2017). Thematic analysis is a commonly used data analysis technique in qualitative research, it helps the researcher to identify core experiences within the data, "it centres on the contents of the participants' story and the meanings inherent in it" (Holloway & Wheeler, 2010, p. 204). Thematic analysis was chosen as the data analysis method for the study reported in this thesis and a detailed description of the chosen method is provided later in this chapter.

Rigour

Rigour in qualitative research is a way of establishing trust in the findings of a study. Guba and Lincoln (1985) identified four key components to demonstrate rigour, namely credibility, transferability, dependability, and confirmability (Ryan et al., 2007). These four criteria together form the trustworthiness of a study and are explained later in this chapter. Trustworthiness refers to the ability of the researcher to confirm the study findings (Polit & Beck, 2017) and sets out to show the study findings are a worthy inquiry (Guba & Lincoln, 1985). In addition, reflexivity and positionality are important parts of the researcher's self-reflection and are also discussed later in this chapter. Reflexivity refers to the process followed by researchers to analyse and reflect on their own personal values, which can affect data collection and interpretation of study findings (Polit & Beck, 2017). Positionality refers to the researcher's awareness and consideration of their ability to impact or influence their research, this may be attributed to their life experiences and is addressed through a position statement (Jafar, 2018). A positionality statement has been provided in Chapter one of this thesis.

Qualitative suitability to explore the research question

In the study reported in this thesis, the research question explored a specific population's experiences of a relatively under-researched phenomenon. Qualitative research is usually conducted when there is little known about the phenomenon and therefore a qualitative approach was appropriate. PCOS is a distressing condition, and thus focusing on building the researcher-participant relationship was vital so that participants were given time to share the journey which led to a diagnosis of their condition. It was also important to collect data in a way that allowed participants to voice their experiences in a safe environment. Qualitative approaches mirror these needs and allow for the comprehensive and collaborative exploration of the behaviours, feelings, and lived experiences of participants. It was determined that a qualitative design comprehensively captured the aims and research question by exploring narrative recounts of WA women's PCOS diagnosis. Thus, a constructivist paradigm was selected.

3.1.3 Mixed methods

Mixed method research refers to the collection and analysis of both qualitative and quantitative data within a study (Bowers et al., 2013) and is chosen when the research question warrants both qualitative and quantitative research approaches. Mixed methods may have a greater focus on either the qualitative or quantitative approach, known as a dominant status, or both may be represented equally. The decision to choose either a dominant or equal status structure is influenced by several factors including, the research question, the researchers' philosophical stance (positivist or constructivist), the availability of resources, and the researcher's skills and the target audience (Polit & Tatano Beck, 2012). Ultimately the research question itself dictates the chosen methodological approach. Mixed methods research uses explanatory, exploratory, parallel, or nested designs (Shorten & Smith, 2017) with quantitative and qualitative data collection occurring either sequentially or concurrently within these designs.

The use of a mixed methods approach is often selected by healthcare researchers, as this design allows the exploration of healthcare trends and practices, however, this approach requires more resources and additional research training (Shorten & Smith, 2017). Ultimately, the choice of research method is based on the research questions, aims, and objectives of a study. Current literature includes many existing studies conducted using quantitative methodology, the study reported in this thesis was the first WA study on PCOS, and it was therefore decided a qualitative approach would be best suited to understand women's experience of being diagnosed with PCOS. The following sections will provide a detailed explanation of the chosen method and how it was applied to the study reported in this thesis.

3.2 Research design

Prior to outlining study processes and methods, researchers need to demonstrate an awareness of how bias may occur, and its influence on the findings and highlight strategies to mitigate or address these (Engward & Davis, 2015). This section of the thesis will comprehensively discuss a qualitative descriptive exploratory approach as the chosen design, providing the theoretical underpinnings, and an understanding of positionality and reflexivity.

3.2.1 Qualitative descriptive exploratory approach

As indicated previously, a qualitative approach was best suited to the research problem as it allowed for the exploration of behaviours, feelings, and lived experiences of women who had received a diagnosis of PCOS. It enabled the researcher, as the research instrument, to be immersed in the setting and to collect rich data from the participants, highlighting the depth and fullness of the experiences of women with PCOS (Holloway & Wheeler, 2010). A descriptive exploratory approach is a type of qualitative design that "can be used with a variety of theoretical approaches, sampling techniques, and data collection strategies" (Colorafi & Evans, 2016, p. 16). This design focuses on obtaining a true understanding of the phenomenon under study in a naturalistic state or setting and seeks to obtain responses and feelings based on the lived experience of participants. Hence, qualitative description is appropriate for health environment research, and therefore the study reported in this thesis, as it provides responses to interview questions through an exploration of participants' lived experiences (Colorafi & Evans, 2016). This approach involves the collection of rich data, commonly through interviews but may include observation and other data collection techniques, from a sample of the target population. It is aimed at expanding the understanding of human experiences that are not commonly explored or described in existing literature (Willis et al., 2016), such as women's experiences of being diagnosed with PCOS.

3.2.2 Reflexivity

Reflexivity is the practice of being aware that the personal experiences and biases of the researcher will unconsciously and consciously influence their methodological decisions during the study. Thus, being aware of these factors and how they may shape the construction of research processes and interpretation of findings will increase the rigour of research (Engward & Davis, 2015). Understanding researcher positionality and engaging in reflexivity is vital, and in qualitative research, the reflexive process begins prior to the research commencing and is continuous throughout the research journey (Narayanasamy, 2015). Firstly, the role of the researcher includes managing ethical dilemmas and unforeseen challenges, and the ability to do this without influencing the research is a fundamental part of the research process. For qualitative researchers especially, this process of self-awareness must begin prior to the research being commenced and involves the research team discussing ways to prevent bias from affecting data collection and analysis (Reid et al., 2018). Qualitative researchers are involved in natural engagement in relationships and settings, and therefore time should be taken to actively question their assumptions and interests to demonstrate reflexive practice (Reid et al., 2018).

Reflexivity can be divided into two types, namely prospective and retrospective. Prospective reflexivity is concerned with the effects of the researcher on the study and retrospective is concerned with the effects of the study on the researcher (Attia & Edge, 2017). In keeping with the need for reflexivity, and building on the positionality statement in Chapter one, the following section highlights the assumptions, preconceived ideas, and possible biases of the researcher for the study reported in this thesis and shows how they evolved over time.

As discussed in Chapter one of this thesis, the researcher had experienced her own journey leading to a diagnosis of PCOS which further developed and strengthened this research interest. Prior to the commencement of this study, the candidate met with her supervision team to discuss any preconceived ideas and assumptions that she had about PCOS and the diagnosis of the condition. The researcher acknowledged preconceived ideas including:

1) All other women with PCOS must be having difficult diagnosis experiences.
2) Women require further support at the time of diagnosis.
3) PCOS is not well managed by General Practitioners (GPs).
4) GPs do not have a good understanding of the condition and so are unable to provide satisfactory care for women suffering from PCOS.

These four points were recognised as possible biases. It was decided after discussion with research supervisors that the candidate would disclose her own diagnosis of PCOS to the participants prior to the interviews taking place. It was felt that this would allow the researcher to develop a rapport with the participants, prior to commencing the interviews. While the researcher disclosed having been diagnosed with the same condition as the participants, the personal diagnosis experience of the researcher was not discussed and opinions on the participants' diagnosis experience were not provided. This was a collaborative decision made by the research team to prevent the data collected from being influenced by the researcher's own experience of being diagnosed with the condition. This demonstrates the researcher's attempt to keep her experience separate from those of the participants and ensure that the emerging picture was of the diagnosis journey of the women interviewed and not her own. The research supervisors monitored this by reviewing interview transcripts and confirming researcher interpretations by conducting an independent analysis of raw data.

While some of the researcher's preconceptions resonated with the emerging picture from participants, her perspective broadened as data was collected and analysed and more insight was gained into the experiences of other women with PCOS. The researcher found there was a mismatch between healthcare professionals and women, with a breakdown in communication between both sides. Women did not present to healthcare professionals knowing what to ask surrounding their diagnosis of the condition, and similarly, healthcare professionals (GPs) did not appear to understand women's journeys leading to a diagnosis of PCOS, often over several years. Reflexivity is important in research and was demonstrated in this study through the researcher's interaction with study supervisors, examination of the researcher's own ideas prior to data collection, and the evolution of the researcher's views over time.

3.3 Sampling and recruitment

The target population for the study reported in this thesis was WA women with an experience of a PCOS diagnosis. Qualitative sampling aims to select suitable participants who can assist the researcher in developing an understanding of the phenomena. Appropriate sampling is important in qualitative research design as it influences the dependability of the findings. Purposive sampling was used to recruit participants who had a lived experience of the phenomena under study and efforts were made to recruit beyond the metropolitan setting. The final sample included four participants from regional settings (Galloway, 2005; Polit & Beck, 2017). The following sections will include the study setting, inclusion criteria, recruitment process, sampling choice, and sample size.

3.3.1 Study setting

The study setting was Western Australia, a state on the west coast of Australia with a reported population of 2.7 million in 2021, mostly (2.1 million) concentrated in the greater areas of Perth city (Australian Bureau of Statistics, 2022). Geographical location can directly influence a person's health outcomes and people living in rural and remote areas of Australia are subject to poorer health than those in metropolitan areas. Statistics show that the rural and remote populations of Australia have shorter life spans, higher rates of hospitalisation, disease, and injury, increased risk of death, and poorer access to and use of primary healthcare services (Australian Institute of Health and Welfare, 2022). People living in rural and remote areas are disadvantaged in relation to healthcare and are more likely to have poorer health outcomes and face barriers to accessing healthcare compared to those living in metropolitan areas (Australian Institute of Health and Welfare, 2022).

There are different healthcare services available across metropolitan, rural, and remote areas of Western Australia, including public and private services, and access to these vary, depending on where an individual resides. Across WA health there are more than 80 hospitals spread over 2.5 million square kilometres, with six tertiary hospitals in the Perth metropolitan area. A tertiary hospital refers to a major teaching site, providing an extensive range of services and often specialising in specific areas of care for the state (Government of Western Australia, 2022). Metropolitan healthcare services include tertiary and general hospitals, emergency services, specialists, General Practitioners, and clinics including urgent care and after-hours clinics.

The Western Australian Country Health Service (WACHS) provides a range of services for people living in rural and remote areas of WA including emergency services, regional hospitals, integrated district hospitals, GP clinics, community health centres, nursing posts, and the Royal Flying Doctors Service (RFDS). Nursing posts are staffed by highly skilled nurses and doctors (in some instances) providing basic necessary healthcare to communities. The RFDS provides emergency aero-medical transfers from rural and remote areas of WA and is funded by Commonwealth, State and Territory Governments (Royal Flying Doctor Service, n.d.). Some rural and remote patients are also eligible for the patient-assisted travel scheme (PATS) providing access to their nearest medical specialist service that is not available locally (Government of Western Australia, 2022). Despite these services, it is important to note that there is a significant disparity in WA between rural, remote, and metropolitan service accessibility. People requiring access to healthcare services may be disadvantaged due to geographical location with limited-service availability in rural and remote areas of the state. This has the potential to influence the diagnosis, treatment, management, and outcomes of patients' conditions. While many participants in this study were located throughout the Perth metropolitan region, participants from rural areas also had the opportunity to contribute, which helped to capture a broader understanding of the phenomenon being explored.

3.3.2 Inclusion criteria

The study reported in this thesis was designed to understand women's diagnosis experiences of PCOS in WA. As such, women were invited to participate in the study if they met the inclusion criteria of (1) a diagnosis of PCOS within the last two years, prior to participation in the study, by a medical doctor, (2) were of childbearing age, namely in the range of 18 - 45 years of age, (3) were English speaking and able to read and write in English, (4) were currently residing in and had received their diagnosis of PCOS within WA and, (5) were not currently receiving active treatment for a mental health disorder, excluding prior diagnosis and current treatment for anxiety and depression. The inclusion criteria were chosen based on the aim of the study and to help protect women who may be considered vulnerable, despite otherwise meeting the inclusion criteria. Although the final selection criteria (number 5) were to exclude women receiving treatment for mental health issues, it was decided to include participants with anxiety and depression, as these conditions are well reported throughout the literature as being closely associated with PCOS (Damone et al., 2019; Elsenbruch et al., 2006; Hollinrake et al., 2007; Wang et al., 2012). Women with one or both mental health conditions were therefore not excluded from participating in the study as it provided a true representation of women with PCOS and their diagnosis experiences.

The value of qualitative data is reliant on the memory of the women included in the study. Therefore, much consideration was given to time's impact on memory; the cohort of this study included women diagnosed with PCOS within the last two years to help with the recall of the information being provided by the participants. This approach was supported by a study on the accuracy of memory recall relating to medical history, which demonstrated a clear correlation between the length of time since the procedure and the ability to recall facts accurately (Cohen & Java, 1995). In this WA study, limiting the length of time since diagnosis to two years, aimed to ensure that information obtained from women diagnosed with PCOS was as accurate as possible and true to the original account of events.

3.3.3 Recruitment process

Recruitment occurred through an advertisement (Appendix A) created by the researcher and shared on the social media platform, Facebook. Through the strength of social media and the researcher’s online connections, the advertisement was disseminated through multiple channels including PCOS support groups, women’s health forums, and a radio station. The researcher was invited to do an interview about PCOS for the Australian Broadcasting Corporation during the recruitment stage of the research, in which study details were shared and a call for rural participants was advertised. Women who met the inclusion criteria were offered an opportunity to volunteer and further information was given to women who expressed interest in the study through a participant information sheet (Appendix B). This method of recruitment was chosen with the aim of being able to reach women who had lived experience of the phenomenon. Recruitment of study participants commenced in March 2019, with the first interview taking place in April 2019. The second wave of recruitment occurred in February 2020 to reach women living in rural areas of WA and confirm data saturation. All participants were provided with and asked to sign written consent forms agreeing to participate in the study (Appendix C).

3.3.4 Purposive sampling

There are two types of sampling methods used in research, the first is probability sampling, which is commonly used in quantitative research and the second is non-probability sampling, which is more widely used in qualitative research (Polit & Beck, 2017). Non-probability sampling is used to select a group of people with experience of the phenomenon being studied. Purposive sampling is an example of non-probability sampling that is used to target a select group of the population (Galloway, 2005). Participants in this PCOS study were selected using purposive sampling, as they had a personal experience of being diagnosed with PCOS and met the study inclusion criteria, and were willing to discuss both their experiences and perceptions related to this phenomenon (Holloway & Wheeler, 2010). Prior to recruitment and data collection, snowball sampling was considered as a means of increasing the sample size and achieving data saturation. This is a variation of purposive sampling that allows the researcher to gain access to difficult-to-reach individuals who are identified by early study informants, to add new participants to the study if required (Polit & Beck, 2017). However, snowball sampling was not required for this study as women with an experience of PCOS diagnosis were keen to participate and were recruited through exposure to study advertising materials and purposive sampling.

3.3.5 Sample size

There are no set criteria for the size of a sample in qualitative research, as the final number of participants is based on the information needs of the study and sampling continues until no new information is discovered and saturation occurs (Polit & Beck, 2017). Therefore, data saturation determines the size of a sample in qualitative research studies, and in this study, the anticipated sample size was approximately 12. This was based on similar qualitative studies using semi-structured interviews including; a study on 10 first-time breastfeeding mothers (Jia Choo & Ryan, 2016), a study on physical activity in pregnancy interviewing 14 participants (Weir et al., 2010), and a study on obesity treatment in 15 adolescents (Lindelof et al., 2010). However, as data saturation had not occurred with the anticipated sample size of 12, further interviews were conducted to reach saturation and provide a full picture of WA women's experience of being diagnosed with PCOS (Sargeant, 2012).

Data saturation became evident after 16 interviews, as the researcher identified that no new concepts of importance were emerging from the data collected. A way of testing data saturation is adding more interviews after reaching perceived data saturation to ensure no new information emerges (Polit & Beck, 2017). As such, a further four interviews were conducted to ensure that data saturation had occurred (Holloway & Wheeler, 2010), making a total of 20 interviews conducted. In addition to data saturation, this final sample size was supported by a review of existing literature that found other qualitative studies which used similar sample sizes. Examples of these include a breastfeeding study of 18 women with increased BMI, using semi-structured interviews and inductive thematic analysis (Lyons et al., 2019); a study of 20 women with gestational diabetes mellitus regarding their ongoing screening, using semi-structured interviews and framework analysis (Dennison et al., 2021) and a study of breast cancer patient experiences, in which 21 participants were interviewed, using semi-structured interviews and a thematic analysis approach (Ciria-Suarez et al., 2021).

3.4 Data collection

Semi-structured interviews are a qualitative data collection technique that uses a question or topic guide to assist in the collection of narrative data about the phenomenon under study. The researcher as the research instrument follows the guide, however, it is not rigid and participants are encouraged to speak freely, sharing their experiences in their own words (Polit & Beck, 2017). This technique is often used in health-related research as it allows the researcher to understand the participants’ experiences and is an effective method of collecting rich data and unique participant experiences via open-ended questions (DeJonckheere & Vaughn, 2019; Mira & Heather, 2006; Polit & Beck, 2017). Data collected through in-depth interviews allow participants to share their experiences using open-ended questions. This allows the generation of rich data and individual knowledge to be explored comprehensively (Gelling, 2015). Semi-structured interviews were used to collect data in this study using an interview guide (Appendix D) to ensure consistency in the data collected across participants. A guide comprising open-ended questions, designed in response to the study's aim and objectives, was used to encourage participants to describe their PCOS journey (Whitehead et al., 2013). The broad topics covered by the interview questions were women’s diagnosis experiences, support received from healthcare providers, education needs and information provision, and suggestions and recommendations by women to improve current care and practices. Hence, the researcher was able to collect rich data surrounding the phenomenon under study (Mira & Heather, 2006; Polit & Beck, 2017) and explore participants’ experience of PCOS (Gelling, 2015).

Participant interviews were conducted over a 13-month period between April 2019 and May 2020. Most of the interviews (n=16) were conducted face-to-face, however, where this was not possible or not preferred by the participant, video call and telephone interviews were offered. Participants from the rural areas of WA (n=4) were interviewed by telephone. Face-to-face interview venues were decided by participants. The chosen interview venues provided naturalistic and private settings, where participants could freely express their experiences (Holloway & Wheeler, 2010). The face-to-face interviews were conducted in women's homes in Perth suburbs or in a private meeting room at Curtin University when the home environment was not suitable for various reasons, including a shared or noisy environment or personal preference. The Curtin University, Bentley campus is located south of Perth and interviews took place in a room inside the School of Nursing.

Interviews were all digitally recorded with the permission of the participants. The average interview time was 50 minutes. The researcher was the interviewer for the study which allowed immersion in the data and the opportunity to build rapport for the collection of authentic information. Demographic information, such as age, level of education, country of origin, ethnicity, type of healthcare professional who diagnosed the condition (GP/ endocrinologist/ gynaecologist), length of time since diagnosis, treatment options provided at the time of diagnosis, current treatment for the condition and number of pregnancies and births, were collected from the participants. The information collected helped to aid the transferability of the findings by allowing the researcher to describe the participant group for the study. Field notes taken by the researcher included notes on the setting, facial cues, body language, signs of emotional discomfort and comfort levels and, emerging themes (Phillippi & Lauderdale, 2018). Notations were also made of participant names, locations, and others who were present at the interview such as children. This information was used to help the researcher to reconnect and remember the interview and participant while listening to audio recordings during data analysis.

3.5 Data analysis

Thematic analysis is a qualitative research method for identifying, analysing, organising, reporting, and describing themes found within the collected data. It provides a flexible approach and can be used by researchers with varying levels of experience. One of the advantages of this approach is that it can be used by novice researchers and is a useful method for exploring each participant's perspective, highlighting the similarities and differences in their experiences (Nowell et al., 2017). As data collection and analysis generally occur simultaneously with qualitative research, thematic analysis of the data commenced following the first participant interview. Thematic analysis aided the researcher to identify core experiences within the data as "it centers on the contents of the participants' story and the meanings inherent in it" (Holloway & Wheeler, 2010, p. 204). Interview recordings were transcribed verbatim by a professional transcriber employed to convert the audio recordings into text for analysis. Rigour in qualitative research refers to the trustworthiness and integrity of study findings (Polit & Beck, 2017). As such, the accuracy of transcriptions was checked by the researcher against the audio recordings of the interviews, increasing rigour and helping to immerse the researcher in the data (Holloway & Wheeler, 2010). Whilst the intent was to member check, the start of the COVID-19 pandemic coincided with the end of the data collection and continuation of data analysis thus preventing a member check as originally planned. The trustworthiness of this study will be discussed in further detail later in this chapter.

Inductive coding was used throughout data analysis, allowing meaning to emerge from the experience of the participants as captured by the raw data (Thomas, 2006). Meaning units are excerpts from narrative interview data and include words, sentences, or phrases used to describe the phenomenon under study. Once identified the meaning units were reviewed and coded. These were then clustered and collapsed according to emerging patterns and the process continued until overall themes with their linked sub-themes emerged (Holloway & Wheeler, 2010). NVivo version 12 Mac (QRS International) data analysis computer software was used to manage and store the collected data, allowing complete and methodical interpretation and ongoing review as required (Bazeley & Jackson, 2013).

Analysis and interpretations were reviewed with study supervisors to ensure consensus in interpretation. When variations existed during analysis further data were collected to ensure the researcher had grasped a full understanding of the phenomenon and data saturation had been reached. Data analysis revealed four themes, with fourteen linked sub-themes. The four main themes were: 'lead up to diagnosis', 'diagnosis of PCOS', 'life after diagnosis', and ‘listening to women’. Chapter four (Findings) provides details of the sub-themes linked to each emerging theme.

3.6 Trustworthiness

The trustworthiness of qualitative research relies on the ability of the researcher to confirm that the study findings are an accurate representation of the participants’ experiences (Polit & Beck, 2017). Rigour is a way of establishing trust in the findings of a study. Guba and Lincoln (1985) identified four key components to demonstrate rigour, namely credibility, transferability, dependability, and confirmability (Ryan et al., 2007). These four criteria, and how they were assured by the research team, will now be described.

According to Guba and Lincoln (1985) credibility is a result of activities leading to the increase in dependable and reliable findings being produced. To demonstrate credibility, qualitative researchers should aim to provide confidence in the truth and believability of the research being presented (Polit & Beck, 2017). Credibility was demonstrated in this study through data triangulation, a method used by researchers to establish validity in their findings by using two or more approaches (Whitehead et al., 2013). The type of data triangulation used was space triangulation where women from both metropolitan and rural areas of WA participated in the study. This allowed multiple perspectives to be explored by the researcher and a comprehensive understanding to be obtained, reducing the risk of premature conclusions being reached (Polit & Beck, 2017). As indicated previously, the initial 16 participants all came from the metropolitan area, with data saturation becoming evident. To confirm saturation further sampling and data collection were undertaken to capture the perspective of women living in rural areas, to see if their experience resonated with those from the metropolitan area or if new concepts emerged. The researcher verified the understanding of what participants described in their interviews through independent and separate data analysis of transcribed interviews by the study supervisors. The credibility of data unique to the participants' experiences was also assessed through reflexive practice to identify any preconceived ideas and assumptions, recognising that this would also help ensure the quality, trustworthiness, and credibility of the study (Colorafi & Evans, 2016). Credibility relies on dependability being achieved.

Dependability is the second component used to demonstrate rigour, described in Guba and Lincoln (1985) framework, and refers to the reliability of data over time and conditions (Polit & Beck, 2017). As discussed in the data collection section of this chapter, an interview guide (Appendix D) outlining five semi-structured questions, was followed to ensure consistency across all 20 interviews. The same researcher conducted all 20 interviews, strengthening consistency in data collection and reducing possible biases. Data collection and analysis occurred simultaneously throughout the study, adding to dependability as data analysis directed further data collection, and constant comparison of the data occurred throughout the process (Maher et al., 2018). This allowed the researcher to follow emerging themes and patterns in the data with appropriate questioning to determine when data saturation was starting to become obvious and any to decide on the need for further data collection. An audit trail is evident through the reliability of the findings, as documents generated and data collected during the study are available for external reviewers (Holloway & Wheeler, 2010).

The third concept of Guba and Lincoln (1985) framework is transferability which refers to whether the qualitative findings can be transferred to other settings or groups (Polit & Beck, 2017). Providing rich descriptions may allow external reviewers and readers to form conclusions about the study and determine whether it is worthy of their attention (Guba & Lincoln, 1985). It also allows the reader to assess the relevance of the study in similar contexts permitting the transferability of the findings. The transferability of this study is supported by the detailed description of the study's methodology contained in this chapter and details about the study participants and findings provided in Chapter four (Findings).

According to Guba and Lincoln (1985), the final concept of their framework is confirmability and refers to whether the research findings are clearly obtained from within the data without bias from the researcher (Tobin & Begley, 2004). In this study, the audit trail included detailed methodology, data collection and analysis decisions, and outcomes and findings. The audit trail can be used by an external reviewer to assess trustworthiness by tracing the data to the original source revealing the accuracy and relevance of the data. This is demonstrated by the researcher through clear documentation of the evidence that led to the conclusions (Streubert & Carpenter, 2011) provided in Chapter four of this thesis. Participant quotes are included in Chapter four to support interpretations of the findings, demonstrating the accuracy and honesty of the findings as reported by the researcher (Tufford & Newman, 2010).

3.7 Ethical considerations

The study reported in this thesis was conducted in accordance with the National Statement on Ethical Conduct in Research (2007, updated 2023) which provides requirements for research conducted with or about people, their data, or tissue (Australian Government, 2023). Ethical approval was gained prior to commencing the study through the Curtin Human Research Ethics Committee, approval number HREC 2019-0026 (Curtin University, 2016).

Participants who met the study criteria and volunteered to participate were given a study information sheet (Appendix B) outlining the aim of the study and their expected involvement. Participants were provided with the opportunity to ask questions and clarify study information with the researcher, before deciding whether to participate. The women were informed that involvement was voluntary and that they had the right to withdraw from the study at any time without any repercussions (Holloway & Wheeler, 2010).

Confidentiality and anonymity are practices employed by researchers to protect the identity of participants. Confidentiality involves removing any identifying information obtained during data collection (Allen, 2017). Anonymity refers to collecting information from participants without acquiring personal information that could identify the participants (Allen, 2017). As qualitative data collection in an interview involves direct interaction between the interviewer and the interviewee it is not possible to maintain anonymity. Hence the researcher strived to maintain confidentiality instead. The use of raw data with descriptions of the study including the setting and demographic information and the extent of this information was carefully considered by the researcher (Streubert & Carpenter, 2011). All participants were asked to sign consent forms following their agreement to participate in the study. Confidentiality of the participants was maintained throughout, with the researcher de-identifying transcribed interviews by removing participant detail and replacing it with a participant number (1 – 20) according to the order they were interviewed in. Participant details were stored separately from the transcripts to decrease the possibility of re-identification and linking individuals to the data they provided. Only the research team had access to the audio recordings and study notes taken during the interviews, as guided by Holloway and Wheeler (2010).

Measures to protect participants were explained by the researcher to participants prior to the interviews being conducted. The potential for participants to experience distress from reliving their experiences and sharing them with the researcher was discussed with study supervisors prior to interviews being conducted. It was not the role of the researcher to offer therapeutic intervention, but instead, self-referral to counselling services for debriefing was discussed with all participants. It was acknowledged that this may be required following the disclosure of sensitive information, as guided by Streubert and Carpenter (2011). As the researcher was the instrument for data collection, it was imperative that the researcher-participant relationship was maintained and the rights of the participants were respected (National Health and Medical Research Council, 2015). All participants were offered full support, and an adverse events protocol was developed to guide measures to be taken if a participant became distressed or upset. One interview was halted by the researcher as a participant became upset and the availability of appropriate referral was discussed with the option to continue or terminate the interview. The participant chose to continue with the interview following a short break. A plan for potential debriefing was also in place for the researcher with study supervisors, however, this was not necessary during data collection.

3.8 Data storage and management

All participant information including demographic information, audio recordings, and transcribed interviews were stored on a password-protected computer, that only the researcher had access to while data were being transcribed and analysed. These data were then transferred and stored on the Curtin University central research data storage (R drive) repository while the study was being conducted, which is set up according to standard Curtin Information Technology Services security and safeguarding protocols. Access to the R drive for this study included the researcher and the two Master of Philosophy research supervisors. The transcribed interviews, signed consent forms, and field notes were kept in a locked filing cabinet in the researcher's home office while actively being used and then hard copies of records were handed over to Curtin University Information Management and Archives for appropriate management and storage. Electronic records were removed by deletion and audio recordings were overwritten to ensure that no information was retrievable in compliance with the requirements of Curtin University to protect the privacy of all participants in the study. A professional transcriber had access to the audio recordings of the interviews for the purpose of transcribing, these files were shared by the researcher through a Dropbox account (secure file storage server). Files were deleted following transcription and access was removed by the researcher to protect participant identity. Original hard copy documents will be kept for a period of seven years after study completion, after which time they will be disposed of by Curtin University Information Management and Archives in conjunction with the Research Office at Curtin, in accordance with the State Records Act of 2000 (Western Australian University Sector Disposal Authority [WAUSDA], 2013).

3.9 Conclusion

To summarise, this chapter presented the qualitative descriptive exploratory approach used to conduct this study within WA. Ethical permission was obtained from the Curtin University Human Research Ethics Committee and purposive sampling was used to recruit 20 participants through social media. Participants were asked a series of five semi-structured questions through face-to-face and telephone interviews to explore their experiences with obtaining a PCOS diagnosis in WA. Transcribed interviews were analysed using a process of thematic analysis, with trustworthiness ensured through the criteria of credibility, dependability, confirmability, and transferability. Research data was stored through Curtin University’s R drive in accordance with the Western Australian University Sector Disposal Authority (WAUSDA, 2013). Chapter four, Findings, that follows provides the findings that emerged from the exploration of raw accounts of participants' PCOS diagnosis experiences in WA. It includes participant demographics and presents the four themes namely, 'lead up to diagnosis', 'diagnosis of PCOS', 'life after diagnosis', and 'listening to women' and their linked sub-themes.

Chapter Four

Findings

The aim of this qualitative descriptive study was to explore Western Australian women's experiences of receiving a diagnosis of PCOS. Such knowledge helps in identifying areas for improvement and provides HCPs with insights to strengthen the communication of the diagnosis and information provision to women and, improving their ongoing management. Thus, helping to tailor care with the specific needs of women with PCOS in mind. The women interviewed were asked to share their experiences surrounding PCOS diagnosis including lead up to diagnosis, receiving their diagnosis, living with the condition and life after diagnosis. This allowed each woman to tell her own story, recalling medical history and experiences to the best of their abilities. The study criteria included diagnosis within the last 2 years, this time frame was chosen to optimise recency of the diagnosis experience and improve recall. Purposive sampling was used to recruit women who had personal experience of the phenomenon under study. Women were recruited as participants for the study on a voluntary basis through a social media advertisement.

A descriptive exploratory approach was used as the chosen methodology. This allowed the researcher to obtain a true understanding of the phenomenon under study, within a naturalistic setting, as the majority of the interviews were conducted in the women's homes. The researcher explored participant perceptions that had formed, based on their experiences and interactions with HCPs. This chapter (Chapter Four) provides participant demographics and findings of the analysed data. Tables have been used to provide diagrammatic representations of the demographic information and themes and sub-themes to enhance the understanding of the findings presented. Participant quotes are used throughout the chapter to support the interpretation of the data.

Data collection and analysis occurred simultaneously. Of the interviews conducted four were by telephone and 16 were face-to-face. Interviews were conducted over a 13-month period between April 2019 and May 2020. Five semi-structured questions were used to ensure consistency in the interviews. The questions were designed around the aims and objectives of the study and were supported by prompts to aid discussion. Interviews were transcribed and meaning units identified, which in turn were reviewed and coded according to emerging patterns establishing themes and subthemes. Data analysis computer software (NVivo version 12 Mac QRS International) was used to manage and store the collected data, allowing the researcher to ensure the data was interpreted and reviewed completely and methodically (Bazeley & Jackson, 2013).

4.1 Participant demographics

A total of 20 women were interviewed. Data collection was ceased once no new data emerged from the interviews, indicating that data saturation had been achieved. Data saturation was observed during interview 16 and confirmed with a further four interviews conducted to demonstrate this (Sargeant, 2012). The participants involved in the study were aged from 23 to 41 with a mean age of 28 years. Sixteen participants were from metropolitan areas and the remaining four were from rural areas within WA. Fifteen of the 20 women were born in Australia with five being born in other countries including: France, Singapore, Ireland, Poland and New Zealand. One woman identified as Aboriginal and her contribution was significant as Indigenous women have a higher prevalence of PCOS with greater health issues compared to non-Indigenous women (Boyle & Teede, 2012; Boyle et al., 2017). Having an inclusive cohort of participants allowed a wide perspective of lived experiences to be explored. Of the 20 women, five had given birth and 15 were nulligravida, meaning they had never been pregnant. Sixteen of the women were diagnosed with PCOS by their

GP and four were diagnosed by a specialist. More detailed demographic information is provided in Table 1 (below).

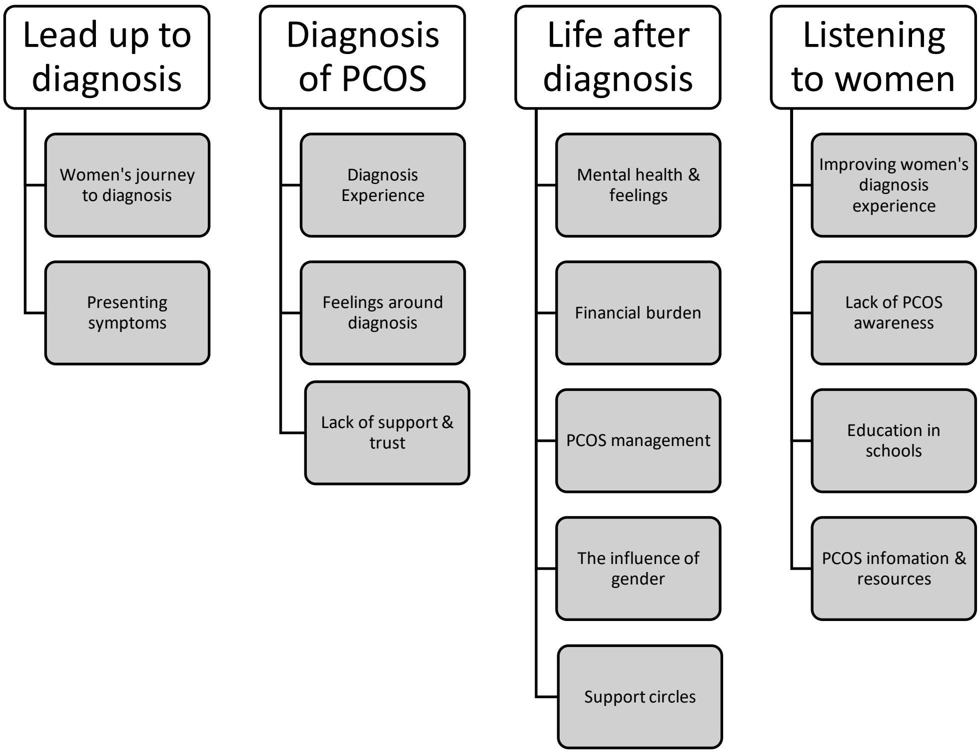
Table 1: ***PCOS study participant demographics***

Demographics	**Number**	**Percentage (%)**
Age		
18-24	5	25
25-34	14	70
35-42	1	5
Highest level of education		
Tertiary	18	90
High School Year ≥ 10	2	10
Country of birth		
Australia	15	75
Other	5	25
Location in WA		
Metro	16	80
Rural	4	20
Diagnosed by		
General Practitioner (GP)	16	80
Specialist	4	20
Pregnancies		
Nulligravida	15	75
Given Birth	5	25
Ethnicity		
Caucasian	17	85
Asian	2	10
Aboriginal	1	5

4.2 Findings

Data analysis revealed four themes, with fourteen linked sub-themes. The four main themes were: ‘lead up to diagnosis’, ‘diagnosis of PCOS’, ‘life after diagnosis’ and ‘listening to women’. Figure 2 below provides details of the sub-themes linked to each emerging theme. To protect confidentiality, each participant was assigned a number according to the order in which they were interviewed, this is demonstrated using Participant 1 (P1) to Participant 20 (P20) (P = participant). Direct quotes from participant raw data have been linked directly to interpretations to demonstrate confirmability of the findings. Quotes have been presented verbatim with grammatical errors left to preserve the participants' voice and to fully capture each woman's journey and experience as told by the participants individually.

Figure 2: ***Themes and sub-themes***



The following sections present the detailed interpretations related to each of the four themes and their linked sub-themes.

4.2.1 Lead up to diagnosis

The first theme highlighted the participants' experiences leading up to a diagnosis of PCOS, identifying anything that was considered to be significant in the woman's journey. It was an opportunity for women to share their experiences and tell their stories. The participants recalled interactions with HCPs and the symptoms that they presented with for investigation. The theme ‘lead up to diagnosis’ had two linked sub-themes, namely, ‘women’s journey to diagnosis’ and ‘presenting symptoms.’ These sub-themes will now be discussed.

4.2.1.1 Women’s journey to diagnosis

For many participants the process of arriving at a diagnosis commenced in adolescence. In telling their stories they described their medical history, age of menarche and hormonal contraception prescribed by HCPs. For some women their path to diagnosis took place over several years, seeking care from multiple HCPs in the hope of getting answers in relation to their presenting health issues. Some participants reported turning to the internet to find information and answers corresponding with what they were experiencing. Women described the various forms of hormonal contraception that they had been prescribed and were using, often for long periods of time. These included the oral contraceptive pill (OCP), NuvaRing, Implanon and intrauterine devices (IUDs). Women reported being prescribed the OCP for a range of reasons including acne, painful periods, heavy bleeding, cyst management and irregular periods, all from varying and sometimes young ages.

> ‘*I was about 13, I had my first hospitalisation with an ovarian cyst. So, I saw a couple of gynaecologists and specialists and the only kind of option or treatment was to go on the pill. So, at 13 I was put on the pill.*’ (P15)

Some women linked the OCP with masking their PCOS symptoms which they reported only becoming apparent when they ceased hormonal contraception. Participant 17 voiced “*I almost feel like if I hadn’t come off the pill that I would have gone maybe undiagnosed unless I started to have issues when I was trying to have children.”* An experience similar to Participant 18, who recalled “*…it wasn’t until I came off the pill that I actually realised my cycles were irregular, because I’d been on it pretty much every day since I was like 14 or 15 years old*.” Participant 15 described the onset of PCOS symptoms after ceasing the OCP as,

"*… once I stopped the pill last year, I got hit pretty hard with some of the symptoms of PCOS. I had acne all over my face and my back*."

The long-term prescription and use of the OCP as a treatment option for PCOS masked symptoms and prevented any further follow-up, the underlying problems still remained and, in some cases, women perceived that the OCP also had negative effects. Participant 13 had the experience of being on the OCP for 8 years and having negative effects stating "*…I decided to come off the pill. That was due to mental reasons, I felt that it was affecting my mental state."* There was frustration for some women who felt that doctors did not evaluate treatment and they reported having to source their own information. There was concern about the continued prescription of the OCP over many years without health checks occurring simultaneously. Participant 11 stated, "*so many times I'd go see my doctor, get a repeat of my script and it's just 'here's your script', like no discussion about anything else*", highlighting her frustration with the HCP not practising what she considered their due diligence.

For some women, their journey to receiving a diagnosis of PCOS took place over a period of time commencing in adolescence and involving multiple HCPs. Women reported turning to the internet in their search for answers and information surrounding their presenting symptoms. Although GPs were usually the first HCPs women consulted, further information was desired, and feelings of confusion emerged for these women in their search to understand their condition. Participant 13 stated "*… I took my own initiative to Google but then it's like does that make it worse? I just didn't really know where to go because like, the GP wasn't helping. Google was just making it worse."* Another woman used the internet to try to obtain more information on PCOS following investigations by her doctor who suspected the common endocrine condition.

> *'It's [PCOS] still quite confusing to get your head around it. So did like a bit of research and looked into all different types of websites to try and understand it. That's what I did before I went and saw the doctor again to get my results.' (P11)*

4.2.1.2 Presenting symptoms

Participants described a variety of symptoms leading to their diagnosis of PCOS including emotional, mental and physical symptoms. Some women reported experiencing symptoms for many years before meeting diagnostic criteria. Symptoms included acne, cysts, unwanted hair growth, hypoglycaemia, irregular periods, fluctuating moods, weight gain, high body mass index (BMI), heavy menstrual bleeding, high testosterone, hormonal imbalances, pain and premenstrual stress (PMS).

Commonly women described multiple symptoms, as recalled by Participant 4 "…*my BMI's quite high and I have like facial hair and really irregular periods*." Participant 5 shared *"I had a lot of acne, skin problems… they just kept saying that it was my skin and I kept arguing that it was hormonal."* While some symptoms were physically evident such as acne, weight gain, excessive hair growth in unwanted areas of the body, others were not evident externally. Some symptoms experienced were more acutely serious, affecting women as they went about their daily lives:

> *'If I don't eat regularly like every 3 hours or so I will suddenly just go into a slump, I get really shaky, I can't think properly, I just need to eat immediately. Once I eat within like 20 minutes, I'm ok again.'* (P7)

Participant 17 also shared her experience of having 'unseen' symptoms and the impact this had on her health.

> *"I think because as well it's like it [PCOS] affects your hormones, it affects your self-image and your confidence and fertility and then that can cause other health conditions in terms of mental health as well."*

One woman, Participant 20, described experiencing PCOS symptoms from a young age and how it affected her life, stating "*I've always had really heavy periods, it affected my schooling, I couldn't go to school when I had my periods, I was just flooding all the time. Lots of pain, my PMS was like awful."*

In summary the women in this study were affected by the presenting symptoms of PCOS, both seen and unseen. The reported symptoms outlined above included heavy bleeding, hypoglycaemia and hormonal issues. The women's comments have identified the effects on their self-esteem and mental and physical health, highlighting the pervasive impact on their lives.

4.2.2 Diagnosis of PCOS

The second theme captured the women's feelings, emotions and interactions surrounding their diagnosis of PCOS. Women used descriptive words to articulate their feelings. The women's diagnosis experiences included their interactions with HCPs and the reported lack of support and trust they encountered. The theme 'diagnosis of PCOS' had three linked sub-themes, namely, 'diagnosis experience' 'feelings around diagnosis' and 'lack of support and trust.' These will be presented in the following sections.

4.2.2.1 Diagnosis experience

Diagnosis experiences encompassed the interactions women had with doctors surrounding their diagnosis, how they perceived the information being given to them and how it was delivered, all of which played a significant role in the women's journey. The women's interactions with HCPs were a large part of their diagnosis experience and included categories in the data which have been illustrated below.

The ***delivery of diagnosis*** by the HCP was significant to participants, with the lack of time allocated causing women to feel rushed with no time to digest the information and ask questions. One participant indicated that she would have appreciated being advised to book a longer appointment when receiving a diagnosis of PCOS, highlighting a possible gap in current services and communication from the HCP. One woman (P17) suggested the recommendation of double appointment slots when attending to receive results, allowing sufficient time for questions, explanation, information provision and collaborative care when developing a plan.

"… so they [GPs] kind of like try and get you out the door… it would have been nice maybe if I'd known what was ahead, I would have maybe booked a longer session." (P17)

Women linked ***bulk-billing*** services to being rushed. In the Australian Medicare system, some GPs eliminate the cost of a consultation for patients by not charging more than the government fee; this is known as 'bulk-billing'. Some women in this study attributed inadequate consultation times to bulk-billed appointments, *"I feel like the bulk bill ones [GPs] are the ones that you don't get much out of."* (P8). Participants perceived a difference in the care provided by GPs, depending on whether they offered a bulk-billing service or fees payable:

> *'I don't know if it is because she [GP] is a bulk bill, but they tend to just give you the diagnosis and then brush you off kind of thing… I asked, 'what I can do', there was no help kind of thing.'* (P13)

Women felt that when one paid the GP or HCP for a service it resulted in that individual being more invested in establishing a professional relationship with the patient, compared to a bulk-billing service provider:

> *'I just think the level of care and empathy shown [is different] and I feel as well maybe if you're paying… that person [GP, fees payable] wants you to continue coming to them so they're more likely to try and establish that rapport or trust with you rather than… bulk billing [GP] sometimes you don't get the same GP or… they don't really have time to look at the notes or less likely to look at the notes*.' (P17)

Unmet expectations were described when appointments were reported to be rushed, impacting overall diagnosis experience and failing to provide PCOS management options the women were satisfied with. Women linked these unmet expectations with bulk-billing services offered by some HCPs.

> *'It was a very quick visit. She [GP] basically looked at the results and said, 'okay yes, this is PCOS' and, then that was it. She [GP] actually said 'it's not the end of the world, it's just what it is, and you can go and do your own research on it'. So, it was like okay. I was kind of annoyed. I don't know if she said that because she knew I was a nurse*.' (P14)

As well as feeling rushed during her appointment, P14 also felt that assumptions were made about her level of knowledge or understanding which may have prevented more detailed information being provided.

In addition to feeling rushed during appointments, another factor that impacted the diagnosis experience was whether the diagnosis was received in person or by telephone. Participant 9 revealed that after receiving the diagnosis by telephone, she recalled crying following the appointment: "*She [GP] told me over the phone… it didn't allow for me to ask as many questions or just have the time to kind of have her relay information to me."*

Lack of connection when delivering the news was also attributed to doctors' communication skills and perceived lack of sensitivity which women described as negatively impacting their experiences. One woman stated:

> '*I went to 3 doctors initially… the first one said you know you need antidepressants and to get a part-time job. The next one told me to suck it up, literally told me to suck it up… I'm like oh my gosh. I'm coming to you for help and yeah, not very helpful and then by the time I went to the third one I had a goitre… But yeah, they're certainly not optimal.'* (P20)

One participant who was unable to get an appointment with her regular doctor and was given an appointment with an alternative HCP at the practice she attended, describing the difference in her experience, feeling that her needs were unheard.

> *'…Yeah, probably couldn't have been said any more horrible from him... I didn't even get a hello. I got quite emotional… for him to just be so blasé and abrupt about it was really awful and, I said to him 'so what do I do now?' And he said well there's nothing you can do now. He said we'll put you back on the pill and I said 'I don't want to go on the pill because I'm trying to conceive'… he printed me out a flyer off the computer about PCOS, handed it to me and that was it. That was literally it.'* (P15)

Women reported the ***gender of the HCP*** as contributing to them feeling comfortable in the interaction. Receiving a diagnosis from an unknown GP, having no previous rapport and being given a diagnosis from someone on a first encounter were all contributing factors to the women's diagnosis experiences. However, it was also described by some participants that the gender of the practitioner made a difference in their level of comfort with the HCP, with some feeling better able to relate to a female GP.

> *'I felt more comfortable with my GP, the female… seeing the male specialist it just felt like, I didn't feel comfortable enough with his body language or you know his questioning to be able to then ask him further questions.'* (P15)

Women chose to see a female GP instead of a male because they identified the diagnosis time as having the potential to be emotionally evoking, highlighting the importance for women to feel comfortable with the HCP involved in their care. For some participants this meant gender selection of the GP prior to the appointment being made.

> *'I went and saw a female GP at the same practice. So, my family sees a male GP but, for those kinds of things I felt like a female would probably be better and I got quite emotional, so I didn't want to cry in front of him.*' (P3)

Participants sought female GPs due to a belief about their relatability and ability to empathise as a woman themselves.

> *'I did have a [male] family GP growing up that was quite dismissive and jokey… by the time I was about 15 I only wanted to see female GPs… I felt that they had a better lived experience of being a woman and also, they would understand things more and have more of an interest in women's issues and hopefully tend to take stuff more seriously as well.'* (P7)

Another participant (P3) expressed that another female may have more interest in women's health conditions. What became evident is that decisions to select a female HCP resulted from previous negative experiences with male HCPs in relation to reproductive health issues.

> *'I still remember quite vividly describing one period to this one [male] GP and he just kind of cringed and was like oh, here's the pill, like get out of my office kind of thing. They just don't want to talk about it and yeah still to this day there's some that probably still do that.' (P3)*

While it was clear that the women in the study reported in this thesis had a general preference for female HCPs, when seeking a HCP, when they described their actual experience, many reported poor care from GP irrespective of gender.

Women described what they looked for in a GP and what they considered a ***'good doctor'***. Identifying a HCP through the recommendation of others, who was thorough and could offer reassurance, provided written resources and involved the patient in their care, ensuring that there was a clear plan were all important criteria.

> *'I think it's really important to have someone who is really thorough… every time I went and saw my new GP at the end of every appointment, I'd always come out feeling really like reassured and like yeah, we've got a new plan. I felt like I'd actually got something done… I felt like it was worth my time.'* (P18)

Participant 14 (below) described a 'good doctor' as someone who appeared to hear her and her needs, highlighting that being listened to was important. Women also valued explanations surrounding the condition and being provided with care options by the HCP. Participant 14 revealed that a 'good doctor' was: "*just someone, that you know will actually take the time and listen to you and explain things and not just quick 5 minutes in and out, 'there's your results, off you go I don't really care'.* (P14)

The ***appointment duration*** was another important factor for women in their care and subsequent journey, being able to have the time to ask questions and receive the information that they required to feel supported. Participant 15 recalled "*…it was less than 10 minutes and he had stood up by the time he handed me the flyer and was opening the door."* Similarly, another participant shared her experience, reporting insufficient time during the diagnosis appointment for questions and processing of information.

> *'I felt like there was a lot of unanswered questions but in the sense that maybe I didn't have time to process…I just kind of felt she was a bit like sort of cut and dry and maybe, I think I just needed someone to be a bit more empathetic when they were diagnosing me with this [PCOS].'* (P17)

Women identified the importance of being offered ***referral to specialists*** following diagnosis of PCOS. There was a need for more PCOS information and advice and at times women felt they were met with resistance from their GPs, especially regarding referrals to specialists. Participant 20 describes her frustration when she was referred by her GP to an endocrinologist following her diagnosis of PCOS and was then refused care by her GP should she follow through with the specialist appointment, "*…she didn't like endocrinologists, she actually said to me if I go see one, she will refuse to see me. I was like what the hell I'm just trying to [get help]. Anyway, totally frustrating trying to get help."*

One concern reported was ***doctors not listening to women.*** One participant felt that her concerns were not being taken seriously, forcing her to do her own research when dissatisfied with what the HCP had provided her with. There was also a loss of trust as a result of such interactions between women and HCPs.

> *'I went back, and I told her [GP] 'I've been reading that women with PCOS are prediabetic or they have insulin resistance'… and she said, 'oh yes so you are insulin resistance you were right'… 'so I was right, and you told me no you're not because your blood sugar is fine?'.'* (P2)

Access to doctors in rural areas was a challenge faced by some women who described the difficulties in finding a doctor who could assist with PCOS management away from metropolitan areas. Women were not always eligible for the patient assisted travel scheme (PATS) which provides financial assistance for some rural and remote residents and frustration was expressed in not having access to much needed specialist care when living in a rural area.

> *'Specialists that's really hard, we have GPs here…it's very limited and it's so remote. I mean the closest other town is Karratha which … takes just over 2 hours to drive there and that's a similar situation. There's nothing really there either and the doctors that are here they just seem to be kind of useless. It's just, it's really hard if you want to see someone. You pretty much do have to go to Perth to see someone and it … takes a lot of time and unless it's funded through the health system it's expensive.'* (P20)

Making the decision to seek an opinion and care from another HCP when living in a rural area requires factoring in large travel times to and from the clinics. One participant discussed the perceived benefits of seeing a GP further away with better support being offered.

> *'I was talking about this with my partner and we were saying that it's probably going to be a smart idea to go to a different GP which is 2 hours away…which is obviously a big drive but there's no point having a GP if you're not getting any support at all, so it*

> *is probably worth seeing them less regularly and getting more when you do go there.'* (P16)

There were many reasons why women sought a ***second opinion*** including dissatisfaction with care, lack of support, unprofessionalism, insensitive reactions by the doctors and perceived lack of knowledge on the condition.

> '*She (GP) actually was saying…this shows you have PCOS, she kind of laughed while she was saying it... 'if you don't have the knowledge that's fine, just say it, just refer me onto someone else'…I'm not annoyed that she didn't know because everyone can't know everything about it but I was just more annoyed that like you weren't straight up and said I don't have a lot of knowledge on this but go see this person or you know go, refer me to a specialist just anything.*' (P14)

Second opinions were sought by some participants in their diagnosis journey when they were not getting the answers they were looking for, "*so I'd been to different doctors, dermatologists and then last year I went and saw a different doctor and … she's basically said that I met the criteria for PCOS"* (P5). Second opinions were sought to develop participants' understanding of PCOS when initial care and information was considered to be insufficient. Participant 6 shares her search for more information, *"I guess also second opinions as well are helpful to really understand what you've got. I guess Google is not always the best but then pamphlets aren't the best either."*

Recommendations from friends and family were considered useful when seeking a second opinion when women were not getting the support and care they needed or they were not satisfied with the doctor they had initially seen, as described by P14:

> *'I've actually gone back to see a different GP, another female one that I got recommended and that has been a lot better… a much better experience to be honest…I just felt like the first GP just didn't really care but I felt like maybe she also just was a bit nervous because she didn't really know how to explain it.'* (P14)

Women's diagnosis experiences highlighted a collection of issues perceived by the women interviewed, these directly involved their interactions with HCPs. Women shared their diagnosis experiences and feelings around diagnosis of the condition.

4.2.2.2 Feelings around diagnosis

Participants reflected on their experiences during the interviews, expressing their feelings around receiving a diagnosis of PCOS. Feelings varied between participants, many overlapped or were shared feelings. Participant 18 said she felt upset and overwhelmed, *"...I remember when… she had the results from the ultrasound and the blood test and everything. When she [GP] told me, I remember being quite upset, I remember crying and being quite overwhelmed and upset."* Feeling upset when receiving a diagnosis of PCOS was common for women; Participant 16 shared a similar sentiment:

"… [I was] really upset because I had, which is silly, but I had this fear of getting really hairy like a man and it (sic) getting worse and the pain getting worse." The women in this study described a myriad of feelings including being upset, overwhelmed, relieved and annoyed, in response to receiving a diagnosis of PCOS. Participant 9 was one who felt a sense of alleviation on receiving her diagnosis: "*It made me feel a little bit relieved because it gave me an answer I guess."* (P9)

Participants also expressed feelings of denial, having difficulty coming to terms with the diagnosis and needing time to reach a point of acceptance.

"I don't know I think … a bit of denial for a little while. I was kind of like it'll just come better …I sort of admitted to myself that maybe I did have PCOS." (P4)

Self-blame was another response with participants feeling to blame for their condition and symptoms.

"*I was quite upset. I don't think I cried though, I think I cried afterwards, I kept it together…I wasn't happy, predominantly because I felt like it was my fault that it had gotten to that state."* (P7*)*

Women reported feeling stunned when receiving a diagnosis of PCOS. Participant 17 stated "*I was a little bit, you know you're a bit shocked and I didn't really ask any questions at the time."* Similarly, Participant 3 described feelings of shock and being unable to process what her HCP was saying at the time of diagnosis, "*I think I just went into kind of shock of what she*

[GP] was saying and I didn't really take in…it's lifelong and then I think I just zoned out after that."

The initial negative feelings women experienced at the time of diagnosis sometimes improved when information and help was identified surrounding PCOS.

> *'Yeah, it kind of felt like my world came crashing down a little bit when I got that diagnosis because I didn't really know that it wasn't kind of the be all and end all… there was help available and… once I kind of got that information and I felt …relieved and oh this is, the journey's starting now really.' (*P18)

Feelings experienced around PCOS diagnosis encompassed a variety of different emotions described by the participants interviewed. The impact diagnosis had on women was explored above with raw accounts of the way women felt at the time of receiving their PCOS diagnosis. A perceived lack of support and trust from HCPs was reported by the participants.

4.2.2.3 Lack of support and trust

Women recounted what they described as a lack of support from HCPs. Participant 1 shared her experience: "*I did ask about what PCOS is…all she [GP] did was print out some information and give me that to read… I didn't actually get any real support from the doctors…everything that I've learnt has come from me."* Participant 13 voiced similar experiences and felt "*… that the GPs aren't willing to give support or anything".* Lack of support, led to feelings of upset and unhappiness, *"I don't know [I felt] shocked and sad and like ... where do I go from here, if you're not going to offer me any support like what I am supposed to do now?"* (P13)

Participants highlighted a perceived lack of understanding and knowledge surrounding PCOS by HCPs, suggesting that HCPs need to improve their understanding to be able to better support women in managing the common endocrine condition.

> *'I definitely don't think there's enough support when you get diagnosed because even though you know it's not the doctor's fault or anything they don't fully understand, and you know they tell you oh it can lead to infertility… I definitely just think doctors definitely just need a little bit more information on it.'* (P1)

Women wanted the opportunity to be provided with information and to ask questions in a collaborative way. When this was not achieved it led women to feeling upset, highlighting the importance of the need for a collaborative care model and provision of options. Women wanted to be enabled to make informed choices about the management and treatment of their condition, which was often lacking, as described by P11:

> *'I was like is there anything I can do to balance my hormones? [The GP said] 'The only thing we can do is put you back on the pill' but I'd already expressed my concern that I don't want to be on that for mental illness. So that kind of really upset me because that's the only option they were giving me.'* (P11)

Building a rapport between the women and HCPs was considered to be the foundation of a trusting relationship, further highlighting the importance of collaborative care. Women felt it was important that the HCP got to know them so that they could involve them in their management, treatment and care provision. Participant 13 described her interaction with an HCP who she felt had no true knowledge of her:

> *'She [doctor] literally told me that I shouldn't diet because I'm already skinny… I find that really kind of rude because I was like you don't really know what I'm eating, you haven't even taken the time to get to know me.'* (P13)

The need for a trusting relationship between the woman and her HCP was also commented on by Participant 11: *"I had a feeling I was going to have issues, I wanted to see a doctor from the get-go who I thought I'd trust."* Being unable to build trust with the HCP impacted women's perception of their care. Some women, like Participant 4, felt this affected their understanding of their condition:

> *'I don't think I would have trusted [the doctor] … I would have … gone and done my own sort of research …There are a lot of doctors out there that just want to see you, do obs and then off you go.'* (P4)

Those women who were able to build a good relationship with their HCP described placing trust and hope in their decision-making, as stated by Participant 12, *"I thought I trust him [HCP]. If he thinks that it's the best thing to try then I'm willing to do that and I will take* *the risk.*" When the opposite was true, a lack of trust and support was felt to negatively impact the women's' diagnosis experiences. Lack of support was linked to a perceived lack of understanding surrounding PCOS by the HCP. The absence or presence of trust negatively or positively impacted women in their care experiences. Collaborative woman-centred care was recognised as being important, with HCPs getting to know the women they were caring for and ideally involving them in their planning of treatment and management options.

The trials of women's diagnosis have been described in the theme 'diagnosis of PCOS' and subthemes above. In summary the main areas raised by women, in the study reported in this thesis, when exploring their diagnosis experiences were the delivery of PCOS diagnosis; the perceived effects of the gender of the practitioner and the difference it made to the women's level of comfort with the HCP. Participants also described what they considered to be a 'good doctor'; and discussed appointment duration. Women shared their reactions when they felt GPs did not refer appropriately to specialists; and gave their perceptions of doctors not listening to them; and how they were affected by rural access to doctors, second opinions and specialists. The following theme follows the women's journey and explores 'life after diagnosis' for the women.

4.2.3 Life after diagnosis

The third theme which was the largest theme related to life after diagnosis. Diagnosis of a multisystem condition brought a variety of emotions for the women, but it was only the beginning of the journey. The experiences women had following diagnosis of PCOS, affected their physical, mental and emotional health. This theme encompassed the following five sub-themes that explored 'mental health and feelings', 'financial burden', 'PCOS management', 'the influence of gender' and 'support circles.'

4.2.3.1 Mental health and feelings

Women experienced mental and emotional challenges as a result of the pathophysiology of having PCOS. They disclosed mental health issues such as depression which in turn impacted their physical and emotional well-being.

> *'I had really bad depression and I've never had a problem with depression before, but it was really like I couldn't even smile at my kids and when I looked at them, I just felt like I hated them. I didn't have any nice feelings towards people. So yes, I was really depressed, my sleep was crazy, exhausted. I put on heaps of weight and I still am on a rollercoaster of weight.'* (P20)

Mental health issues were described as being linked to physical symptoms of PCOS. One woman described the impact on her mental health, caused by treatment of her acne, one of the symptoms of PCOS.

> *'When she [GP] said there's nothing that they could really do about it…for me it was more frustrating because it just impacts my mental health when I know I've got to take these antibiotics [for my skin] every day and I'm sick of taking them but I know the minute that I stop it goes in the other direction and then that affects me not wanting to go out, not wanting to do anything. It hurts, like I can't sleep'.* (P5)

Another cause of mental health issues for women was fertility issues, a commonly reported symptom of PCOS experienced by women in the study. Participant 3 describes her journey and the emotional challenges she faced while trying to conceive while her friends were announcing their pregnancies and the subsequent impact this had on relationships, and support networks.

> *'It got too hard constantly having to explain ourselves like as to why we couldn't go to baby showers or go to first birthdays. Why I cried every time people came out and said 'oh we're pregnant'. We got tired of dancing around friends who were pregnant and in turn them kind of not speaking to us. So yeah, pretty much came to a decision not to talk to anyone else about it (trying to conceive) and if they did ask, we would tell them but even in that situation, I leave that to my husband to do now because I just can't do it.'* (P3)

Having an awareness of how common mental health issues are for women with PCOS caused women to make changes to their lives and lifestyles, implementing self-care programs.

Women became focused on learning to understand what it meant to be living with the condition. Developing preventative strategies to help with her mental health and emotional wellbeing gave Participant 1 an understanding of how she could manage her wellbeing:

> *'I'm trying yeah with the mental health because I know PCOS can lead to depression so I'm trying to do the whole balancing...if I do get emotional, I sometimes go for a walk. But it's also talking to friends, family. I've got a friend whose mum has PCOS so they know what I'm going through. Obviously, symptoms are different…I tend to just for mental health instead of bottling everything in if I need to talk, I talk to someone.'* (P1)

Similarly, Participant 3 made lifestyle changes to assist with having this endocrine condition.

> *'I mean some of my coping mechanisms at the beginning probably weren't great, but I've learnt now that especially how hectic my own work and study life is I can't be out drinking every night and you know and I can't be doing stupid things like reverting back to old ways. I just can't do that…that's why the house is full of plants, it's a coping mechanism like you know.'* (P3)

Some women were educated about diet and exercise and were provided with recommendations to improve their overall health by their HCP. Women became sensitised to linked symptoms and there was an increased focus surrounding body image and healthy eating for some women. Mental health and emotions were subsequently acknowledged. Women felt increasingly responsible for making good choices about their diet following recommendations for management of PCOS.

> *'I don't feel like depressed or anything like that but it's definitely you're always thinking about like how you look and what you're eating and is it correct. You know you feel guilty if you eat bad food and stuff like that.'* (P6)

Women developed coping mechanisms to deal with having PCOS. Physical symptoms of PCOS impacted women's mental health and emotional wellbeing. The impact of diagnosis also had reported financial impact.

4.2.3.2 Financial burden

While some women came to terms with what it meant to be diagnosed with a chronic condition and others suffered with mental health issues associated with PCOS, women were also faced with the burden of health care costs related to their condition. Women described the high costs involved in investigations for symptoms experienced prior to receiving their diagnosis and then ongoing treatment of the condition. The added frustration was that sometimes all of the expenses did not lead to a desired outcome, as Participant 20 explains, *"I had just given up. I was like no one's going to be able to help me because you know by this stage, I'd spent thousands of dollars and nothing, just nothing was working."*

Women reported that medical costs associated with the treatment and management of PCOS were not disclosed or discussed by HCPs. Hidden, unexpected costs related to having the condition were highlighted by Participant 11:

> *'I think that's the only thing, cost isn't discussed which I suppose it's not the most important but it's the reality of it that it's going to cost money. I was saying that one thing… you don't really think about is the cost associated with having PCOS. So, there's the metformin which isn't that expensive in the long run but then the specialist appointment was like $350. The extra blood tests that weren't on the bulk billing list were hundreds of dollars.'* (P11)

The diversity of symptoms of PCOS resulted in a variety of different costs, with Participant 6 relating the high cost of menstrual products due to 'irregular periods and bleeding':

> *'I got my period for 2 weeks and then I had 2 weeks off and then I got my period again for 2 weeks and then you have a week off and then you get spotting and then you have your period and it's like, oh my God I can't afford this amount of tampons.'* (P6)

In contrast, Participant 11 described the costs of her 'fertility issues' whilst trying to conceive, following diagnosis of PCOS:

> 'T*he semen sample was hundreds, like $350. That internal [test] with the dye, I think that was like $400 and then the injections and stuff it costs about $150 a week and then missed out on work because I have to get blood tests to go to specialist appointment.'* (P11)

Women shared the financial burden associated with PCOS, both leading up to and following diagnosis, highlighting the need for more transparency around the potential costs associated with living with the condition by HCPs.

4.2.3.3 PCOS Management

Women diagnosed with PCOS were presented with medical and non-medical approaches for management of the condition by their treating HCP. Some women were referred to specialists and allied health teams, including fertility specialists, endocrinologists, dieticians, exercise physiologists, gynaecologists and dermatologists. While other women opted for a self-management approach and as some described a 'natural approach', both medical and non-medical management options were explored by women following diagnosis.

Lifestyle changes were reflected on, following diagnosis of PCOS. Changes to diet and exercise were described by participants, often made by the women themselves through their own research and engagement with HCPs.

> '*I used to go to the gym, I don't anymore because it's closed [COVID]…I go for a run every morning or go for a walk to the beach every morning. Then if I don't go in the morning, I'll go to see the sunset…I just try to keep active and I eat less. I drink more water and I eat definitely more healthy. I eat lots of veggies and fruits and fish and avoid like you know, fatty, deep fried foods.'* (P19)

Perceived benefits of making lifestyle and diet changes, including regularisation of menstrual patterns were shared.

> *'I engage with a health coach who gives me meal plans every week, so I mean I haven't lost a lot of weight obviously because of the polycystic ovaries [PCOS] doesn't really help but I have lost weight to the point where I am getting now a regular period so that's good.'* (P3)

While diet and exercise were seen as beneficial to women, one form of management that caused concern was the OCP. Women shared a reluctance to use the OCP as treatment for PCOS due to reported side effects, including negative impact on women's emotional wellbeing. Participant 7 shared her experience with the OCP and her reasons for declining it as a treatment option for PCOS. "*I found that the emotional effects it had [OCP] were not worth it, so I* *basically point blank went 'I'm not going with the pill'".* Similarly, another participant also shared concern surrounding the OCP as treatment recommended for the management of her PCOS, based on her prior experience with the medication.

> *'One of the concerns was what the oral contraceptive, the symptoms of what you can get from that was a bit more concerning than the PCOS… Because of the fact that I had quite a lot of side effects from the pill before I went off it as well with all of my emotions and everything… I was a little bit worried about going back on the pill because of that.'* (P6)

Women reported the need to be informed of alternatives to the OCP for treatment options in the management of PCOS. Participant 19 recalls the treatment option offered by her HCP at the time of diagnosis, "*…they [HCP] said, if I wish I can go back to the pill, which I said 'no' and they said, 'there's no medication, just healthy lifestyle'."* Women who were not satisfied with the OCP as a treatment option offered by HCPs turned to online forums to explore other options through discussions with other women living with PCOS. Participant 13 shared her search for treatment options other than the OCP when she was not satisfied with the recommendation by her HCP.

> *'I found a lot of forums where people had been told the same thing, that the only treatment for [PCOS] symptoms was the pill but then I'd also found other people who had obviously gone down the natural road and tried that so that's what helped me to try that… You know I was kind of like it can't, it can't just end there, there has to be more to it.'* (P13)

Participant 2 reflected on discussing treatment options other than the OCP with her GP and reported a lack of support and some scepticism after disclosing that she would like to engage in naturopathy, "*I made the mistake of telling him I wanted to go see a naturopath and he said, 'well why?' I said well because 'I believe in helping me with herbs and natural stuff' but he said Ah no!"*

Similarly, Participant 1 discussed her willingness to explore natural options as medication was not an option for her, voicing "*I'm at the moment trying more natural things…trying the pretty* *much you know the old Chinese medicines, herbals and all-natural healthy things instead of medication because I can't do medication."*

Women talked about taking charge of the management of their PCOS symptoms to try to the find the right way forward for themselves and their own best suited treatment. Medical and non-medical approaches for management of the condition were identified and some women were referred to specialists and other HCPs to establish a plan that encompassed individual symptoms and needs.

4.2.3.4 The influence of gender

Women shared the way they believe PCOS is viewed by the wider community encompassing their friends, family, partners, HCPs and colleagues. They reported experiences of sexism and stereotypical assumptions and stigma surrounding PCOS and the impact that this has on women suffering from this condition. Participants experienced having assumptions made about them by HCPs based on physical appearance, without appropriate history taking. This led to them feeling not heard or believed and demoralised by care provision, often opting not to continue with the HCP.

> *'She looked at my size… She was like you need to eat half the amount and I was like I don't even eat a lot now. What do you expect me to eat? Survive off?… I didn't go back to her again because she just really annoyed me. She made me feel so bad that I just wanted to cry and I don't cry easily but I just felt so depressed and like awful after I'd seen her. It was not nice.'* (P20)

Women with PCOS summed up their experiences of living with a woman's health condition and described it as something that is not openly discussed. They felt that the condition was not represented fairly in mainstream media or in the same way that other health conditions were. As described by Participant 16 "*…you see diabetes gets a lot of exposure…heart disease gets exposure, kidney disease all of those kinds of things but PCOS gets nothing that I see when I work with health promotion and stuff."* The focus on other health conditions, excluding women's health issues, was highlighted by another participant who believed women's health including menstrual cycles were not freely discussed. Feeling it was coupled with the way women are raised to view female reproduction as something which is hidden.

> *'If you have another disease it's talked about a little bit more. Say for example if you had MS… it's discussed in the media... I think maybe with PCOS it's because it is linked with fertility, it's linked with women issues, some things that women don't talk about. I've never spoken about my period so freely in my life.'* (P11)

Participants highlighted perceptions around the role of women in society and gender inequality, seeing these as contributing to conditions such as PCOS not being openly discussed. The issues of infertility linked to PCOS made women feel inadequate in relation to socially constructed views of female body functioning.

> *'I think that we need to be able to discuss our issues and what's going on and I feel like a lot of the time obviously there's inequality in gender and women's issues are always just pushed aside and if we can't have babies, we're kind of lesser… I don't know if it's the old school way, but we were kind of taught to be quiet about these things.'* (P13)

Women reported experiencing discrimination surrounding PCOS describing it as a condition that was not taken seriously, as summed up by Participant 7 "*…women's health isn't taken seriously, especially with the symptoms, it can be seen as hysteria or women being irrational or making it up*." Often this was due to the presenting symptoms of PCOS which when taken individually appeared to relate to body image with HCPs subsequently having difficulty making the link to PCOS, with participants experiencing a dismissing of their symptoms by HCPs.

> *'When the main presenting symptoms is weight, hair and acne I feel like that also leads it to… not taken as seriously… because we're [women] seen as vain or self-indulgent... especially the weight thing because I know that with a lot of other medical doctors, I've seen it's like oh you've got extra weight therefore this is the cause of the problem.'* (P7)

Participants reported a perceived inadequate focus in society on women's health, leading to a lack of understanding around such issues including PCOS. Women described the 'stigma' experienced around PCOS, and the inadequate focus contributing to a lack of PCOS information, awareness and support for women living with the condition. Participant 9 shared her experience, "*I guess there's a little bit of a stigma about female health and how our issues are perceived. I mean there's still not a very good understanding of even just women's cycle in general."* Stigma surrounding women's health was experienced by women with PCOS, this led to women feeling unsupported and isolated without the information they needed, as described by Participant 3.

> *'There's such a stigma around it [PCOS] still, which is frustrating because it makes it hard to find information or find people that can support you because it's just, no one wants to talk about it. If it's not there, you can't see it, it's not real you know… yeah definitely there's a stigma.'* (P3)

Comparisons were made between PCOS and other general health conditions, with women's health reported as not being openly discussed in society due to feelings of embarrassment associated with symptoms of PCOS, specifically those linked to changes to the physical appearance of women. The stigma surrounding the condition highlights the underlying pressure on women to maintain their physical appearance to feel accepted within society. Image was reported as being important to women and common symptoms of PCOS include acne and facial hair, which may alter women's appearances, changing their perceptions of themselves. Participant 15 sums up her experience and feelings around these aspects of the condition.

> *General things such as heart conditions… that don't particularly have, I guess for women, embarrassing side effects or symptoms you know but when it comes to image… things like facial hair and acne and you know all that kind of stuff I guess as a woman it does feel embarrassing and so you wouldn't really want to talk about it. (P15)*

The prospect of raising public awareness by opening discussions about PCOS was raised by some women who suggested this may lead to further acceptance of the condition by women and within society. Women disclosed that they felt awareness may lead to an increase in support available and help in preventing stigma experienced by women with PCOS, as described by Participant 15.

> *'I think so many women actually go through it [PCOS]. It's like if we all just said something, you know someone would understand what's happening. But as soon as it gets to the point of you know judgement or feeling or looking you know in your mind ugly, I guess it's not really spoken about.'* (P15)

Women shared experiences of sexism, stereotypical assumptions and stigma surrounding PCOS and the impact of this. Women reported the lack of focus on women's health and subsequently women's health conditions such as PCOS by society, mainstream media including social media and HCPs. There was an acknowledgement by women regarding the lack of support around the condition due to it not being openly discussed.

4.2.3.5 Support circles

Women's 'support circles' were made up of HCPs, friends, family and significant others. Some participants had positive experiences with their support network and found this beneficial following diagnosis.

> *'I think I'm pretty lucky I've got really amazing friends around me, so even if they don't know how it is, they you know, they can show compassion and try to understand. So, I did not feel like I was not understood or left alone with all this.'* (P19)

For some women their 'support circles' grew, developing into a network of people following their diagnosis. Support was gained through social media forums where women bonded over a shared experience. Participant 17 shared her experience, turning to social media to broaden her support circle and find other women who were experiencing living with PCOS.

> *'I think with all sort of issues it's always good to have knowledge or some sort of support network which is why I sort of turned to searching about groups on Facebook … so I could maybe link in with other women who have it [PCOS] or hear stories of what other women are going through or see what doctors or specialists, people have gone to about it.'* (P17)

Another woman, Participant 3, used social media to start blogging about her PCOS journey, forming her own support network and connecting with other women going through a similar experience. Here she shares where her support came from:

> *'Recently I've gotten back into the blogging stuff with a friend who's got endo, so we run an Instagram page for that and that is a great support network because we've*

> *actually reached a lot of people globally who [are] complete strangers but again you post something and they're like it's alright we're going to get through this. Like that's the whole sisterhood there.'* (P3)

Receiving a diagnosis of PCOS gave some women the opportunity to discuss their experiences with family members who were then able to provide support and through open disclosure shared similar experiences of their own. Participant 11 summed up the support she received from her mother who disclosed her own history of PCOS, strengthening their existing mother-daughter relationship.

> *'Having at least someone to talk to about it is nice and understand what you're going through and when you are talking about something, they get what you're talking about which is nice… I mean we've always had a strong relationship but it's definitely that little bit more intimate now.'* (P11)

'Family' was largely portrayed as the main support for many of the women. Some women discovered that family members were also living with the same condition. Participant 18 shared her experience: *"I realised that there is so many people around me with the same syndrome that I had no idea. Then I think that was very helpful to actually talk about it with other friends, that they're dealing with the same."* Having someone to relate to with lived experience of the condition was seen to be of benefit to the women.

One woman shared her experience following diagnosis and her desire to connect with other women with PCOS for support during difficult times, not knowing what to expect with the condition and to navigate feelings associated with the condition.

> *'One thing actually that I said to my husband, is I want to talk to someone else who's been through this because I don't know if I'm overreacting... it'd be good to have a friend in the same situation and then be like 'hey did this upset you?' and to know if that's normal or just be like, oh well it's the next step, let's just keep going. Like that was actually, that's hard.'* (P11)

In summary women experienced different emotions and feelings around having PCOS and reported perceived benefit in having someone to disclose to and share their diagnosis with, preferably someone who had been through a similar experience. Family, friends and significant others played large roles in supporting women with PCOS. Participants also reported turning to social media to connect with other women going through a similar experience for support, encouragement and reassurance. The power of social media was highlighted with its ability to positively impact lives, providing women with the opportunity to strengthen their support network.

4.2.4 Listening to women

The final theme addressed women's thoughts about the condition and focused on listening to what they had to say regarding their experiences, journey and views on the ideal future of women's healthcare. It encompassed a reported lack of awareness around the condition, recommendations for education on PCOS in schools and a focus on PCOS information and resources as identified by the women. Four sub-themes emerged from women sharing their PCOS journey and experiences. The sub-themes included: 'improving women's diagnosis experience', 'lack of PCOS awareness', 'education in schools' and 'PCOS information and resources.'

4.2.4.1 Improving women's diagnosis experience

Participants provided suggestions for HCPs diagnosing women with PCOS in the hope of seeing a change in care provided in the future. Women reported wanting to feel heard by HCPs and treated in an empathetic manner. This is summed up by Participant 20, who said, "*listening to the patient is really important. I mean obviously I know my body… I'm the one that's been living in it all these years…it would be nice if they [HCPs] would take what you're saying more seriously."* Similarly, Participant 15 shared her experience calling for HCPs to demonstrate empathy and reporting feelings of frustration when receiving specialist care that did not meet expectations.

> *'Have a bit of empathy perhaps… it's almost like they [HCP's] just forget that we're humans and this diagnosis actually means something to us. You know to them they're reading words off a piece of paper, it's not their body. You know those words impact us and it is our body and it's really frustrating, really, really frustrating you know being 25 and having to deal with this and know that there's every possibility now that I can't conceive a child.'* (P15)

Participant 1 expressed her desire to see HCPs increase their education around PCOS to better support women receiving care, including diagnosis and management of the condition "*I don't know what they [doctors] do at uni…but even just a short thing about PCOS and how to support women, she [GP] didn't really know much about it herself so she couldn't really help me."* Referral to specialists was suggested when it was perceived that GPs lacked the knowledge to provide care for women with PCOS, as expressed by Participant 14 "*I would just say that not everyone [GP] is going to be a specialist in that area which is fair enough… not everyone has to know everything about it but just don't brush it off. Just refer on to someone else."*

Some women called for specific information relating to the many diverse aspects of management, for example, improvement in the disclosure of side-effects of medication prescribed for the management of PCOS was requested by participant 11, *"It [metformin] made me sick for so long even…there was no, like even if like say this might happen. Even my husband was in the appointment, and he goes is there any side effects and she's [GP] like no."* Similarly, some women asked for full disclosure of tests used to diagnose PCOS, to ensure transparency and to help reduce concerns experienced by women. Participant 12 stated: *"The bloods I had no clue, I knew the ultrasound was looking for cysts or something wrong with the ovaries but yeah the bloods I knew they were hormones, but I wasn't explained about anything."* Participant 11 also shared a similar experience and reported feeling unprepared for the investigations requested, *"I went in, the sonographer was like we'll do an internal…it would have been nice to have been a bit prepped for that."* Another participant (16) expressed the need for information provision for women prior to PCOS investigations ordered by HCPs.

> *'I think it's important before people test for something that they may give people a little bit of information about it… if she'd [GP] said go and have a look at this stuff before you have your ultrasound, and we'll talk about it when you come back… I wouldn't have felt as concerned.'* (P16)

Women reported wanting to be involved in their care, to help develop an understanding of investigations ordered and medication prescribed by HCPs. Women described a need for further information provision from HCPs surrounding PCOS, prior to diagnosis of this condition. Referring women to specialists should be considered to improve women's diagnosis experiences.

4.2.4.2 Lack of PCOS awareness

Despite the prevalence of PCOS in society women identified that this condition is not well known by the general public. As reported by Participant 3, "… *even though through research polycystic ovaries is one in ten women, it's so common but no one talks about it."* Participant 16 suggested a need for open discussion: *"I think we're getting better, but I just don't think we're quite there because I certainly wouldn't have heard about PCOS in the community at all I don't think."* Women clearly felt that a lack of conversation around PCOS may be a contributing factor to lack of public awareness.

Acknowledgement of the role that social media and the media have in spreading awareness surrounding PCOS was identified by women in this study, driving the need for education to increase awareness. The power behind social media and the media was recognised by participants, with the women calling for the media to play a greater role in public awareness of the condition.

> *'I feel like people find out about things from the TV or the internet and it's… [PCOS] just not spoken about on any of those. It's not, like there's no posters up… unless it's like a friend has it or your sister has it or someone that you know has it, I don't think anyone really will just stumble upon it you know on the TV or the internet… That's my experience anyways.'* (P18)

With a reported lack of public awareness surrounding PCOS, women also described a perceived lack of awareness by men. Participant 18 shared her experience *"… my husband didn't know what it [PCOS] was… I showed him…that Jean Hailes website and we went through that together."* Participant 17 shared a similar experience in her relationship stating *"I* *had a partner… I did speak to him about it [PCOS]… he was very… conservative. Even in terms of like female health in general and sexual sort of health in general, yeah very unaware of all of that."* Participant 19 shared her partner's reaction to her disclosure of PCOS diagnosis *"My partner and my friends, they were surprised, they were asking what it [PCOS] is because like no one knew."* Women were of the view that some men were unwilling to discuss PCOS and subsequently shared their thoughts on the importance of men's awareness of the condition.

> *I think if there's a lot of women with it then men should have some kind of understanding of what's going on and be a little bit more supportive… I've just, I found guys just don't want to talk about it. It's not fun, it's not related to sex, if it's not going to interfere with that then they really don't [think they] need to know about it.* (P12)

Women in the study reported in this thesis suggested that support surrounding diagnosis may be increased through educating men and partners of women with the condition and offering women the choice to include their partners in appointments and conversations about the care they receive. Participant 11 shared her opinion: "*male education… like partner education… I obviously know more because I research it more and I'm a woman so I kind of know how my body has been*." The PCOS journey for women included difficult discussions with partners who were often unaware of what the diagnosis meant. Participant 13 shared her experience of disclosing her diagnosis of PCOS to her partner "*when I told my boyfriend about it [PCOS diagnosis] he kind of like just shut down. It was like, you can't get pregnant?"* Increasing education around PCOS may help both women and men to have a better understanding of the condition, and increased knowledge may help with improving the support being offered and received in relationships. Participant 13 continued to share her thoughts around increasing men's awareness of PCOS.

> *'I think boys need to have an understanding that this [PCOS] isn't the end. Like even though we have hormonal imbalances we're not any less of a woman, we can do*

> *everything, and they need to understand that even though it is something that's in our body, it doesn't change us, and we can do things to help it.'* (P13)

Women in the study reported in this thesis described a perceived disassociation between men and PCOS, describing what they saw as a result of men's inability to directly experience the condition, which contributed to their lack of understanding and awareness. Women with the condition highlighted the need to increase public awareness surrounding PCOS and the importance of having open conversations with family, friends and the wider community to enable women with the condition to receive more support.

4.2.4.3 Education in school

Women described the need to be better prepared for irregularities in reproductive functioning as part of school reproductive health. Education received in high school surrounding women's health was described by participants and they made recommendations for there to be increased focus on the menstrual cycle to help prepare women for possible issues they may experience. Participant 9 shared "*I definitely think that schools should teach it more in-depth, not just the 'birds and the bees' but everything else related to like sexual health."* Participant 13 shared her similar views on the perceived lack of education in school surrounding women's health conditions including PCOS.

> *'I definitely think in high school when we're all starting to get our periods… they need to introduce these things that might go wrong or might be happening in your body so that we can point it out and not just like when I was in high school just get put on the pill.'* (P13)

The concept of improving health education in school was also raised by Participant 9:

> *'One thing comes to mind is I guess in school it wasn't taught at all, especially when we had those health classes and it's all like the ovum and the sperm you don't talk about anything else really that's about it or even like human biology in year 11 and year 12… I guess public health campaigning [is important].'* (P7)

Participants continued to report that sexual education at school focused on conception and contraception not fertility issues and women's health conditions such as PCOS.

> *'I mean looking back on school and stuff a lot of health ed was just about how to practice safe sex, you never got told about the issues that you could [have as a female] … It was mainly if you don't have safe sex you're going to get pregnant.'* (P3)

Feelings of frustration were expressed by participants who identified a lack of education in school surrounding PCOS, calling for women's health conditions to be incorporated into the school curriculum.

> *'There was not one single thing mentioned when I was in high school or primary school… Not one thing was ever mentioned about it [PCOS] and that's quite frustrating … I wish I had of known back then…so definitely there needs to be a bit more education in schools. Just that I think it definitely needs to be part of you know human bio and sex ed and all that kind of stuff in schools. I really think it needs to be, yeah widely educated everywhere.'* (P15)

Participants voiced the need for education about women's health conditions in high school and identified that while teachers play a vital role in educating students, shared responsibility by parents was important in increasing awareness and education of the condition. Participant 9 voiced "*I feel that maybe parents, you know should encourage that open conversation about those things…then when more people talk about it, more people are willing to research it…then you're going to find more ways to fix the issue.*" (P9). Similarly, Participant 3 suggested that increasing PCOS awareness needs to be a shared responsibly, recognising the role teachers play in educating children "*I don't want to put the sole onus on the teachers to do it because it's not up to them, but they do have a big impact in children's lives at a time where they are going through puberty and stuff.*"

A perceived lack of education surrounding women's health conditions in high school around pubescent years was reported by participants to result in women feeling unprepared when diagnosed with conditions such as PCOS later in life. To overcome this education gap and to help increase awareness surrounding the condition, women in the study reported in this thesis, suggested that PCOS should be added to the sexual education curriculum in schools, with both males and females being informed and educated on the condition and other women's health conditions. Women with PCOS felt that while teachers play a vital role in educating students, there needs to be a shared responsibility by parents.

4.2.4.4 PCOS information and resources

When HCPs did not provide clear information resources, some women were unable to recall the recommendations provided, highlighting the benefit of written and online resources for women at the time of diagnosis. As recalled by Participant 11, *"She [GP] kind of explained it herself and then she did mention something about a website, but I, she didn't write it down or anything, I remember she just mentioned it."* Similarly, Participant 20 recalled her search for information following diagnosis and limited information provision by her HCP, stating, "*I was Googling but she [GP] didn't really give me anything else apart from the low carb [diet] and suggesting to do the HIT training (high intensity training), that was about all she said*."

Information provision at the time of diagnosis provided by HCPs varied. For some participants, it included both written and online resources. Websites were described as being the preferred source of information by Participant 18. "*She [GP] gave me… a fact sheet. I'm pretty sure it was just a one-page, back-and-front kind of fact sheet about PCOS and then a website called Jean Hailes. I found that website probably the most helpful."*

One participant, who also identified herself as being a HCP, reported noticing online marketing specifically targeting women with PCOS. The importance of HCPs providing evidence-based resources and information was highlighted by participants, who suggested it would ensure women are able to make informed decisions about their care. Participants in this study described products that were aimed at women to manage their PCOS by purchasing online supplements and, diet and exercise programs, which may not have been from credible sources.

> '*It was like buy this pack or you know do this 30-day fitness plan and meal plan. It was all because it had PCOS brand on it and I just thought it would have just sucked so many people in who didn't know that and were just vulnerable and kind of just wanted to do the right thing by themselves*.' (P4)

Women reported being dissatisfied with the information provided by their HCP, highlighting the need for further information provision by HCPs to improve women's diagnosis experiences. Women suggested the provision of information resources at diagnosis may increase their understanding of PCOS and empower them in decision-making, aiding to involve them in the management of their condition. Participant 13 reflected on her diagnosis experience, making these suggestions:

> *'Obviously, pamphlets and information would really help me. She [GP] kind of just told me to go home and to look into it kind of thing and I don't think that's where it should go, I think they're the ones with the medical knowledge. I don't know anything about this, I've got no medical background, no biology background. I don't understand anything that's going on with me, I don't know why this has happened or what's happening kind of thing.*' (P13)

Women also talked about conducting their own research on PCOS, to increase their knowledge base to aid in management and understanding of the condition. Self-guided research helped women be in charge of their health and not to be totally reliant on the HCP. However, a starting point from HPCs may be beneficial to help women pursue evidence-based resources: "*I was doing research myself from you know reading up more about what it is [PCOS]… how it's going to affect you in the long run… Learning as much information as I can… they recommend getting your mind, body and spirit all connected.*" (P1)

Another participant, P6 also shared how she obtained information on the management of PCOS including dietary recommendations through sources other than her HCP, including through books and dedicated software applications.

> *'I've actually got some cookbooks that are designed for PCOS. So, I've been also reading them, and I've got apps that, you know I've got recipes and foods that you can have, you know try and avoid these but stick with these. So, it's mainly just apps and books.'* (P6)

In summary women accessed PCOS information and education through their HCP but also through books, websites, apps and other resources. Participants in the study reported in this thesis preferred written resources and websites containing PCOS information and described these sources as being helpful. Information provision at the time of diagnosis varied and lack of information at diagnosis often led participants researching PCOS information for themselves.

4.3 Conclusion

Chapter Four highlighted the data collection and analysis process used, participant demographics and findings of the analysed data. Data analysis discovered four themes including fourteen subthemes. The four main subthemes included: ‘lead up to diagnosis’, ‘diagnosis experience’, ‘life after diagnosis’ and ‘listening to women’. The themes and sub-themes were explored in detail throughout the chapter using the voices of the participants to validate interpreted data. Key findings from the interviews conducted included concerns raised surrounding the long-term use and prescription of the OCP by HCPs that may mask PCOS symptoms and, further information provision by HCPs at the time of diagnosis including written PCOS resources. There was also recognition by women of the impact on their mental health and emotional wellbeing and, of the physical changes caused by PCOS including those that were not visible to others. Women in the study also suggested that HCPs diagnosing and caring for women with PCOS should refrain from making assumptions about the woman’s level of knowledge that may prevent further information from being provided, especially in the case of women who were HCPs themselves. It was evident through the findings of this study that it was considered important for women to be involved in their care to improve diagnosis experiences. Women with PCOS proposed that HCPs should offer second opinions and referrals to specialists to help to prevent unmet expectations, disclosing any costs associated with PCOS where possible.

It was evident through exploring women’s diagnosis experiences of PCOS that receiving a diagnosis of the condition was emotional for women, highlighting the need for sensitive care from HCPs. Women described a perceived lack of support from HCPs, indicating the importance of women having their own ‘support circle’ and trust in their HCP. Women described the need for increased public awareness surrounding PCOS, with perceived gender inequality contributing to PCOS not being openly discussed in society. Findings from this study also suggest mainstream media and social media need to be used to increase awareness of the condition as used in health promotion of other health conditions. This study highlighted the importance of women being heard and being able to talk freely about PCOS, the need for women’s health to take a higher priority in society, with an improvement in PCOS education starting from sexual education at school. Chapter Five will provide a comprehensive discussion of the findings from this qualitative PCOS study against existing literature.

Chapter Five

Discussion

This study explored women's experiences of receiving a diagnosis of PCOS in Western Australia, using a descriptive qualitative exploratory approach. Rich data was captured from participants, providing an opportunity for women to share their experiences and tell their stories. It was important to develop a comprehensive understanding of the PCOS diagnosis experiences from the perspective of women diagnosed with the condition to identify how best to support them in their journey to and after diagnosis by providing HCPs with insight into the needs of women with the condition. Twenty women, who met the study's inclusion criteria, volunteered to participate in semi-structured interviews, guided by five open-ended questions, as outlined in previous chapters of this thesis. Thematic data analysis was used to identify the themes and sub-themes.

The four main themes that emerged were 'lead up to diagnosis', 'diagnosis of PCOS', 'life after diagnosis' and 'listening to women'. These themes captured the experience of women, prior to and during their diagnosis of PCOS. Participants also described how the diagnosis of PCOS impacted their lives and highlighted recommendations for how to improve the diagnosis experience and provide follow-up care and support. This chapter discusses the findings presented in Chapter Four within the context of existing literature. In addition, the discussion also identifies the study's strengths and limitations, and highlights implications for clinical practice, making recommendations for education of HCPs, further research and, changes to policy and service design to improve women's PCOS diagnosis experience.

5.1 Lead up to diagnosis

As mentioned, women who participated in the study reported in this thesis described their experiences of the 'lead up to diagnosis' and its influence it had on their overall diagnosis experience. Participants identified aspects that they considered to be significant in their journey, recalling interactions with HCPs and the symptoms that they presented with for investigation. The two sub-themes that emerged linked to this major theme were ‘women’s journey to diagnosis’ and ‘presenting symptoms’.

5.1.1 Women’s journey to diagnosis

Study participants reported that it took several years from the onset of symptoms to being diagnosed with PCOS. For many respondents, their symptoms commenced in adolescence with multiple HCPs being consulted over a lengthy period. This experience resonates with findings from other studies where women saw multiple HCPs over a number of years before a diagnosis of PCOS was confirmed (Avery & Braunack-Mayer, 2007; Ballard et al., 2006; Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Hillman et al., 2020). Women from the present study described HCPs focusing on the treatment of individual symptoms, which in some cases masked symptoms and delayed diagnosis of PCOS. This was often linked to the prescribing of oral hormonal contraceptives for a range of PCOS symptoms and has also been reported in other study contexts such as the United States of America (Goodman et al., 2015), the Czech Republic (Vrbíková & Cibula, 2005) and Turkey (Yildiz, 2015). Women in other contexts have disclosed not wanting to commence using oral contraceptives as a treatment option for PCOS (Williams et al., 2015) and have expressed frustration with this recommendation from HCPs (Tomlinson et al., 2017). This aligns with participants in the present study feeling dissatisfied with management approaches to PCOS due to the long and convoluted journey to diagnosis and the focus on symptom treatment. The persistent focus on symptoms by HCPs resulted in dissatisfaction with care, delayed diagnosis and women's ongoing suffering with PCOS.

5.1.2 Presenting symptoms

The findings from the present study demonstrated that participants had a variety of presenting symptoms that affected their reproductive, physical and mental health, supporting the view of PCOS as a multi-system endocrine condition (Gibson-Helm et al., 2017). PCOS presents with so many symptoms that can be linked to other conditions and therefore, can be overlooked.

Reproductive symptoms of PCOS such as irregular periods were experienced by many participants in our study. It has been suggested that women who were prescribed oral hormonal contraception by their HCP, may have symptoms of PCOS masked (Avery & Braunack-Mayer, 2007). PCOS symptoms including irregular periods and infertility, may not be apparent and women may not seek treatment or investigation until they have ceased hormonal contraceptives and are trying to conceive, uncovering a diagnosis of PCOS. Women in our study reported that as adolescents going through puberty presenting with symptoms of PCOS they were overlooked, and the symptoms were linked to normal features of puberty by HCPs. Findings from Hillman et al. (2020) and Avery and Braunack-Mayer (2007) support this. They found that women were told by HCPs that irregular periods were common for women and teenagers and, hence PCOS was not investigated but rather dismissed. Presenting symptoms of PCOS are varied and can be misconstrued by the treating HCP if they occurred during puberty or adolescence or were linked to other conditions. Hence, the possibility of confusing PCOS with something else, meant that doctors were often not definitive in their diagnosis and took a trial-and-error approach.

Brantelid et al. (2014) emphasised the pertinent role nurses, midwives and other HCPs have in supporting women to manage menstruation, highlighting the need for collaborative care between HCPs and the importance of the nurse or midwife in supporting the diagnosis of PCOS. According to Brantelid et al. (2014), midwives and nurses should offer support to women regarding sexuality, menstruation, conception, fertility, puberty and menopause and care should be specific to the individual needs of the woman to facilitate a supportive relationship. Participants in our study reported heavy menstrual bleeding with impacts on schooling and increasing financial burden. The cost associated with menstrual products may impact the mental health of young women who might not be able to afford sanitary products on a monthly basis (Cardoso et al., 2021). Menstruation-related symptoms contribute to a loss in workforce productivity, with recommendations for women and girls attending work and school to have more flexibility to assist with managing issues associated with menstruation (Schoep et al., 2019).

Acne is a commonly experienced symptom of PCOS (Badawy & Elnashar, 2011; Dennett & Simon, 2015; Legro et al., 2013; Tomlinson et al., 2013; Williams et al., 2015; Witchel et al., 2020), with a much higher prevalence in adolescent girls and adult women with PCOS than those without the condition (Ramezani Tehrani et al., 2021). Participants in our study reported the presence and impact of acne as a PCOS symptom. They described it as a physical burden, occurring over the face and other areas of the body. Hormonal contraceptives were reported to be used as a first-line option to treat acne as a symptom of PCOS (Fauser et al., 2012; Goodman et al., 2015; Vrbíková & Cibula, 2005; Yildiz, 2015). While antibiotics are used in the management of acne caused by PCOS to minimise the discomfort experienced, they are a second-line treatment and are recommended for short-term use only (Buzney et al., 2014). In a study by Surya et al. (2021), it was suggested that HCPs should screen all women presenting with acne for PCOS due to the link between acne and systemic conditions, particularly endocrine disorders.

The International Guideline for PCOS and the Rotterdam diagnostic criteria recognise that ***ovarian cysts*** are not a feature of PCOS and instead highlight follicles as a defining feature of the condition. The definition of polycystic ovarian morphology using the Rotterdam criteria is 12 or more follicles of a specific size (Monash University, 2018). According to Spritzer (2014), small cysts are often seen on ultrasound in adolescent girls without the condition before menarche, further supporting why cysts are not considered a feature of PCOS. However, cysts were a reported symptom of PCOS by participants in this present study with women describing how their journey to diagnosis led to the discovery of cysts through diagnostic investigations due to pain caused by their ovarian cysts and subsequent hospitalisation. This finding is supported by literature from Dennett and Simon (2015) and Snyder (2006) who describe cysts as a feature of the condition and Gibson-Helm et al. (2017) identifying ovarian cysts as a key concern for women with the condition. However, as cysts are not a symptom in the diagnostic criteria PCOS goes unidentified for some women.

Women in the present study felt their concerns surrounding ***unwanted hair growth*** were not taken seriously by HCPs as the symptom was related to body image, resulting in embarrassment and reluctance in discussing their PCOS symptoms (Avery & Braunack-Mayer, 2007). Previous evidence from Boyle et al. (2012), supports this with excess or unwanted hair growth, self-reported by 38% of women with PCOS, indicating that hirsutism is a common symptom of the condition. Women diagnosed with PCOS felt they had failed to conform to ideals of femininity (Kitzinger & Willmott, 2002). However, despite the embarrassment and negative self-image that symptoms such as hirsutism gave women, they felt without that physically evident symptom being present they were less likely to be provided with treatment and management options (Avery & Braunack-Mayer, 2007). Women experience excessive hair growth with PCOS and are reluctant to discuss it with their HCP because of their discomfort. Therefore, in order to identify this symptom and help with arriving at a diagnosis, HCPs might have to be the ones to open the conversation rather than waiting for the woman to bring it up.

A few participants in this present study described ***hypoglycaemia***, reporting that regular food intake was required to prevent feeling symptomatic. This was echoed in findings by Dennett and Simon (2015) highlighting that women with the condition who have insulin resistance may experience hypoglycemia, hyperglycemia and also intense carbohydrate cravings. Women's diagnosis experiences of PCOS, presenting symptoms and experience of living with the condition vary. It is evident from the literature that impaired glucose tolerance, insulin resistance, type 2 diabetes mellitus and gestational diabetes mellitus are increased in women with PCOS (Bednarska & Siejka, 2017; Cassar et al., 2016; Du Pon et al., 2019; Kakoly et al., 2018; Monash University, 2018; RACGP, 2018). Oral glucose tolerance testing is the recommended screening method for women with PCOS (Ortiz-Flores et al., 2019), with benefits from early detection and intervention including medication, diet and lifestyle changes (Gupta et al., 2022). According to the International Evidence-based Guideline for the Assessment and Management of PCOS (2018), women with the condition are considered at high risk for developing gestational diabetes, impaired glucose tolerance and type 2 diabetes if they have a BMI >25kg/m^2 or for Asian populations >23kg/m^2, history of abnormal glucose tolerance or family history of diabetes, hypertension or are from a high risk ethnicity (Monash University, 2018). Therefore, in order to identify the risk of type 2 diabetes mellitus in women with PCOS, HCPs should consider the benefit of oral glucose tolerance testing following diagnosis.

Often women with PCOS are affected by issues of ***weight gain*** and find themselves classified as overweight (Lim et al., 2012; Lim et al., 2013; Zhang et al., 2019). They described their change in weight as a 'rollercoaster', sharing that weight gain was a symptom of the condition they struggled with. Lim et al. (2012) indicates that due to the known associated risks of obesity in women with PCOS, clinical management of the condition should include prevention and management of obesity. Many participants in the present study wanted to lose weight to improve their PCOS symptoms and for the overall health benefits. For some losing weight helped to improve other PCOS symptoms including regulating periods. This finding echoes recommendations, from Lie Fong et al. (2021) and Ryan and Yockey (2017), of 5-10% weight loss for women with PCOS to improve symptoms of the condition. In reviewing the literature there is no specific diet recommended for PCOS (Cowan et al., 2023) and limited evidence of effective weight loss management strategies (Kataoka et al., 2017). Further evidence and research are required in this area on the effectiveness of different diets and weight loss management strategies for women with PCOS. The development of specific programs to manage weight loss and diet for women with the condition should be further explored.

Pain associated with PCOS was reported by participants in this study. Women described having high amounts of pelvic pain and for some a fear that pain would increase following a diagnosis of PCOS, due to unknown expectations of the condition. Pain and discomfort have been reported among symptoms of PCOS in other studies (Jedel et al., 2009; Martin et al., 2017). While pain is not a recognised symptom of PCOS and it is not part of the criteria used in diagnosing the condition (Monash University, 2018), women's reporting of this symptom should be considered when HCPs are making a diagnosis. The need for pain management in care following diagnosis should also be evaluated by HCPs and discussed with women diagnosed with PCOS who are experiencing pain.

There is evidence of the link between ***mood disorders*** and PCOS (Osibogun et al., 2020), participants in this study reported mental health symptoms of PCOS including fluctuating mood and premenstrual stress (PMS), describing their change in mood as being 'awful'. Women with PCOS are at an increased risk of mood disorders, and it is recommended that women with the condition are screened for mood disorders (Deeks et al., 2011; Dennett & Simon, 2015). Additionally, a link has been found between high body mass index (BMI) and negative mood in women with PCOS, with regular physical activity reported to improve mood

(Deeks et al., 2011). This aligns with the findings of our study where a few participants described weight gain affecting their mood. Negative mood can impact physical, psychological and social factors (Deeks et al., 2011). Women in the study reported in this thesis described the impact of their fluctuating moods on their everyday lives, highlighting the need for HCPs to screen women diagnosed with PCOS for mood disorders.

The diagnosis of PCOS may bring relief to women who have been experiencing a collection of symptoms (Avery & Braunack-Mayer, 2007) and further emphasise the importance of obtaining a diagnosis for women. Findings from the study reported in this thesis indicate participants' relief at receiving a diagnosis of PCOS and having a name for the group of symptoms they experienced. Findings from Gibson-Helm et al. (2014) and Gibson-Helm et al. (2017) corroborate the recommendation of a timely diagnosis of PCOS and report that delayed diagnosis may affect women’s health and quality of life.

5.2 Diagnosis of PCOS

The diagnosis experiences reported by participants in this study included their interactions with HCPs and the reported lack of support and trust they encountered. The theme ‘diagnosis of PCOS’ had three linked sub-themes, namely, ‘diagnosis experience’ ‘feelings around diagnosis’ and ‘lack of support and trust’. These sub-themes will be discussed within the context of existing literature in the following sections.

5.2.1 Diagnosis experience

Participants in the present study identified the need to have adequate time allocated for the medical appointment in which they received their diagnosis. This would allow time to ask questions (Avery & Braunack-Mayer, 2007) and receive much-needed information. There was also a desire for follow-up appointments (Hillman et al., 2020) as a one-off appointment did not meet the needs of women diagnosed with PCOS. Women disclosed that their presenting symptoms were often overlooked by the HCP (Galea & Parekh, 2023) and considered to be atypical, dismissing the significance of the symptom resulting in a lengthy journey to diagnosis. Women identified the need to prioritise women's health and reduce the stigma around PCOS (Ismayilova & Yaya, 2022a) in the general community through an increased awareness of the condition. Hence, a greater community focus on PCOS is needed to support women with the condition.

Some data collection for the study reported in this thesis took place during the Covid-19 pandemic which triggered a participant to highlight their telephone consult at the time of diagnosis and their discomfort with telehealth consultations, preferring instead in-person appointments as supported by Sloan et al. (2022). Telehealth refers to consultation with an HCP via telephone or video. While post-pandemic there has been a move towards more online consultations (Bukstein et al., 2022; Monaghesh & Hajizadeh, 2020; Ramaswamy et al., 2020; Taylor et al., 2021), these should be used with caution with women with PCOS as the lack of in-person contact may prevent patients from discussing some concerns (Ftouni et al., 2022). It is recommended that initial diagnosis appointments with HCPs and women with PCOS should be in person to allow for the development of rapport and trust (Sloan et al., 2022) with the option of online follow-up appointments aligned to the individual woman's level of comfort with this mode of interaction. While there are reported concerns around confidentiality and data security in existing literature (Houser et al., 2023), this was not raised by participants in the study reported in this thesis. It was identified that HCPs played a crucial role in women's overall diagnosis experience and adequate appointment time at the time of diagnosis was perceived as being important to the participants in our study. Additionally, Sampson et al. (2013) reported that giving the patient the choice of appointment duration is beneficial to ensure their needs are met. In support of this, it was found that a shorter appointment duration was linked with higher rates of inappropriately prescribed medications by HCPs (Neprash et al., 2023). Given the above findings, HCPs need to collaborate with women to determine what works best for them, particularly around the delivery of the diagnosis, and the suitability of face-to-face consults versus using telehealth.

Getting a second opinion and having the option to be referred to a specialist, was reported by women in this study, as being important when recalling their diagnosis experience. There were many reasons women opted for a second opinion including dissatisfaction with the initial care provider. Benbassat (2019), recognises that patients have the right to obtain a second opinion and where there is a difference of opinion, they have the option to choose what aligns with them and is most appropriate for their individual case. Participants in this present study raised wanting to be referred to a specialist for a second opinion, often citing dissatisfaction with the initial care received. Benbassat (2019) highlighted that when patients obtained a second opinion, it resulted in a change of diagnosis (15%), a change in treatment plan (37%) or both (11%). Where second opinions have been sought, they have been found to have resulted in a major change in diagnosis, treatment or prognosis (Benbassat, 2019; Payne et al., 2014). Second opinions improved outcomes and patient satisfaction. Women valued getting a second opinion from another HCP and reported being dissatisfied with their diagnosis experience when referral to a specialist by their primary HCP/GP was not offered. Second opinions are important to improve the outcomes and satisfaction of the patient and highlight the importance of HCPs offering referrals to women diagnosed with PCOS for further input in the management of the condition.

5.2.2 Feelings around diagnosis

Receiving a diagnosis of PCOS, resulted in women reporting a myriad of emotions. For some women diagnosis brought relief and for others, it brought negative feelings of self-blame and fear. Exploration of patients’ experiences of receiving a diagnosis, revealed that how patients reacted to receiving a diagnosis was influenced by their life and social factors (Kirby et al., 2020). Feelings around diagnosis varied between participants and the study reported in this thesis differed from studies on diagnosis experiences of other conditions, where the benefit of a support person was explored. In a study by Schofield et al. (2003), it was found that patients had better satisfaction and lower anxiety when they were prepared for the diagnosis of cancer and that being accompanied by a chosen support person(s) at the time of diagnosis was beneficial. Based on findings from other studies focusing on the diagnosis experiences of patients, HCPs diagnosing women with PCOS should consider discussing the role of a support person(s) at the time of diagnosis to improve support and overall patient experiences.

Exploration of PCOS diagnosis experiences in this present study found participants valued the provision of written resources from their HCP at the time of diagnosis of PCOS. This was echoed in the study by Schofield et al. (2003) who found that patients preferred receiving clear information regarding their diagnosis, this included receiving written resources, having the opportunity to discuss their feelings relating to the diagnosis, being reassured and having their questions answered on the same day. Similar views have been found with other conditions such as cancer, where patients expressed, that they struggled emotionally throughout the process of diagnosis and were concerned and did not always understand the investigative process. Findings from the study by Pujadas Botey et al. (2020) included the importance of involving patients in their care, having access to other patients' lived experiences of the diagnostic process and condition and, that increased support offered by HCPs may improve experiences for patients and their family members in the lead up to receiving a diagnosis. Our study highlighted that the diagnosis of PCOS generated questions from women and provided HCPs with an opportunity to give women information, including written resources. GPs were commonly the initial source of contact for women experiencing symptoms of the condition and current quantitative studies surrounding PCOS diagnosis experiences were unable to explore information needs of women at the time of diagnosis (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017). Women in our study have reported their information needs were not always met at diagnosis and they were dissatisfied with the provision of information by their HCP. Given the findings from our study and other studies focusing on diagnosis experiences of patients, HCPs diagnosing women with PCOS should be prepared to answer questions that women may have surrounding diagnosis and should consider the provision of written resources to improve support and overall patient experiences.

5.2.3 Lack of support and trust

Participants in the present study reported a perceived lack of support and trust from HCPs and expressed the need to improve women's PCOS diagnosis experiences by increasing HCPs' knowledge surrounding the condition. Similar to other studies by Lin et al. (2018) and Tomlinson et al. (2017), participants in the current study felt there was a general lack of empathy towards women with PCOS from the medical profession. Patients who trust their HCPs report fewer symptoms, higher quality of life and greater satisfaction with their recommended treatment (Birkhäuer et al., 2017). Women in the study reported in this thesis were not alone in experiencing feelings of lack of trust toward their HCP. Women with PCOS, compared to those with a general health concern, reported a greater lack of trust in their HCP's opinions and more arguments with their HCP, than women without PCOS. Women with PCOS perceived their HCP made less effort and were less qualified to treat women with the condition compared to treating women with general health concerns (Lin et al., 2018). These findings align with those reported in this thesis and indicate a perceived lack of support from HCPs at the time of PCOS diagnosis and following diagnosis, highlighting a potential gap in current services and care provided to patients. Nurses and midwives are well positioned to play a fundamental role in the process of diagnosis (Newman, 2016) supporting specific individual needs (Brantelid et al., 2014) and educating patients to improve their knowledge and self-management of chronic health conditions (Jarelnape et al., 2023). The involvement of nurses and midwives in patient care following the diagnosis of PCOS has been highlighted as a measure that may positively improve the patient experience following the diagnosis of this condition.

5.3 Life after diagnosis

Diagnosis of PCOS brought a variety of emotions for women, but it was only the beginning of the journey. The experiences women had following diagnosis of PCOS, affected their physical, mental and emotional health. The theme 'life after diagnosis' encapsulated five sub-themes, including 'mental health and feelings', 'financial burden', 'PCOS management', 'the influence of gender' and 'support circles', these will be discussed and compared to the existing literature in the following sections.

Mental health issues including anxiety and depression were described by women in the study reported in this thesis as being linked to their physical symptoms of PCOS and having a negative impact on their mental health (Patil et al., 2023). There is a high prevalence of anxiety and depression associated with chronic conditions such as hypertension, diabetes and cancer, all potential comorbidities of PCOS (Ma et al., 2021; Yang et al., 2013). As such it has been recommended that HCPs should have a greater focus on patients' mental health following the diagnosis of a physical health condition (Yang et al., 2013). Patients with chronic illness report higher levels of pain and are more likely to develop depression, women in the present study also experienced anxiety and depression. Incidences of depression are higher in females with chronic disease and the link between depression and chronic diseases is likely due to physical and social dysfunction and the financial burden experienced as a result of having a chronic disease (Ma et al., 2021).

The role of gender in the experience and impact of conditions is apparent through research that suggests women experience pain differently from men due to hormonal factors (Paller et al., 2009) and that women are more likely to experience greater chronic pain (Malon et al., 2018) and suffer greater pain-related distress. Research on endometriosis has found women with the condition experience high levels of psychological distress and management of the condition should encompass physical and mental well-being assessments from HCPs, acknowledging the impact endometriosis can have on patients' mental health (Brasil et al., 2020; Hadjiconstantinou, 2017). Women with endometriosis were found to have higher levels of depression compared to women without the condition, with the association between endometriosis and depression largely linked to chronic pelvic pain (Facchin et al., 2015; Gambadauro et al., 2019). HCPs should be aware that chronic pain and distress may be linked to hormonal factors, this is pertinent in the care of women with PCOS who may experience anxiety and depression and gives insight into the differences between men and women and the approach to care that should be considered by HCPs.

As PCOS is a female issue there is likely to be a high incidence of anxiety and depression among women with the condition. It is important for HCPs diagnosing women with PCOS to be aware of the higher incidents of anxiety and depression in women with chronic conditions and the link between pain and chronic conditions. The impact that the experience of pain can have on one's mental well-being is important for HCPs to acknowledge and consider when providing care to women with PCOS. A holistic approach to pain management that addresses both psychological and physical factors is therefore important (Vadivelu et al., 2017; Yao et al., 2023), ensuring the needs of women with the condition are met. As mentioned previously in this chapter, pain management should be considered for women with PCOS based on individual need. HCPs diagnosing women with PCOS should enhance their understanding of the condition including linked conditions and comorbidities and should screen women diagnosed with PCOS for mental health conditions and symptoms. An understanding of the impact pain may have on women's well-being is important and will allow HCPs to further support women with PCOS.

The ***financial impact*** of PCOS contributes to women’s mental health being affected. Women in the study reported in this thesis described the burden of health care costs related to PCOS, including high costs involved in investigations for symptoms experienced prior to receiving their diagnosis and then ongoing treatment of the condition. People with chronic illness are not only burdened physically and mentally by a disease but also financially and may experience loss of work and income due to symptoms of the condition, treatment and physical impairment (Schofield et al., 2016). Chronic illness can impact individuals and their families through the cost of living with the disease and detrimental socioeconomic impact (Jeon et al., 2009). Some families and individuals living with chronic disease are faced with difficult economic decisions such as choosing between care and the cost of basic living when managing a long-term condition (Jeon et al., 2009). Participants in the present study shared the financial hardship they faced living with the condition and the cost associated with their journey to a diagnosis of PCOS. According to Van Der Biezen et al. (2016) and Razavi et al. (2021) whose studies compared types of healthcare providers, care by Nurse Practitioners (NPs) resulted in lower resource usage, was more cost-effective care, required fewer medication prescriptions and demonstrated lower rates of emergency department referrals than GPs. It was found that the cost differences between NPs and GPs were 34% for low-risk patients and 21% for high-risk patients, highlighting that NPs offer a cost-effective model of care for patients. The available information surrounding the financial and physical burden of PCOS further validates the need for individualised support by nurses following the diagnosis of the condition. Given the findings from the present study and other literature related to women’s health conditions, there is a need for workplace policies that address PCOS as a chronic condition with the potential to impact work, providing initiatives such as supported sick leave. Similar recognition should also occur within the health system, through the provision of medical rebates for PCOS care, helping to relieve some of the financial burden to women.

Participants in the present study shared their experiences of medical and non-medical ***PCOS management*** approaches offered by their treating HCP. Some women were referred to specialists and allied health teams, including fertility specialists, endocrinologists, dieticians, exercise physiologists, gynaecologists and dermatologists, and had a multidisciplinary team (MDT) approach in the management and treatment of their PCOS. It is well documented in existing literature that the management of PCOS is improved when women with the condition are treated using an MDT approach (Nemchikova & Frontoni, 2022; Wolf et al., 2018a). There are recommendations, within existing literature, for multidisciplinary clinical care to be implemented globally to improve patient satisfaction and management of PCOS (Wolf et al., 2018a). A multidisciplinary approach to PCOS was found to lead to early identification and treatment of comorbidities. Hence, it is recommended that multidisciplinary PCOS clinics be implemented to provide care and support for women with the condition (Patil et al., 2023).

Participants raised HCP gender, indicating a preference for a female GP in keeping with a study by Nolen et al. (2016). ***The influence of gender*** was supported by evidence that revealed that female physicians were found to display more empathy towards their patients than male physicians (Howick et al., 2017). In a study by Tsugawa et al. (2017) on readmission and mortality rates of patients treated by male versus female physicians, findings suggested patients treated by female physicians had lower mortality and hospital readmission rates than those treated by male physicians. These findings build on existing literature demonstrating that male and female physicians' practice differently (Baumhäkel et al., 2009; Berthold et al., 2008; Elgendy et al., 2022; Greenwood et al., 2018; Khan et al., 2018; Kim et al., 2005; Tsugawa et al., 2017). In other studies, (Elgendy et al., 2022; Greenwood et al., 2018) there was a reported increase in mortality for women with acute myocardial infarction (heart attack) when treated by a male doctor. Female patients presenting with myocardial infarction were less likely to receive guideline-directed care and had worse outcomes in hospital compared to men (Elgendy et al., 2022). Greenwood et al. (2018) found that women who were treated by a male emergency physician following a myocardial infarction had a 12 per cent increase in death.

However, it is not just about the gender of the HCP, it is also about the condition. The issue with cardiac cases is that there is a bias that pervades resulting in misdiagnosis or delayed diagnosis of myocardial infarction in women. This is based on the belief that men are more likely to suffer from myocardial infarction, however after menopause women have an increased risk (Burns et al., 2023). There is evidence to demonstrate that the sex of the diagnosing HCP appears to be linked with the likelihood of being diagnosed with the condition, women are more likely to be diagnosed with a female-specific condition such as PCOS if their HCP is a female (Burns et al., 2023). Findings suggest gender of the HCP can affect patient outcomes and that there is a gender bias surrounding women's health conditions. Recognising that gender is a significant factor in the development of many diseases is important, and it is fundamental that HCPs understand gender-driven differences (Burns et al., 2023). HCPs should consider referring patients with PCOS to a female GP if it is the preference of the patient and opening a conversation to discuss options as this would be beneficial for women being investigated or diagnosed with PCOS.

Women's '***support circles'*** comprised HCPs, friends, family and significant others. Participants in this study reported positive experiences with their support network and found their 'circle' to be beneficial following diagnosis. For some women their support came from other women with the condition who they connected with through online support groups and forums. According to Ismayilova and Yaya (2022b), women with PCOS would like to engage with age-specific support groups and mental health groups following the diagnosis of the condition. Support groups provide a safe place for women to share their experiences and symptoms with other women diagnosed with the condition. Referral to support groups by HCPs and engagement in the groups may help women with PCOS to share information and experiences, receive emotional support, reduce isolation and connect with other women with the condition (Avery et al., 2020; Ismayilova & Yaya, 2022b). Similar findings were reported in a study on endometriosis support groups by Shoebotham and Coulson (2016), additionally, women also gained reassurance and coping strategies from support groups. However, negative aspects of online support groups for women with endometriosis were also reported including what was perceived by some women as negative stories and experiences, concerns regarding the accuracy of information shared, and the sharing of confidential, personal and emotionally evoking information. The study reported in this thesis found support groups were perceived as beneficial to women with PCOS. However, the existing evidence around negative aspects of support groups should be used to develop preventative strategies aimed at avoiding such outcomes, enabling support groups to be more beneficial.

5.4 Listening to Women

What women had to say around their PCOS diagnosis experiences, journey and views on the ideal future of women's healthcare included a reported lack of PCOS awareness, recommendations for education in schools and a focus on PCOS information and resources. The theme 'listening to women' had four linked sub-themes, namely, 'improving women's diagnosis experience', 'lack of PCOS awareness', 'education in schools' and 'PCOS information and resources. These sub-themes will be compared to existing literature in the following sections.

To ***improve women's diagnosis experiences***, participants in the present study asked for full disclosure of investigations ordered to diagnose PCOS and medications prescribed to ensure transparency and to help reduce women's concerns. There were recurrent findings throughout this study with women describing the need for more PCOS-related information from HCPs, not only at the time of diagnosis but also prior to diagnosis of the condition. How HCPs deliver the diagnosis of PCOS can impact the well-being of women significantly, subsequently affecting their understanding of the condition and the way they feel (Ogden & Bridge, 2022). Similarly, in a study on women's diagnosis experiences of endometriosis, Lamvu et al. (2020), found that women experienced a difficult journey to diagnosis, reporting that HCPs lacked the ability to listen to their concerns and that HCPs recommended treatment and management options that did not align with the women's needs and goals. Existing evidence around PCOS diagnosis experiences with the findings of this study could be used to improve diagnosis experiences for women. HCPs should consider the individual needs of the patient and the positive impact of information provision in the lead-up to and during diagnosis of the condition. Future resource planning including collaborative care with a nurse or midwife to provide education should be considered as part of the PCOS diagnosis care offered to women.

Participants in this present study identified that despite the prevalence of PCOS in society (Gibson-Helm et al., 2017), the general public has a perceived ***lack of PCOS awareness*** (Rao et al., 2020) which results in the absence of open dialogue around PCOS. Participants in the study reported in this thesis felt that increasing PCOS awareness was important and individual knowledge on PCOS varied, with the main source of information reportedly from HCPs. A study by Alshdaifat et al. (2021) found women who had been diagnosed or were being investigated for PCOS had a greater awareness of the condition, compared to those without PCOS. Jabeen et al. (2022) highlighted the need for governments to increase public awareness around PCOS particularly due to the complexity of the condition and the subsequent impact it can have on the lives of women with the condition. Existing evidence around the lack of PCOS awareness and current findings from this study should be used to drive awareness of PCOS in the community. A visible focus on the condition and increasing awareness will help to improve support for women living with PCOS. Women's health extends beyond reproductive health and it is important to increase public and HCP awareness of conditions such as PCOS, endometriosis and menopause (Burns et al., 2023). Collaboration with policymakers, service providers and local governments is integral to the implementation of strategies to increase awareness of PCOS.

Inadequate PCOS ***information provision*** and dissatisfaction with the information provided at diagnosis were reported in the literature (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017) and in this present study. In literature on improving information and resources, for cancer patients, it was recommended that information provision should be individualised and realistic and delivered with an empathetic approach and positive expectations. Information should address the diversity of patients' experiences and care should be patient-centred (Hyatt et al., 2022; van Vliet et al., 2021). HCPs may need to increase their understanding of PCOS to better support women with the condition and have knowledge and resources to provide to women at diagnosis. In a study by Burns et al. (2023) it was reported that medicine residency programs excluded education on PCOS (n=40%), contraception (n=30%) and fertility (n=70%). Hence, further attention is needed to improve medical education ensuring adequate curricula coverage of these important conditions.

Women in this present study reported that sexual ***education in schools*** focused on conception and contraception not fertility issues and women's health conditions, leaving women feeling unprepared when diagnosed later in life. Participants identified that while teachers play a vital role in educating students, shared responsibility by parents was important in increasing awareness and education of the conditions such as PCOS. In a qualitative study on the delivery of sexual education in school by Rose et al. (2018) it was found that middle school sexual education sessions included puberty, reproductive systems, relationships, hygiene and pregnancy prevention. It was reported that there were many barriers to the delivery of sexual education information including the maturity level of students and comfort level of teachers. In a systemic review of sexual education in school, it was found that sexual education was mainly aimed at reducing at-risk behaviours and topics included the human immunodeficiency virus, sexually transmitted infections and unwanted pregnancies (Lameiras-Fernández et al., 2021). Consideration should be given to teaching girls in school about what is normal in puberty and how to monitor their own bodies, watch for changes and learn how to talk openly with caregivers and seek medical advice.

In summary, women in this PCOS study described a perceived inadequate focus in society on women's health, leading to a lack of understanding of conditions such as PCOS. Women described experiencing stereotypes, discrimination, sexism and stigma around PCOS. They felt that this inadequate community focus contributed to a lack of PCOS information, awareness and support for women living with the condition.

5.5 Study Strengths

Strengths of the study reported in this thesis include the use of a qualitative approach to explore in-depth the lived experiences of women diagnosed with PCOS. Previous quantitative research around women's diagnosis experiences of PCOS have not been able to explore the concept in-depth or in detail (Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Peña et al., 2022). Another strength of this study was the interview length, it allowed for rapport building as on average interview lengths were 50 minutes. A further strength of the present study was its inclusion of participants from rural areas to explore their PCOS diagnosis experiences within often resource-poor settings. This allowed for a better, broader understanding of women's PCOS diagnosis experience to emerge which is useful in supporting the transferability of findings to other contexts.

5.6 Study Limitations

This research was undertaken for a Master of Philosophy degree, where the primary researcher was a student and developed research skills as part of the higher degree by research (HDR) journey. In qualitative research, the researcher is the research instrument, and the results therefore may be affected by the skill level of the researcher (Pezalla et al., 2012). For this study exploring women's diagnosis experiences of PCOS in WA, the candidate was supervised by two experienced nursing and midwifery researchers. The supervisors provided guidance and oversight to reduce the likelihood of findings being influenced by a novice-level researcher. A descriptive exploratory approach was the chosen methodology as it addressed the aims and objectives of the study and aligned to the academic requirements of a Master of Philosophy. A limitation of the chosen methodology is that it does not provide an in-depth review, however, it did allow insights into the PCOS diagnosis experience of the participants who volunteered to share their stories. Lastly, the target population for this study was WA women with a diagnosis experience of PCOS, findings of this study represent the experiences of the twenty women from the select participant group and may have limited transferability to women with PCOS in other contexts. This thesis, however, provides sufficient information for the reader to determine which findings from this study may be transferrable to different contexts.

5.7 Recommendations

This section collates the recommendations and implications for clinical practice that were presented in this discussion chapter. While much has been published regarding PCOS, there remains limited literature on the diagnosis experiences of women obtained through a qualitative approach and from the perspective of WA women. It is paramount that the findings reported in this thesis are used to inform the education of HCPs involved in PCOS care to improve the current services offered to women. This WA study demonstrated that women did not feel supported at the time of diagnosis by their HCP. The following recommendations and implications for clinical practice are important for HCPs and women to support and improve current services and care.

5.7.1 Recommendations for Clinical Practice

- Study participants raised the length and purpose of the medical appointment for the delivery of the PCOS diagnosis, highlighting the need for further consideration of how they are scheduled, with consideration to the mental wellbeing of patients. Participants identified that appointment time constraints prevented them from asking questions pertinent to their new diagnosis. This then resulted in a lack of understanding of PCOS which led women to search the internet for answers. Hence, enough time should be allowed for information provision by HCPs and treatment and management options to be discussed and for women to ask questions. Follow up appointments should be arranged to allow women time to reflect on all that they have been told at the diagnosis appointment and raise any further questions and confirm the plan of care, including ongoing investigations and monitoring. Evidence supporting this recommendation shows that longer appointment times in primary healthcare settings are associated with better quality of care and improved outcomes for patients (Mayor, 2016). Another approach to increase the effectiveness of appointments is by ensuring continuity with the HCP so that rapport develops between HCP and patient, allowing for more collaborative care provision. Continuity of care with a chosen GP is associated with greater satisfaction by patients and should be considered for patients with chronic conditions (Lautamatti et al., 2020) such as PCOS.
- Women in the present study described symptoms of PCOS affecting their self-esteem and mental and physical health, highlighting the impact the condition has on their lives and the importance of holistic care for women with PCOS. HCPs should provide a holistic care approach that includes care and information related to physical, social, emotional and spiritual wellbeing for women. Incorporating discussions of mental

health, screening for anxiety and depression and offering appropriate support and referrals should be standard with PCOS care.

- Use of the International evidence-based Guideline for the Assessment and Management of PCOS (Monash University, 2018) recommends the use of the Rotterdam criteria (2003) to diagnose PCOS. HCPs are, therefore, encouraged to use these diagnostic criteria as it will help to prevent underdiagnosis of the condition and improve women's PCOS diagnosis experience.
- The importance of holistic care provision for women with PCOS was evident from the study reported in this thesis. Care of women with PCOS should encompass the multidisciplinary team (MDT), including nurses and midwives to support women during and following the diagnosis of the condition. The role of the Nurse Practitioner is very valuable in this space where women's health is a focus of their practice. An MDT approach to PCOS is needed to provide care for all aspects affected by the endocrine condition including reproductive, metabolic and psychological health. Existing evidence from Nemchikova and Frontoni (2022); Wolf et al. (2018a) found improved management of PCOS with an MDT approach. Additionally, such an approach would be of value in the prevention, early detection and management of comorbidities associated with PCOS. The provision of timely information using an MDT approach will also allow women to understand the potential for comorbidities, enabling them to put preventative strategies in place to monitor for symptoms and seek early intervention through referral to an appropriate specialist.
- HCPs should acknowledge that women go through a lengthy and often frustrating journey to have their PCOS diagnosed. Therefore, HCPs should adopt a sensitive approach, understanding the perspectives of the women and working collaboratively with them to improve their PCOS diagnosis experience. Additionally, HCPs need to

have an understanding that women with PCOS might not feel comfortable raising symptoms such as hirsutism and obesity due to fear of being blamed or shamed. A sensitive approach is needed with the HCP steering the conversation in a positive way (Governrnent of Western Australia, 2020).

5.7.2 Recommendations for Education

- The provision of PCOS literature at the time of diagnosis was suggested by participants in this study. Women diagnosed with PCOS may experience a myriad of emotions and the provision of resources at diagnosis, allows women the opportunity to review the information when they feel less overwhelmed and have more ability to understand the information. Findings from existing literature support the need for improvement in information provision at diagnosis including information on PCOS features, management of the condition, support group contact details, and online PCOS resources (Avery & Braunack-Mayer, 2007; Gibson-Helm et al., 2014; Gibson-Helm et al., 2017; Tomlinson et al., 2017). PCOS information needs should be targeted to the individual and HCPs should provide newly diagnosed women with written resources or referral to online resources, depending on their preference. Such resource provision at diagnosis of PCOS may further support and improve the overall diagnosis experiences of women and will also help women to prepare for follow-up appointments.
- The need for HCPs to increase their knowledge and awareness of PCOS was a finding from the study reported in this thesis. It is important to increase PCOS content in entry to practice medical courses and for GPs to complete ongoing professional development on PCOS. There is evidence that shows that conditions like PCOS and menopause are not well covered during undergraduate medical degrees. Improving HCP knowledge, awareness and understanding of PCOS will help HCPs to better support women being diagnosed with the condition (Burns et al., 2023).

- Women need to be empowered to take a more active role in their diagnosis and care process. HCPs should be supported through education and training to assist with timely diagnosis and provision of holistic care using an MDT approach with women as collaborators in the care process.

5.7.3 Recommendations for Research

- As noted from the discussion earlier in the chapter, there is a paucity of information related to weight management and lifestyle changes specific to the management of PCOS. Hence it is recommended that future research focus on exploring weight management for women diagnosed with PCOS, adopting a holistic approach to include lifestyle modification, healthy nutrition and appropriate exercise regimes.
- Participants in this present study highlighted the lack of information provision at the time of diagnosis but detailed information on the types of information and the mode of delivery were beyond the remit of the study. Further research is needed to address aspects of health literacy related to being newly diagnosed with PCOS and its subsequent management. Studies should investigate what women need to know and how they would like this information to be delivered to them.
- The rapport between HCPs and women being diagnosed with PCOS was highlighted in the discussion with trust in the HCP appearing to improve the diagnosis experience. Further research is needed to explore strategies that HCPs can use to strengthen rapport given the difficult journey to diagnosis for these women. Future research should also examine the inclusion of nurses and midwives to support PCOS diagnosis and subsequent care, with a potential for nurse-led follow-up models of care.

5.8 Conclusion

This chapter discussed the findings of the study reported in this thesis, comparing them with the existing body of knowledge. PCOS diagnosis experiences of women have not been previously qualitatively well researched, and this is the first WA study known, to date, exploring women's diagnosis experiences of the condition. Findings from this study support existing literature, indicating the need for improvements to the diagnosis process, communication of the diagnosis and subsequent care for the woman. Findings from the present study align with existing research and strongly demonstrate that women require support around receiving a diagnosis of PCOS. It is commonly undiagnosed and therefore true representation of the number of women affected by the condition is unknown. PCOS is a multisystem condition that can cause issues with reproductive, endocrine and menstrual health, impacting women in a multitude of ways. The current study has contributed to the growing body of knowledge surrounding PCOS by providing a voice for WA women, enabling their experiences of receiving a PCOS diagnosis to be used to help improve current practice and care. Findings have further demonstrated the importance of supporting women through their journey of diagnosis and with their subsequent care to manage PCOS. The study has also highlighted the important role that HCPs play in the diagnosis of PCOS and in the ongoing support of women receiving care for this condition.

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Appendix A advertisement

Curtin University

VOLUNTEERS NEEDED FOR RESEARCH STUDY.

An exploration of Western Australian women's experience of receiving a diagnosis of Polycystic Ovary Syndrome (PCOS).

WOMEN WITH PCOS NEEDED

We are conducting a research study to explore PCOS diagnosis experiences.

We are looking for women with PCOS who meet the following criteria:

- **Diagnosed with PCOS within the last 2 years**
- **Diagnosis by a medical doctor**
- **Women between the age of 18 - 45 years**
- **English speaking women, who can read and write in English**
- **Women diagnosed and living within Western Australia**
- **Not currently receiving active treatment for a mental health disorder excluding anxiety and depression**

If you are interested in participating in the study or would like further details, please contact directly through this page or alternatively:

SARA VENESS
Email: sara.zimdahl@postgrad.curtin.edu.au Mobile:

THANK YOU.

Appendix B Patient Information Sheet

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INFORMATION LETTER FOR WOMEN
(TELEPHONE AND/OR FACE-TO-FACE INTERVIEWS)
Exploring the experiences of WA women, receiving a diagnosis of Polycystic Ovary Syndrome (PCOS).

Why are we doing the study?

There has been limited research looking at women’s experiences of receiving a diagnosis of PCOS. Additionally, it has not captured the experience specific to women in Western Australia. This study will explore diagnosis experiences of Western Australian women with PCOS to help obtain an understanding of some of the issues surrounding diagnosis faced by these women.

Who is carrying out the study?

The research is being conducted by Sara Veness (student) as part of a Master of Philosophy higher degree. Sara will be supervised by Assoc. Prof. Ravani Duggan and Dr. Lesley Kuliukas.

What will the study tell us?

Although we are aware of some of the implications PCOS can have on women as a multisystem condition we have little knowledge around PCOS diagnosis experience from the woman’s perspective. New knowledge will help health care providers’ understanding of the impact PCOS diagnosis can have on women and how this may contribute to the perceived significance of the condition, future management and engagement with healthcare professionals and services. The aim of the study will be to explore the diagnosis experiences of women with PCOS. This understanding will help improve care of women such as yourself by healthcare professionals.

What will you be asked to do if you decide to take part in this study?

If you consent to participate, you will be invited to a face-to-face interview. The interview will be at a time and date convenient to you and will be audio recorded. The interviews will be transcribed but names will be replaced with pseudonyms, and any identifying information will be removed. Participation in this study is completely voluntary. As a participant you are free to withdraw at any time.

Is there likely to be a benefit to other people in the future?

Your feedback could assist us to understand the issues that women such as yourself are faced with when receiving a PCOS diagnosis and the impact these issues may have on women.

What is my involvement in the study?

Your involvement in the study will be to participate in a one-to-one interview to share your perceptions of your PCOS diagnosis experience. The interviews will ideally be conducted face to face, however if this is not possible or you would prefer a videocall interview, this can be arranged.

The interview will be digitally recorded and carried out in your home or an agreed place according to your preference. It is expected that the interview may take 60 minutes. You will be contacted by the researcher once the information from the interviews has been put together. The researcher will send you an email or letter, this will identify common findings from the interviews and will give you the opportunity to ensure the researcher has captured the experience you shared. The researcher will then follow up with a phone call once you have had time to read the information. This will allow the researcher to clarify findings and answer any questions.

Where is your information kept?

All information will be stored on a password protected computer that only the researcher has access to and will also be stored on the Curtin University Research (R) drive during the research as a safety backup. The transcribed interviews and field notes will be kept in a locked filing cabinet in the researcher's home office while actively being used and then transferred to the Curtin University R drive and deleted from the personal computer. Audio recordings will also be securely maintained on the Curtin University central research data storage. All data will be kept for a period of 7 years after completion of the study and then destroyed.

What about my privacy?

Interview transcripts will have all personal information removed and will be coded by a number to ensure confidentiality. All the information we collect will be kept private and confidential. Only the researcher and supervisors will know your identity. The findings of the research may be published in an academic journal, but you will not be identifiable. A transcriber will be used to transcribe the interview.

What if I feel I cannot continue with the interview or need follow up after?

Recalling your experience of diagnosis may result in a feeling of distress. If you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns or upset, you can stop the interview and discontinue. If you become distressed during the process or afterwards, please contact:

Lifeline -Telephone: 13 11 14
Crisis Care - Telephone: 1800 199 008 (Free call)
Mental Health Direct – Telephone: 1800 220 400 (Free call)
Mental Health Emergency Response Line (MHERL) – Telephone: 9224 8888 or 24-hour hotline: 1300 555 788

Bulk-billing Psychologists:

Helen Fowler & Associates

Ph: 9472 4411
Suite 3, 76 Canning Highway, Victoria Park.

Twice Blessed Wellbeing Psychologists
Phone: 9250 7125
24 Keane St, Midland.

Who has approved the study?

Curtin University Human Ethics Committee have approved the study (HRE2019-0026

Who to contact if you have any further questions or concerns about the organisation or running of the study?

The researcher, Sara Veness on 0426798661 or supervisors; Assoc. Prof. Ravani on (08) 9266 2055 or Dr. Lesley Kuliukas on (08) 92662088 will be available by phone call or appointment to answer or clarify any questions. If you have any concerns or complaints, you can contact the Curtin Human Research Ethics Committee on (08) 9266 7863 who are monitoring the study.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number 2019-0026). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Researcher Integrity on (08) 9266 7093 or email hrec@curtin.edu.au

What to do next if you would like to take part in this research:

If you would like to take part in this research study, please read and sign the consent form provided.

THANK YOU FOR YOUR TIME.

Appendix C Participant Consent Form

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CONSENT FORM
PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND PARTICIPANTS CAN WITHDRAW AT ANY TIME WITH NO IMPLICATIONS.

I ....have read

Given Names Surname

the information explaining the study entitled;

An exploration of Western Australian women's experience of receiving a diagnosis of Polycystic Ovary Syndrome

I have read and understood the information given to me and agree to participate in the study. Any questions I have asked have been answered to my satisfaction.

I understand that I may withdraw from the study at any stage.

I understand that the interview will be recorded, and I consent to this.

I understand that in the event of this work being published, as a participant, I will not be identifiable in any way.

Dated .... day of 2019

Signature ....

Appendix D Interview guide and questions

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INTERVIEW GUIDE & QUESTIONS

Interview guide

Thank you for agreeing to participate in this study. The aim is to try to discover more about the experiences women have had when diagnosed with Polycystic Ovary Syndrome (PCOS).

Each interview will be digitally (audio) recorded and will begin by asking whether you have any questions before the recording commences. It will be noted that recording can be stopped at any time throughout the interview as requested. To maintain confidentiality participants will be de-identified when transcribing occurs, and the interviews will be conducted while you are alone if preferred. You will be asked open ended questions to allow you to share your experience with the researcher. The list of questions below will be used as a prompt or guide, not to direct the conversation. The questions will be flexible depending on the direction the interview takes.

Feel free to decline to answer any of the questions I may ask as we go.

1. Could you describe the events leading to your diagnosis with PCOS?
2. Can you describe how you were given the diagnosis of PCOS and how this made you feel?
3. Could you identify what you found supportive from your healthcare professional during the diagnosis journey?
4. Please identify resources and education strategies that you found useful surrounding your PCOS diagnosis.
5. Thinking back on the care that you received, what suggestions or recommendations would you make to improve care to women such as yourself?