Healthcare Delivery for Polycystic Ovary Syndrome in Canada: Exploring Women's Experiences with Diagnosis and Management and Identifying Areas of Improvement

MSc Thesis

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ABSTRACT

Background: Polycystic ovary syndrome (PCOS) affects 6-10% of women and has a range of impacts on women's reproductive, psychological, metabolic, and cardiovascular health. A lifelong condition, symptoms of PCOS may start in adolescence and extend into post-menopause. Despite being such a pervasive disorder, with significant burden of disease for some women, it may be underrecognized within the medical and general communities. Recent studies suggest that women with PCOS may not be diagnosed early or receive appropriate guidance and information from physicians. Little is known about women's experiences in Canada. This thesis explores experiences with diagnosis and management in Canada and assesses the barriers and facilitators women face while seeking care for their condition.

Methods: Research questions were addressed using a multi-methods approach. Participants were recruited from online PCOS groups on Facebook, Reddit, and stand-alone PCOS forums. An online questionnaire measured participants' time to diagnosis, number of doctors seen, and satisfaction with information provided. Descriptive statistics, Chi-square tests, Fisher's exact tests, and Spearman's rank correlations assessed characteristics of the sample and correlations between demographic factors and satisfaction measures. Twenty-five follow-up interviews were held over the phone to elicit greater richness of experiences. Qualitative data were analyzed using thematic analysis and the interpretive description framework.

Results: The e-survey was completed by 296 women aged 18-60 with a self-reported diagnosis of PCOS. Approximately a third (34%) of respondents waited for more than 2 years before attaining a diagnosis and 41% saw 3 or more doctors. Most participants were dissatisfied with the information provided to them about PCOS (66%). Many did not receive any information about lifestyle management (42%) or medical therapy (28%). Barriers to diagnosis and management included lack of knowledge and/or concern in physicians. Women received insufficient information about PCOS implications (including mental health) at the diagnosis and subsequent visits. Few participants had physicians who were involved with PCOS management.

Peri- and post-menopausal women especially lacked support and medical information on how to manage symptoms. Facilitators to diagnosis and management included self-education, self-advocation, and social support. Women identified a need for greater PCOS awareness in primary care physicians and the general community. Few women had heard of PCOS prior to their diagnosis.

Conclusion: This thesis found delays to diagnoses and dissatisfaction in women around the care and information they received from doctors. Perceived lack of knowledge and engagement in physicians resulted in most barriers to diagnosis and management. Few participants had physicians whom they could rely upon for information and guidance. Greater awareness of PCOS is needed in the medical community, particularly in primary care. Women and girls may benefit from greater PCOS awareness early in life in health class at the elementary and/or secondary levels.

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ABBREVIATIONS

AES: Androgen Excess Society

BMI: Body Mass Index

CC: Clomiphene Citrate

CHERRIES: Checklist for Reporting Results of Internet E-surveys

CM: Complementary Medicine

COCPs: Combination Oral Contraceptive Pills

COREQ: Consolidated criteria for reporting qualitative research

CVD: Cardiovascular Disease

GP: General practitioner

HRQoL: Health-related Quality of Life

LM: Lifestyle Management

NIH: National Institute of Health

OB-GYN: Obstetrician-gynecologist

PCOS: Polycystic Ovary Syndrome

PCP: Primary Care Physician

RCT: Randomized Controlled Trial

T2DM: Type 2 Diabetes Mellitus

CHAPTER 1 – INTRODUCTION

1.1 Problem statement

PCOS refers to a constellation of symptoms that is prevalent in 6%-10% of women [1]. There is no cure for PCOS which has consequences for psychological, metabolic, reproductive, and cardiovascular health in women. PCOS is associated with insulin resistance, central obesity, and dyslipidemia which can place women at a higher risk for developing type II diabetes and cardiovascular disease [2, 3]. Women with PCOS commonly struggle with menstrual irregularity [4], infertility [5], hirsutism [6], acne [7], eating disorders [8], and mood disorders [9].

PCOS impacts multiple facets of a woman's quality of life due to its constellation of symptoms. Due to the potential breadth and complexity of symptoms, women may have to consult multiple health professionals across specialties. Healthcare professionals are advised to diagnose women early and educate women on treatments and lifestyle modification to prevent future risk of comorbidity [10].

Previous quantitative and qualitative studies with adolescents and adults with PCOS have found great rates of frustration and dissatisfaction in women with the diagnosis and care they receive from health professionals. Women face delays with diagnoses and are dissatisfied with the levels of knowledge in physicians and the information they provide [11–16]. Women also describe being discounted or brushed off by physicians [13, 16–19]. Women with PCOS have been shown to have lower levels of trust with their physicians [13, 17].

The U.S. and Australia have established PCOS as a healthcare priority [20]. Very few studies in the literature investigate health care delivery for women with PCOS in Canada, especially with regards to patient experience and satisfaction. It is unknown to the extent of which women in Canada are diagnosed early and are provided the resources they need to manage symptoms. Little to no studies exist which have explored women's experiences with PCOS diagnosis and management in Canada. What little research exists points to the same problems in Canada [16, 21].

1.2 Background

1.2.1 What is PCOS?

Polycystic ovary syndrome (PCOS) is the most common endocrinopathy in women's health [22]. It is also the most common cause of infertility in women, accounting for 90-95% of women in infertility clinics [23]. The etiology and pathophysiology of PCOS are not fully known [24]. The syndrome presents heterogeneously among women and across age [25]. Generally, PCOS is characterized by hyperandrogenism, irregular or no ovulation, and/or polycystic ovaries [26]. Hyperandrogenism is linked to clinical presentations of hirsutism, alopecia, and acne [27]. PCOS is strongly associated with insulin resistance, regardless of BMI [28]. Obesity is prevalent in women with PCOS, which further increases risk of type 2 diabetes [29, 30].

The cause of PCOS has not yet been determined; recent evidence suggests that PCOS may have a neuroendocrine origin [31] and a genetic component [32]. Women with PCOS have been

shown to have lower gut microbiome diversity compared to healthy controls [33]. PCOS is more common in identical twins than fraternal twins [34]. First-degree relatives of women with PCOS are more likely to have higher BMIs and greater incidence of metabolic syndrome, insulin resistance, type 2 diabetes mellitus, stroke, and myocardial infarctions as compared to controls [35, 36].

A high BMI has been shown to increase the severity of PCOS symptoms. A high BMI worsens insulin resistance and hyperandrogenism [30]. Increased weight gain from puberty to young adulthood was shown to be a risk factor for the development of PCOS [37]. Women with PCOS report higher BMI and greater 10-year weight gain as compared to controls [38].

PCOS is associated with an increased risk for moderate to severe depressive and anxiety symptoms, regardless of BMI [9]. Studies report a greater presence of eating disorders and poor body image in women with PCOS [8, 39–41]. The presence of certain clinical features, such as hirsutism, may lead to worsened body image, self-esteem, and sense of “womanhood” [42, 43].

1.2.2 Challenges with diagnosis

PCOS is a complex and perplexing condition for physicians and patients both. Diagnostic criteria vary for adults, adolescents, and peri- and post-menopausal women [10]. Few studies examine women’s perceptions and satisfaction with their diagnosis. What research is available indicates that women face delays in diagnosis and are dissatisfied with the information provided to them about their condition [12, 16, 18, 44].

There appears to be widespread gaps in knowledge and inconsistent approaches among residents and physicians on the diagnosis and management of PCOS [45–49]. Significant clinical variability has been found in physicians in their approaches to the PCOS diagnosis [45, 47, 50]. Studies on physicians’ perspectives revealed their difficulty and confusion around PCOS care, as the spectrum of PCOS presentation can make it hard to determine appropriate diagnosis and management options [51]. It can be difficult for physicians to diagnose PCOS due to heterogeneity in PCOS presentation [52] and complex diagnostic criteria for adults and adolescents [25, 53, 54]. Although international, evidence-based guidelines have been published in recent years [10, 55], it is unknown the degree to which physicians utilize them.

1.2.3. Challenges with management

As there is no cure for PCOS, treatment connotes management of symptoms only. PCOS can be challenging to manage due to its long-term nature and range of symptoms and health consequences. PCOS may present in one woman as menstrual irregularity that can be managed by oral contraceptive pills alone. On the other side of the spectrum, symptoms of insulin resistance, hirsutism, acne, anxiety, and depression may co-occur and have a significant impact on quality of life [9, 56].

Lifestyle management, involving weight loss or healthy weight maintenance, remains the most effective first-line therapeutic intervention [57, 58]. Modification to diet and exercise are important to managing PCOS and reducing the associated long-term health risks. Pharmaceuticals such as metformin and oral contraceptives should be tailored to the individual patient’s risk profile and treatment goals [10, 59–61].

Health professionals well-equipped with knowledge on PCOS and its treatment options and who can provide informational resources to patients along with referrals and follow-up, are vital to management of PCOS [11, 13, 45, 46]. Due to the wide range of symptoms, women may need to consult different healthcare professionals. Primary care physicians (PCPs), endocrinologists, nutritionists, reproductive specialists, and psychologists are some of the health professionals with valuable expertise to guide women with PCOS on their individual management journeys.

Tailored and individualized treatment plans that target the patient's unique symptoms and concerns can address the unique challenges of PCOS and provide patients with positive health outcomes [10, 23]. However, many patients with PCOS experience frustration with the inconsistent approaches of health professionals with regards to both diagnosis and management of PCOS [45]. Mental health impacts of PCOS are often unaddressed in doctor's visits [16, 62, 63]. Studies of healthcare providers found that many need more knowledge on PCOS and have a limited amount of information available for patients about PCOS and its management [45–47, 64].

1.3 Research questions and objectives

My master's thesis concentrates on women who have been diagnosed with PCOS in Canada, and asks the following questions:

1. What are women's experiences and perceptions of their diagnostic process?

2. What are women's experiences managing PCOS with the resources available to them?

My research objectives are to:

1. Identify barriers and facilitators in the diagnosis and treatment for women with PCOS in Canada.

2. Identify resources women with PCOS currently lack in Canada, accounting for age-specific needs.

To answer my research questions, I employed a multi-methods approach (an e-survey and follow-up phone interviews). I distributed an e-survey on various PCOS-specific groups and forums. The survey asked women questions such as: how long it took them to get diagnosed, how many physicians did they have to see before achieving their diagnosis, and how satisfied they are with the patient information provided to them about PCOS. I followed up with telephone interviews for qualitative, in-depth data on women's lived experiences. My interviews had 3 domains: 1) experiences with diagnosis; 2) experiences with management of symptoms; 3) ways in which PCOS healthcare can be improved based on women's lived experiences. For more information on methods, please see Chapter 3.

1.4 Rationale

The literature to date shows that women with PCOS around the world may not be receiving high quality, equitable care. With the gaps in knowledge in physicians, the delayed diagnoses, the lack of satisfaction with provided information, and medical encounters with limited empathy, it becomes clear that something may be amiss with PCOS healthcare delivery in numerous

countries. Delays in diagnosis and unmet informational needs can have long-term consequences, such as an increase in depression and anxiety symptoms [65] and reduced ability to self-manage and improve lifestyle to prevent comorbidity [12, 55].

With such high rates of dissatisfaction and frustration in women with PCOS, along with gaps in knowledge and confusion in physicians, it becomes important to gather insights from this population on what can be improved in PCOS healthcare provision, based on their lived experiences. This thesis explores the lived experiences of women with PCOS in Canada to better understand the meaning of that experience for them and identifies the barriers and facilitators in participants' diagnosis and management journeys. Experiences and needs with PCOS diagnosis and management are explored with consideration to age and life stage, including peri- and post-menopausal stages.

This thesis is important for patient care in that it adds to the body of knowledge related to lived experiences with PCOS, providing insight into patient perspectives on care and well-being, with the goal to inform healthcare providers in their attempts to provide care to this patient population. The best strategy to ensuring patient-centered care in Canada is to include the voices of patients when attempting healthcare reform [66]. Women's perspectives on PCOS healthcare delivery in Canada are needed to address a substantial gap in Canadian PCOS literature.

CHAPTER 2 – LITERATURE REVIEW

This chapter details the various symptoms and presentations of PCOS across the life course, as well as the diagnostic criteria and treatments commonly used and recommended. It then describes prior findings in the literature on women's experiences and perspectives with their diagnosis and management. The chapter concludes with the gaps in literature my thesis will address.

2.1 Symptoms and presentations across the life course

The clinical presentation of PCOS is variable; PCOS refers to a spectrum of symptoms. Patients may be asymptomatic, or they may have multiple gynecologic, dermatologic, or metabolic manifestations. There is also considerable ethnic variation in the presentation of PCOS which primarily relate to hirsutism and metabolic features such as obesity, insulin resistance, diabetes, and metabolic syndrome [67, 68]. PCOS is commonly characterized by menstrual and ovulatory dysfunction and general infertility. Approximately 70% to 80% of women with PCOS present with oligomenorrhea or amenorrhea [23]. Women may face shorter or longer periods, painful periods, with heavier or lighter bleeding [69].

Women with PCOS are at an increased risk for miscarriages [70]. An inability to conceive can have an impact on a woman's quality of life. Feelings of frustration, anger at self and at external circumstances, and feelings of isolation can impact women's mental health and quality of life [42]. In traditional gender roles, a woman's sense of femininity can be drawn from her ability to reproduce and have conventional feminine features [43]. In atmospheres where fertility is prized, women with PCOS can feel shamed and stigmatized due to their perceived lack of fertility or "womanhood" [42]. PCOS features such as infertility, weight gain, hirsutism, and acne have been shown to impact women's sense of self, sense of femininity, and self-confidence [42, 43].

PCOS is further associated with insulin resistance, regardless of BMI [28]. Women with PCOS have been characterized into several phenotypes, including "lean PCOS." Although women with lean PCOS have less severe symptoms than obese women with PCOS, they are still more likely to have insulin resistance, irregular ovulation, hirsutism, acne, and menstrual dysfunction than healthy controls [28]. Insulin resistance is associated with longitudinal increases in BMI, difficulties in weight loss, increased inflammation, and progression into type 2 diabetes when unmanaged [71, 72]. Hirsutism is a common physical manifestation arising from hyperandrogenism and affects around 70% of women with PCOS [73]. Hyperandrogenism may also result in acne and alopecia [7, 27].

PCOS commonly is associated with obesity, which significantly increases the risk of type 2 diabetes [29, 30]. The presence of a high BMI exacerbates menstrual and ovulatory dysfunction, insulin resistance, and hyperandrogenism [30]. Obesity can also exacerbate cardiovascular risk factors such as glucose intolerance, dyslipidemia, and hypertension [74]. Metabolic syndrome has also been found to be associated with PCOS [75]. Adolescents with cooccurring obesity, PCOS, and metabolic syndrome were recently found to have poor quality sleep [76]. Women with PCOS have been shown to have greater rates of obstructive sleep apnea and hypersomnia [77, 78].

Adolescents with PCOS have symptoms that earlier on in puberty are often confounded by normal puberty symptoms, such as irregular menstruation or ovulation [54, 79]. What differentiates adolescents with PCOS from adolescents without PCOS is the potential for clinical or biochemical hyperandrogenism [53, 79]. Adolescents with PCOS may experience earlier menarche and adrenarche [79]. PCOS often leads to adolescents becoming insulin-resistant and overweight or obese [24, 79]. Some findings suggest that adolescents may be especially vulnerable to mental illness. Symptoms such as weight gain, acne, and hirsutism can affect adolescents' psychological and emotional ill-being [80, 81]. Adolescents with PCOS often face mood disorders from their symptoms and report greater impacts on their quality of life [81, 82].

There is a higher prevalence of anxiety and depressive symptoms in adult women with PCOS [9]. The prevalence remained high even after accounting for BMI across groups [9]. An association existed between mental health and hirsutism and insulin resistance in the sample, although the directionality of the relationship could not be determined [9]. The prevalence of binge-eating disorder and bulimia disorder is also high in PCOS [39]. PCOS was also found associated with decreased sexual satisfaction [78] and problems with body image [40, 83].

Longer-term health consequences of PCOS may also include endometrial, ovarian, and breast cancers [84]. The long-term health consequences of PCOS which extend into post-menopause have not been fully determined [85]. Current evidence suggests that the cardiometabolic risk profiles in peri- and post-menopause in women with PCOS begins to match those of controls, despite the persistence of hyperandrogenism [85, 86]. More longitudinal research is needed to understand PCOS presentation and associated health consequences in women in perimenopause and post-menopause.

2.2 Diagnosis of PCOS

2.2.1 Diagnostic criteria

In current practice, there are three main diagnostic definitions of PCOS. The 1990 National Institute of Health (NIH) criteria includes 2 necessary criteria: chronic anovulation and clinical and/or biochemical hyperandrogenism [87]. The Androgen Excess Society (AES) has two necessary criteria: clinical and/or biochemical hyperandrogenism and ovarian dysfunction (oligo-anovulation and/or polycystic ovarian morphology) [22]. The 2003 Rotterdam criteria necessitates any 2 of the following 3 criteria: oligo-anovulation, clinical and/or biochemical hyperandrogenism, and polycystic ovaries [88]. Table 1 below illustrates the three main diagnostic definitions.

Table 2.1 Summary of diagnostic criteria.

	NIH (1990)	Rotterdam (2003)	AES-PCOS (2006)
Oligo- or anovulation	✓*	✓	✓*
Clinical or biochemical hyperandrogenism (bioavailable or free testosterone)	✓*	✓	✓*

Polycystic ovarian morphology		✓	

*Indicates a necessary criterion.

Each of the 3 diagnostic criteria above emphasizes the need of a diagnosis by exclusion. Symptoms commonly found in PCOS may also be found in other disorders such as Cushing syndrome, androgen-secreting tumor, idiopathic hyperandrogenism, congenital adrenal hyperplasia, idiopathic hirsutism, hyperprolactinemia, and thyroid disorders [26]. Using the NIH, AES, or Rotterdam diagnostic criteria leads to different prevalence and phenotypes of patients with PCOS; the Rotterdam criteria are more inclusive than the NIH or AES [1].

Screening for comorbidities is important at the time of diagnosis. Patients with PCOS should all be screened for markers of insulin resistance, regardless of BMI [25]. All patients with PCOS should be assessed for individual cardiovascular risk factors and global CVD risk [55]. Cardiovascular risk factor screening includes monitoring weight and weight change, assessing BMI, family history, ethnicity, smoking status, blood pressure and glycemic status in all patients with PCOS, and waist circumference and lipid profiles in those with additional risk factors [55]. Screening for anxiety, depression, and eating disorders is also necessary since the prevalence of these disorders is high in women with PCOS [9, 25, 89].

There is a lack of consistency in the diagnostic criteria used in practice, with physicians not being able to recall which diagnostic criteria they used [45] or correctly identify diagnostic criteria [47]. Diagnostic practices for adolescents with PCOS are also heterogenous, with studies finding significant differences in physicians' use of diagnostic tests and assessments of comorbidities [50, 90]. It can be difficult for physicians to diagnose PCOS due to heterogeneity in PCOS phenotypes [25, 52], complex diagnostic criteria [25], and controversial diagnostic criteria for adolescent populations [53, 54].

Early diagnoses are recommended by several guidelines to help modify the course of PCOS and reduce the risk for long-term morbidity [89, 91]. Women may not be diagnosed early because of a lack of knowledge in physicians [12, 21, 64]. Early diagnosis is not only beneficial for women's long-term health, but it may also lessen the economic burden on the healthcare system. One cost analysis review of the US healthcare system suggests that evaluating and caring for PCOS patients during their reproductive years can exceed $4 billion – 2% of which is attributed to the diagnosis [92]. Most of the economic burden comes from treating emerging comorbidities from PCOS [92]. Early diagnosis may be the only cost-effective strategy to reduce the economic burden of PCOS, while also benefiting women's long-term health.

2.2.2 Considerations for diagnosis across the life course

Normal pubertal development in adolescence can resemble and confound early PCOS symptoms. Adolescents for the first few years after menarche can present with irregular menstruation and ovulation, along with acne and increased hair growth [54]. Normal adolescent ovarian morphology may also include multiple ovarian follicles and larger ovarian volume [53, 54]. Because adolescent physiology can confound PCOS features, diagnosis in adolescents can be challenging. Anovulation is common after menarche, so it is reasonable to delay workup for PCOS in adolescents until they have been oligomenorrheic for at least two years or label adolescents as "at risk for PCOS" [24, 93]. If an adolescent is evaluated for PCOS, it has been

suggested that they meet all three of the Rotterdam criteria before being diagnosed with the condition [94].

Diagnostic criteria for women in peri- and post-menopause are still controversial and unvalidated. PCOS diagnostic definitions have mainly included women within reproductive years. Recent studies have found women with PCOS to continue having hyperandrogenism, with a recent study finding that women with PCOS between the ages of 72-91 years old had greater hirsutism and lower levels of FSH compared to controls [95]. Guidelines suggest that a diagnosis of PCOS could be considered if there is a past diagnosis of PCOS, a long-term history of irregular menstrual cycles, and hyperandrogenism during the reproductive years [55].

2.2.3 Women's experiences and perceptions with their diagnosis

Several qualitative and survey studies have examined women's experiences with seeking and receiving a diagnosis. Feelings of frustration with the PCOS diagnosis are prominent within the literature. Surveys of diagnosis experiences in Australia and international settings have found high rates of dissatisfaction in women with the amount of information their doctors provide at the time of diagnosis about PCOS, lifestyle management, medical therapy options [12, 44, 96]. Women are also often not screened for mental health or provided emotional support or counselling [12, 16, 44].

Feelings of frustration with the diagnosis are also described by numerous qualitative studies. Women report not being given enough information about what PCOS means and what the treatment options are [15, 16, 18, 64]. Most of their health education around PCOS occurs independently after the diagnosis [16, 18, 19, 97]. One qualitative study on the information needs of women with PCOS found they had gained most of their knowledge of PCOS online, and found it difficult to elicit responses from their physicians [98]. A theme that arose was initial self-diagnosis in women whose physicians were unable to provide a diagnosis. Those women had to do their own research and advocate for themselves and why they thought they might have PCOS before attaining a diagnosis [98].

Feelings of dismissal from physicians are also commonly reported by women. Numerous qualitative studies have recounted women's frustrations with being dismissed by physicians and perceiving a lack of empathy in them [16, 18, 19, 82]. A qualitative study in the UK on 32 women aged between 18 and 45 years old found themes of delays to diagnosis, a lack of empathy and information from healthcare professionals, and insufficient help and advice from healthcare professionals [18]. Women reported having to push for a diagnosis when healthcare professionals would not know what to do or not seem to take their symptoms seriously [18]. A final theme in the interviews involved a lack of follow-up from healthcare professionals [18].

A qualitative study with adolescents found that they also experienced a lack of information from healthcare providers [82]. Adolescents felt that their symptoms were brushed off by their healthcare provider and they did not come away feeling like the complexity of their syndrome had been explained to them [82]. They also experienced many strong and negative emotions at the time of diagnosis, such as "shock, disbelief, worry" [82]. Adolescents often experienced stigma and social withdrawal due to hirsutism, acne, and infertility, which worsened their self-image [82]. A PCOS diagnosis can be an important life event for many women. PCOS can be confounding to physicians and women alike; adequate information at the outset is paramount for women to understand what it means to have PCOS and what they may need to watch out for.

2.3 Treatment and management of PCOS

2.3.1 Lifestyle management

Treatment should be tailored to the patient's and the physician's therapeutic goals, as no single therapy is currently available for PCOS [91]. First-line treatments of PCOS include lifestyle management (LM) and hormonal contraception [25]. LM has the potential to treat many symptoms of PCOS simultaneously. A reduction in weight from a lifestyle of a healthy diet and exercise regime has been shown to improve glycemic control, reduce hyperandrogenism, and improve reproductive outcomes [99, 100]. As little as 5% weight loss can improve menstrual regularity and response to fertility medications [101]. LM also functions as a preventative measure for future comorbidities, such as T2DM, cardiovascular disease, metabolic syndrome [99]. PCOS is associated with obesity and visceral obesity [102]. Reduction in visceral obesity (indicated by reduction in waist circumference) is of clinical significance in its ability to significantly decrease risk of many comorbidities, such as metabolic syndrome, diabetes, and cardiovascular disease [102, 103].

No consensus exists on which diet is most beneficial for PCOS. A systematic review of dietary interventions found low to moderate differences in the metabolic, reproductive, and psychological outcomes from different diet compositions [104]. A low-carbohydrate, low-GI, and high-protein diet improved metabolic parameters such as insulin sensitivity [104]. With regards to reproductive and psychological outcomes, weight loss was equally beneficial to women with PCOS regardless of diet composition [104]. Most diet interventions had a high rate of attrition [104]. Women report barriers to sustaining prolonged exercise regimen as part of their LM. Factors like fatigue, lack of time and motivation may inhibit women to adopt an exercise regimen as part of their LM [105].

2.3.2 Medical therapy

Combination oral contraceptive pills (COCPs) are often the most recommended pharmacological treatment for PCOS [106]. COCPs are effective at regulating menstrual cycles, reducing hirsutism, acne, and alopecia [106]. Metformin is a commonly prescribed drug for women to achieve weight loss and increase insulin sensitivity [106]. Metformin's effects on reducing fasting glucose and insulin levels are moderately established [107]. Letrozole and clomiphine citrate (CC) are drugs that have been proven to induce ovulation in women and help them conceive [106, 108]. The beneficial effects of CC appear to strengthen when it is combined with metformin [106, 109]; however, letrozole was associated with a higher live birth rate than clomiphene citrate in a recent review [108]. On its own, metformin is not effective at improving ovulation rates or increasing the rate of live births [107, 108]. If women with PCOS are comorbid with CVD, anti-statins are prescribed to decrease total cholesterol levels and risk for venous thrombosis [106].

2.3.3 Supplementation and complementary medicine

In an Australian survey of almost 500 women with PCOS, 70% reported using complementary medicine (CM) in the last 12 months [110]. About 48% of women reported using more than one type of CM product at a time and 76% saw complementary practitioners (acupuncturists,

chiropractors, naturopaths) in the last 12 months [110]. Recent systematic review and meta-analysis found that acupuncture may help in the recovery of regular menstrual cycles and lower levels of testosterone in women with PCOS [111, 112]; however, there was insufficient evidence for benefits to ovulation and pregnancy [112].

One RCT divided women with PCOS into groups which underwent a lifestyle intervention (LI) with and without herbal supplementation [113]. Half of the women in the intervention group supplemented with a mix of herbs (*Cinnamomum verum, Glycyrrhiza glabra, Hypericum perforatum, Paeonia lactiflora*) and the other half took only one type of herb (*Tribulus terrestris*). The group with more herbs reported significantly better outcomes in rate of ovulation, menstrual regularity, insulin resistance, blood pressure, mental health, and BMI compared to the groups who only took one herb with LI or just the LI [113]. A conclusion could not be drawn on which herb in the mix benefited the intervention group most. Reviews have found that herbs such as *Cinnamomum verum, Mentha spicata, Trigonella foenum-graecum L., Zingiberene officina*, and *Vitex agnus-castus* may benefit menstrual and ovulatory dysfunctions, obesity, insulin resistance, lipid-metabolism dysfunction, and androgen excess [114, 115].

Inositol is a supplement that has recently gained popularity in the treatment of PCOS. Myo-inositol was found to reduce BMI and increase insulin sensitivity to the same effect as metformin but without the side effect of nausea [116, 117] and be more effective at improving fertility compared to metformin [118]. A meta-analysis found that inositol may improve metabolic profile in women with PCOS in addition to reduced biochemical hyperandrogenism and improved ovulation and pregnancy rates [119]. However, more research is needed to fully determine the efficacy and long-term implications of inositol as a treatment for PCOS [120].

A meta-analysis of vitamin D supplementation for PCOS found that vitamin D can improve ovarian follicle development [121]. Vitamin D supplementation in deficient women improved fasting glucose and adiponectin levels (which are linked to metabolic and cardiovascular diseases) [122]. However, the effects of vitamin D supplementation on lipid and glucose metabolism remain controversial [121, 123]. More high-quality evidence is needed to confirm the effects of various vitamin and herbal supplementation on hormone, glucose, and lipid functioning in women with PCOS [119]. Women taking inositol and other complementary therapies are encouraged to advise their health professional (Teede, 2018).

2.3.4 Psychosocial treatment

Psychotherapy and counselling are important resources to help treat mental illness in women with PCOS and help women cope with their condition. As previously mentioned, women with PCOS are at a higher risk for developing anxiety, depression, eating disorders, and poorer HRQoL compared to women without PCOS [9, 124–126].

Exercise and nutrition are known to boost mental outlook and have previously decreased the severity of depressive and anxiety symptoms in PCOS [105, 127]. A 24-week LM program in Belgium consisting of a standard diet, exercise, and psychological intervention found that even without significant changes in BMI, overweight adult women with PCOS reported significantly improved HRQoL [128].

Therapies like cognitive behavioural therapy (CBT) have been used with women to improve quality of life [129, 130]. Adding CBT to lifestyle intervention programs has resulted in increased

weight loss than exercise alone [130, 131]. Support groups and group counselling have been proven effective at providing women with social and emotional support, as well as increasing motivation and confidence [132–134]. A qualitative study explored experiences of women in PCOS support groups and found that support groups helped reduce feelings of isolation, confusion, and increase their sense of empowerment in self-management behaviours [133]. Group counselling combined with exercise interventions resulted in greater weight loss and maximal aerobic capacity than exercise alone [135].

2.3.5 Management across the life course

The following recommendations are summarized from the first international evidence-based guideline (2018) for the diagnosis and management of PCOS [89]. Care for PCOS needs to address patient priorities and be patient centered. PCOS information to be provided to women should be comprehensive, evidence-based, and inclusive of the biopsychosocial dimensions of PCOS across the life span [89].

LM is the first-line treatment for all ages and should be recommended to all patients with excess weight [89]. LM may be particularly beneficial for adolescents as an early start to healthy lifestyle changes may prevent the long-term risks associated with PCOS [24, 89]. Regular monitoring for weight changes and excess weight at each visit or at a minimum of 6–12 months should be planned between the health professional and patient [89]. In combination with COCP, metformin could be considered in adolescents with PCOS and BMI ≥ 25 kg/m^2 if COCP and lifestyle changes are not effective [89].

Overweight and obese women with PCOS, regardless of age, should have a fasting lipid profile at diagnosis (cholesterol, low density lipoprotein cholesterol, high density lipoprotein cholesterol, and triglyceride level) [26, 89]. The frequency of measurement should be based on the presence of hyperlipidemia and global CVD risk. Glycemic status should be assessed at baseline in all women with PCOS, regardless of BMI, and every 1-3 years thereafter, influenced by the presence of other diabetes risk factors [26, 89, 136].

A comprehensive history and physical examination should be completed for symptoms and signs of clinical hyperandrogenism, including acne, alopecia, and hirsutism in adults and adolescents [89]. As ethnic variation in vellus hair density is notable, only terminal hairs need to be considered in pathological hirsutism. Over-estimation of hirsutism may occur if vellus hair is confused with terminal hair. It is important to consider variations in PCOS presentation across ethnic groups. For example, Middle Eastern, Hispanic, and Mediterranean women often present with more severe hirsutism while East Asians are likely to have lower BMIs and milder hirsutism [89].

Anxiety and depressive symptoms should be routinely screened in all adolescents and women with PCOS at diagnosis [89]. If the screen is positive, further assessment and/or referral for assessment and treatment should be completed. Use of pharmacological treatment for anxiety and depression that exacerbate PCOS symptoms, such as weight gain, need careful consideration. If eating disorders are suspected, further assessment and/or referral for assessment by trained health professionals should be completed [89].

Monitoring during pregnancy is important in women with PCOS, given increased risk of adverse maternal and child outcomes [89]. Letrozole should be considered first line pharmacological

treatment for ovulation induction in women with PCOS with anovulatory infertility, followed by clomiphene citrate (alone or in conjunction with metformin), and lastly gonadotrophins as second line treatment for ovulation induction [89].

There is a 2-6-fold increased risk for endometrial cancer in women with PCOS [89]. Optimal prevention for endometrial hyperplasia and endometrial cancer is not known. COCPs or progestin therapy in women with cycles longer than 90 days can be one pragmatic approach [89].

Postmenopausal women presenting with new-onset, severe or worsening hyperandrogenism, including hirsutism, require investigation to rule out androgen-secreting tumors and ovarian hyperthecosis [89]. Little more guidance exists for management in peri- and post-menopausal women in the international guideline and literature. Large, prospective studies on community-based women with extended follow-up into late menopause are needed to explore the management needs of post-menopausal women [85, 137].

2.3.6 Women's experiences and perceptions of management

The literature is increasingly exploring what it means to live with a condition like PCOS and its associated wide range of symptoms. Studies describe women experiencing worry and anxiety about their symptoms (e.g., infertility) [138, 139] and having some activities curtailed due to pain or low self-image (e.g., sports and social gatherings) [139]. Women with PCOS also battle internal and external stigma around certain symptoms, such as infertility, hirsutism, and acne, which do not fit in with "traditional" body presentation in women and are seen as "less feminine" [19, 82, 139–142].

Women also describe lacking sufficient information and advice from physicians for management and having difficulty accessing referrals to specialists [18, 143, 144]. Further, inconsistent approaches to management have been found in studies with physicians, which some women were frustrated by [46, 48, 145]. Mental health is also often unaddressed by healthcare professionals [62, 63]. Higher depressive scores at baseline were associated with greater attrition in LM trials and lower HRQoL levels [146, 147].

LM is one of the most important, and yet challenging, treatment options to adhere to. A UK-based study on 64 overweight and obese women with PCOS found that only a small percentage of women had been referred to a dietician and less than half of the women reported exercising at least once a day [148]. A few studies have reported that women are not given information on LM [12, 44, 144, 149]. Greater information on LM can equip women to successfully manage PCOS. A Saskatchewan clinical intervention with the aim to increase knowledge of PCOS and its treatments surveyed women before and after a 5-6 week intervention [21]. Women came away from the intervention reporting greater confidence in managing their PCOS. Most found information about lifestyle modification and other treatment options as most helpful [21]. Women also reported greater satisfaction with their health care providers after participating in the intervention [21]. Prior to the study, most women felt unsure about what PCOS is and how it affects their health and dissatisfied with the support they received from their primary health care provider in managing symptoms [21].

Frustrations with health providers have led some women with PCOS to lose trust with their physicians [13]. Women with PCOS often access the Internet for informational resources and

social support from online groups or communities [15, 98, 140, 150, 151]. Reading the posts of others with PCOS online gives women access to information about treatment options and serves as social support by enabling them contact with other who are going through similar experiences [19, 143, 150].

Overall, the literature indicates that women with PCOS may not be receiving adequate support to manage their condition – which is often complex and burdensome on quality of life.

2.4 Gaps in literature addressed by thesis

Although some quantitative and qualitative studies from Australia, the UK, Iran, and India have explored women's satisfaction, perceptions, and experiences with accessing care, little is known about the lived experiences of women in Canada. The limited literature that exists on women's diagnosis experiences have described women's frustrations with information provision and delayed diagnoses. There is a lack of such studies being on Canadian populations to assess whether similar problems exist here.

Management of PCOS can be complex depending on the symptomology of the patient. Little is known about patients' firsthand experiences accessing care for the management of PCOS and navigating the healthcare system in Canada. Surveys and interviews exploring diagnosis and management experiences may add to women's experiences found in the literature to help fill the gap in knowledge and inform health policy.

Most qualitative and quantitative studies have not included participants outside of reproductive years; very little is known about the experiences of women in peri- and post-menopause. As discussed in previous sections, significant gaps exist in the literature around the symptoms and treatments women have once outside their reproductive years. Women in peri- and post-menopause may still have to manage certain symptoms that continue past menopause; it is important to explore their experiences with management and accessing care for symptoms to inform future guidelines.

This thesis adds to the literature by exploring the experiences women of diverse ages have getting a diagnosis and managing symptoms in Canada. This research can help identify whether care needs to be improved in Canada and how we may go about improving care by examining the barriers and facilitators women encounter.

CHAPTER 3 – METHODS

This chapter describes the methods used in this thesis to answer the research questions and address the research objectives. It begins with an overview of the multi-methods research design, the underpinning theoretical framework, and describes the data collection and analysis procedures.

3.1 Research design

3.1.1 Cross-sectional online survey

The study design includes a cross-sectional online survey and a follow-up telephone interview, combining both quantitative and qualitative methods in a multi-methods design. Cross-sectional surveys were the preferred method due the descriptive nature of the research questions. Cross-sectional surveys are carried out at one point in time or over a short period to represent a snapshot of the population about which they gather data (Levin, 2006). The cross-sectional survey for this thesis was adapted from a prior publication by Gibson-Helm et al. (2014) [44] with the authors' and publisher's permission. The survey was hosted on SurveyMonkey's (San Mateo, CA, USA) Canadian servers. The choice to digitally distribute the survey, rather than print questionnaires and distribute them locally, was to accommodate the research aim to explore PCOS healthcare delivery in all of Canada.

3.1.2 Semi-structured remote interviews

At the end of the online survey, participants had the opportunity to submit their contact information (i.e., name and email) for a follow-up telephone interview. The telephone interview was semi-structured and in-depth. The purpose of the interviews was to gather in-depth, context-specific information about the nature of participants' diagnosis (thereby elaborating on survey responses), their lived experiences managing symptoms, and ways in which they thought PCOS healthcare could be improved.

The qualitative interview was chosen as the best method to answer questions related to women's lived experiences. Interviews are suited for the exploratory and descriptive nature of the research questions [152]. Advantages of telephone interviews include decreased cost and travel to both interviewer and participant and ability to reach geographically dispersed respondents [153]. Holding the interviews over the phone may set participants at ease when discussing potentially stigmatized symptoms, such as hirsutism or other visible presentations of PCOS [154]. Semi-structured interviews were chosen to allow some flexibility in the order of questions asked and in the degree of prompting and probing [155, 156]. Some participants may be less verbose than others, especially in interviews about stigmatized symptoms found in PCOS.

The interview guide was developed by MI with guidance from Professor Foster. It was composed of three main domains: (1) experiences with diagnosis, (2) daily management of symptoms, and (3) ways in which PCOS healthcare delivery can be improved. The first domain contains questions to allow participants to portray their perceptions of interactions with healthcare providers, impressions of the healthcare system, and perceptions of the quality of diagnosis and information provided during diagnosis. The second domain hosts questions which

allow participants to describe in detail all the treatments or services they have used and are using which have helped them manage symptoms. The third, and last, domain asks women to reflect on their journey with the diagnosis and management and share where they think Canadian healthcare delivery for PCOS may be improved. The last domain serves as a venue to a patient-centered approach for devising recommendations for the improvement of healthcare services in Canada. Understanding women's lived experience of PCOS is essential to meeting their healthcare needs and improving their health outcomes.

3.1.3 Interpretive description

The guiding framework for the qualitative methods is interpretive description. Interpretive description was developed in the 1990s by Thorne and her colleagues to meet the needs of nurse practice research. The interpretative description method was designed to meet the needs of healthcare and nursing inquiries better than other qualitative methods (e.g., phenomenology, grounded theory) which were designed to suit disciplines such as philosophy or sociology. While interpretive description draws from grounded theory, phenomenology, and ethnography, it differs from other frameworks in that no new truth, theory, or explanation of phenomena is formed [152, 157]. The purpose of interpretive description is to "describe and interpret a shared health or illness phenomenon from the perspective of those who live it" (Thorne, et al., 1997, p. 171), while addressing thematic patterns between participants in addition to potential variations between them [158]. Thorne's interpretive description approach suits my research aim of exploring and describing women's experiences managing PCOS in Canada, while being able to differentiate themes between participants of different age groups.

3.2 Participants and Eligibility

The study population includes community-based women above the age of 18 who have been diagnosed with PCOS in Canada (self-reported) and have lived in Canada since the diagnosis. No upper age limit was established to encourage participations from women in older age. Language requirements include the ability to speak, write, and read in English. Participants were recruited to participate in the cross-sectional survey via links on PCOS support groups on Facebook, Reddit, and some stand-alone PCOS forums. Forums can serve as a source of information and advice for treatment-related decision making, making them a popular venue for groups of people with shared diagnoses such as PCOS [150]. Purposive and snowball sampling was used when recruiting participants in online groups and when asking participants to share the recruitment post with any friends they have with PCOS. The PCOS Awareness Association, based in the US, also helped in participant recruitment by sharing the research poster on their Facebook page.

3.3 Data collection

3.3.1 Setting

I collected the data while residing in Ottawa, Canada, which has a population of around 1.25 million [159]. Canada is a country with a population of around 36 million people [159]. Around 18 million are women, of which around 60-70% are between the ages of 18 and 65 years [159].

Survey responses from SurveyMonkey (San Mateo, CA, USA) were hosted on Canadian servers under the University of Ottawa group. I conducted remote interviews at my place of residence in Ottawa, Canada. The scheduled times for interviews were at the discretion of participants. They chose where and when they wanted to hold the interviews.

3.3.2 Procedures

Data collection occurred in a two-step process. First, women's perceptions and satisfaction level of their diagnosis was gathered by an online cross-sectional survey. The survey was adapted from a 2014 study by Gibson-Helm and her colleagues, with their permission and the permission of Oxford University Press (see Appendix B for permission).

The opening screen of the survey included some study and ethics information, with the full study information sheet linked in an embedded PDF. Participants gave implied consent when they pressed "Yes, I agree" to begin the survey. The survey did not collect any identifiable information, including IP addresses, to preserve participants' anonymity. The cross-sectional survey was distributed online from May 2018 to December 2018, being reposted around once a month.

The survey first asked for demographic data (e.g., province of residence, height, weight, education level, work status). Subsequent questions focused on participants' length of time to diagnosis, number of healthcare professionals seen, and satisfaction with various features of the diagnosis (including the information provided to them by their healthcare professional). At the end of the survey, participants had an opportunity to enroll in a draw for 1 of 3 CAD$25 Amazon e-gift cards. Afterwards, participants were asked if they would like to be contacted for a follow-up interview.

Participants who filled out their contact information were contacted by e-mail with information about the nature of the interview and a letter of information and consent form. Participants who were unable to sign their consent digitally were asked for their consent orally during the phone call. I logged oral consent on an "Oral Consent Log" document and logged their permission to be audio-recorded.

Interviews were semi-structured and led by the principal investigator. Each interviewee was compensated with a $25 Amazon e-gift card sent via email. Interviews took place over the phone and 1 was held over Skype due to participant preference. Phone interviews were recorded, with permission, by an Android call recorder app. The Skype call was recorded with Skype's built-in recording capacity. Interviews were held until the principal investigator determined that thematic saturation was reached and no more women in the 40+ age group were available to interview.

3.4 Data analysis

Statistical analysis was performed with IBM SPSS Statistics for Windows, version 25 (IBM Corp., Armonk, N.Y., USA). Categorical data were presented as count and proportions and continuous data were presented as mean ± standard deviation if data followed a normal distribution, or median and interquartile range if data did not follow a normal distribution. Chi-square and Fisher's Exact tests were performed to test for associations between demographic characteristics and experiences of PCOS diagnosis. Spearman's rank-order correlations were

used to assess correlation within satisfaction ratings if the two variables had a monotonic relationship. A p-value of 0.05 was considered statistically significant. Variable distribution in the groups was tested using the Shapiro–Wilk test for normality.

Telephone interviews were transcribed verbatim, compared with recordings for accuracy, and read several times for immersion in the data. Qualitative data analysis took place concurrently with data collection and afterwards. Memos after each interview allowed me to reflect on my positionality and identify emerging themes within and between interviews [155]. I used NVivo 12 to keep track of memos, transcripts, and coding trees. Interview data was analyzed using inductive content analysis, in line with Thorne's interpretive description method [152]. In accordance with Thorne's interpretive description method, I avoided the development of complex coding systems and instead ensured ongoing immersion in the data [152]. Braun and Clarke's (2006) [160] six key stages in the thematic analysis of qualitative data were also followed: (1) Familiarize, (2) Generate initial codes, (3) Search for themes, (4) Review themes, (5) Define themes, and (6) Write up the data analysis. First, each interview transcript was read line-by-line and codes describing content were made in NVivo. Second, notes and codes were grouped into a coding scheme and were used to create categories and sub-categories. Sub-categories were compared and if necessary were merged into larger sub-categories with a more general description of content. Larger sub-categories with similar events, understandings, trends, and incidences were grouped together to formulate themes. Codes and subsequent sub-categories were generated directly from topics raised in the data. The over-arching code categories in papers 1 and 2 (barriers and facilitators) were developed from the research questions.

As a multi-methods study which recruited interview participants from a larger sample of survey respondents, some analytic interface was present which helped tie in results from the quantitative and qualitative results. Findings from the quantitative analysis of the survey were contextualized by some qualitative findings from interviews. The survey was entirely geared towards exploring women's perceptions of their diagnosis, whereas interviews explored multiple domains including the diagnosis. Qualitative results pertaining to the diagnosis helped provide context on results from the survey (e.g., explaining why participants may have been dissatisfied with certain information provided to them).

3.5 Enhancing methodological rigor

To build my interviewer skills as a novice researcher, I attended qualitative research workshops directed by a member of my TAC who is an expert qualitative researcher. In those workshops, I had practice designing interview guides and participating in mock interviews. Before I began interviewing participants, I practiced for them by role-playing an interview with a friend to help me gain insight of the structure of the interview guide and help me memorize it. Finally, I reflected on my skills and new learnings after each interview.

In qualitative research, the investigator is the research tool and so personal beliefs, attitudes, and positionalities all are potential sources of bias [152, 155]. Through constant reflexivity on positionality, I attempted to identify potential biases and reported them in publishing. During interviews, I disclosed that I did not have PCOS to participants who asked. Participants most often asked such questions towards the end of the interview. Otherwise, what all participants

knew about me and my positionality as an interviewer was that I was a graduate student and had an interest in researching PCOS and women's health.

To enhance credibility and confirmability of findings, I and my supervisor, Professor Yaya, independently analyzed transcripts. When reading transcripts, I looked for disconfirming evidence to improve credibility of findings. Furthermore, I held an ongoing reflective commentary during data analysis to further address implicit beliefs and reveal beliefs underpinning decisions. To improve dependability of findings, an in-depth methodological description of the study was included in each manuscript to allow for peer appraisal and study repetition, and I followed the COREQ checklist for reporting qualitative studies (see Appendix E) [161]. For the quantitative section in paper 1, I used the CHERRIES checklist for reporting e-surveys (see Appendix D) [162].

3.6 Ethics

The University of Ottawa REB granted ethics approval for my thesis research project in April 2018. The ethics file number is H-02-18-359.

To ensure protection of human rights, I remained transparent and reminded participants that their participation was voluntary, and they could withdraw their data at any time before publication. The letters of information for both the survey and interview held all the appropriate information to relay the rights of the participants. Before beginning each interview, I summarized all ethics information and repeatedly let participants know that they could ask to stop the recorder at any time and not answer anything they did not want to answer. In the data analysis and publication of findings, all interview participants were coded under a pseudonym. Nobody except me and my TAC has access to transcripts or any participant's personal information.

Survey participants were automatically anonymized unless they choose to disclose their personal information to enroll in the draw, interview, or wish to hear about the study findings. The personal information disclosed in those 3 fields was kept separate from the rest of survey data and will be disposed of once the draw is completed and I have defended my thesis.

CHAPTER 4: ARTICLE 1

“I felt like she didn’t take me seriously”: A multi-methods study examining patient satisfaction and experiences with PCOS diagnosis in Canada

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4.1 Abstract

Background: Polycystic ovary syndrome (PCOS) is a common and complex condition affecting metabolic, reproductive, cardiovascular, and psychological health in women. Previous studies point to widespread dissatisfaction and delays with the diagnosis of PCOS and a lack of information provision by doctors, with few studies on Canadian populations. This multi-methods study explored the perceptions and experiences of PCOS diagnosis in Canada using an online-distributed survey and follow-up, in-depth, semi-structured phone interviews.

Methods: The online questionnaire was completed by 296 women aged 18-60 with a self-reported diagnosis of PCOS. The survey measured time to diagnosis, number of doctors seen, and information provided. Descriptive statistics, Chi-square tests, Fisher's exact tests, and Spearman's rank correlations were used to analyze the sample characteristics and correlations between the demographic factors and the outcome measures. Twenty-five follow-up interviews were held over the phone and analyzed using thematic analysis and interpretive description methodology.

Results: Survey respondents were dissatisfied with the information provided about PCOS (66%), lifestyle management (34%), and medical therapy (38%) at the time of diagnosis. Approximately 34% of respondents waited for more than 2 years and 41% saw 3 or more doctors before attaining diagnosis. Many did not receive any information about lifestyle management (42%) or medical therapy (28%). Interview participants encountered doctors who lacked sufficient knowledge on PCOS to diagnose, chronically dismissed concerns, and did not provide necessary medical information about the condition. Women described benefitting from self-advocation to receive the care they needed from doctors, and self-educating about PCOS using materials they could find online. Younger interview participants whose symptoms began in adolescence would often not understand the significance of symptoms until much later in life, contributing to delayed diagnoses.

Conclusions: Greater education on PCOS for physicians, particularly in primary care, is needed to prevent delayed diagnoses and ensure that patients are provided with reliable medical information about their condition. Greater awareness of PCOS may be necessary for the general population to help women identify symptoms, especially for adolescents and their parental figures.

Keywords: PCOS; polycystic ovary syndrome; survey; interviews; satisfaction; experiences; diagnosis; barriers; facilitators

4.2 Background

Polycystic ovary syndrome (PCOS) is a common and complex disorder that affects 6%-10% of women of reproductive age [1]. PCOS affects many areas of health and well-being across the life span due to its reproductive, metabolic, and psychological impacts [23]. PCOS is the most common cause of anovulatory infertility [163]. In addition to infertility, patients with PCOS have greater rates of obesity [164], type 2 diabetes [30], metabolic syndrome [165, 166], cardiovascular risk factors such as hypertension [167, 168], poor body image [169, 170], eating disorders [8, 171, 172], anxiety and depression [9, 173, 174].

PCOS is diagnosed most with the Rotterdam criteria when 2 out of 3 of the following features are present with the exclusion of other conditions: polycystic ovaries on ultrasound, biochemical/clinical hyperandrogenism, and oligo-amenorrhea [175]. First-line treatments for PCOS include lifestyle management and oral contraceptive pills [26, 101].

It can be difficult for physicians to diagnose PCOS due to heterogeneity in PCOS presentation [52], complex diagnostic criteria [25], controversial diagnostic criteria for adolescent populations [53, 54], and clinical variability in approaches to the diagnosis [45, 47, 50]. Previous studies investigating patients' experiences of PCOS diagnosis have discovered many cases of delays in diagnosis, patients having to see multiple health professionals, and dissatisfaction with the information provided to them about their condition [12, 16, 18, 44]. Delays in diagnosis and unmet informational needs can have long-term consequences, such as an increase in depression and anxiety symptoms [65] and reduced ability to self-manage and improve lifestyle to prevent comorbidity [12, 55]. Despite these potential impacts, there have been few comprehensive studies investigating diagnosis experience in diverse age groups of patients with PCOS, particularly in Canada.

This study aims to investigate patients' experiences and satisfaction with PCOS diagnosis in Canada, including the information provided and whether their needs at the time of diagnosis had been met, accounting for age considerations. The aim will be explored using a multi-method approach: a survey replicated from Gibson-Helm et al.'s (2017) [12] work and follow-up in-depth telephone interviews to address a need for more qualitative studies of patients' experiences with the diagnosis of PCOS.

4.3 Methods

4.3.1 Study design

A multi-methods approach was taken to explore experiences and satisfaction with PCOS diagnosis: a cross-sectional online questionnaire followed up with semi-structured phone interviews. The target population were women over the age of 18, with a self-declared PCOS diagnosis made by a medical professional in Canada, and who have resided in Canada since their diagnosis. The sample was a convenience sample drawn from online PCOS groups on Facebook, Reddit, and various PCOS online forums.

The online questionnaire was hosted on SurveyMonkey, a website for constructing, storing, and analysing online surveys. This questionnaire was adapted from a PCOS questionnaire previously used in published research [12]. The original questionnaire was distributed worldwide and developed with input from a multidisciplinary expert advisory group and piloted with women with PCOS and the study provided a foundation for further research to investigate diagnosis experiences in specific countries [12]. Permission to replicate the survey was granted by the authors and publisher in June 2018. The survey was modified to include eligibility questions, such as participants having been diagnosed in Canada and residing in Canada. The first author tested the survey for functionality before fielding. No pilot testing was performed.

Although survey-based studies can describe many concerns of women with PCOS, qualitative interviews capture first-hand accounts and experiences which can be missed by solely questionnaire-based studies. Qualitative research is well suited to generate data on perceptions of health experience and perceptions of care [152]. To garner more novel results for this study, follow-up in-depth, semi-structured interviews were conducted to identify factors related to PCOS diagnosis that were not included in the survey. Interviews explored women's perceptions and experiences with the diagnosis and management of PCOS, but only the themes relating to their diagnosis experience are explored in this paper.

4.3.2 Research setting

Survey respondents and interviewees participated from across Canada. Canada is a country with 38,005,238 people as of July 2020, with the 4 most populous provinces being Ontario, Quebec, British Columbia, and Alberta [159]. The three most populous provinces after Ontario

(14,734,01) are Quebec (8,574,571), British Columbia (5,147,712), and Alberta (4,421,876) [159]. Surveys were hosted on SurveyMonkey's Canadian servers and phone interviews were conducted by the first author in a private residential office in Ottawa, Canada.

4.3.3 Participants and recruitment

Eligibility criteria included age ≥ 18 years, a self-reported diagnosis of PCOS made in Canada, having resided in Canada since the diagnosis, and an ability to read and speak English. No upper age limit was established to help promote participation from older patients living with PCOS, in the peri- and post-menopausal stages of life. Participants were 296 survey respondents and 25 interviewees. Participants were recruited through posts on PCOS groups on Facebook, Reddit, and online PCOS forums.[1] The survey was advertised entirely online by the first author posting a short paragraph about the purpose of the study along with a recruitment poster and a link to the survey on SurveyMonkey. The PCOS Awareness Association also helped with recruitment by doing a one-time re-post on their Facebook page with the study's recruitment poster and the survey link. Recruitment took place between April and December of 2018. Social media was used as a recruitment strategy to reach a wider sample from across all Canadian provinces. The advertisement posts directed interested respondents to the participant information statement and the questionnaire on SurveyMonkey. The survey was voluntary and open. Upon completion of the questionnaire, participants had an opportunity to submit their contact information (i.e. name and email) for follow-up interviews. Respondents who indicated interest in being interviewed at the end of the questionnaire were subsequently interviewed remotely, over the phone, on a first come first serve basis until preliminary analysis during data collection suggested thematic consistency across most age groups. Interviews were in-depth and lasted around 1 hour (see Appendix C for interview guide on diagnosis).

4.3.4 Data collection

The e-survey includes questions on demographics, PCOS diagnosis experience, information provided at diagnosis, and concerns about PCOS features. No question was compulsory. The

[1] Recruitment posts included gendered, women-specific language. However, not all people with PCOS may identify as women. Due to our recruitment, we will continue to use gendered language in this publication to reflect our sample.

questionnaire was modified to include screening questions on eligibility criteria (e.g., area of residence, country of diagnosis) to ensure that participants resided in and were diagnosed in Canada. There was a total of 25 items distributed across 5 pages. All items were skippable, and participants were option to use the “Back” and “Next” buttons to review answers. Adaptive questioning was used for a few items to reduce the number of items to fill out where possible. Multiple entries from the same browser were preventing by using SurveyMonkey’s multiple responses option; however, IP addresses were not stored to ensure anonymity. Participants had the option to enter a draw to win 1 of 3 CAD$25 Amazon e-gift cards on the last survey page.

The semi-structured interview guide was developed based on themes and gaps identified in previous literature, and included questions such as, ‘Could you describe a typical day living with PCOS?’ and “How did you first learn about PCOS?” The first author conducted all interviews over the phone in their private residential office with no one else present. Twenty-five interviews were conducted over the phone between October and December 2018, lasted 25–90 min and were audio-recorded and transcribed verbatim. Interviews were capped at 25 once data saturation was reached and no more participants in the 40+ age group were available for interview within the sample. One interview was held over Skype™ due to the participant’s preference. Pseudonyms are used here and in all written documents.

4.3.5 Quantitative data analysis

Statistical analysis was performed with IBM SPSS Statistics for Windows, version 25 (IBM Corp., Armonk, N.Y., USA). Responses from the survey, including incomplete responses, were exported, and analyzed by the first author. Answers that were obviously false or incorrectly inputted were removed prior to analysis (e.g. height and weight incorrectly inputted). Categorical data were presented as count and proportions and continuous data as mean ± standard deviation (SD) if data followed a normal distribution, or median and interquartile range if data did not follow a normal distribution. A p-value of 0.05 was considered statistically significant. Chi-square and Fisher’s Exact tests were performed to test for associations between demographic characteristics and experiences of PCOS diagnosis. Spearman’s rank-order correlations were used to assess correlation within satisfaction ratings if the two variables had a monotonic relationship. Variable distribution in the groups was tested using the Shapiro–Wilk test for normality.

4.3.6 Qualitative data analysis

We coded all qualitative interview data, including field notes made during and after interviews, and managed all data in NVivo 12 (QSR International Pty Ltd. Version 12, 2018). In accordance with Thorne et al.'s (2004) [152] interpretive description methodology, an inductive analysis technique was used to analyze data. Themes were derived entirely from the data. Thorne's (2004) [152] interpretive description approach is widely used in nursing research and does not generate new truths or theories but rather describes thematic patterns and commonalities while also accounting for individual variations and provides a product that clinicians can use as a backdrop for clinical decision-making. Braun and Clarke's (2006) [160] six key stages in the thematic analysis of qualitative data were also followed in this study: (1) Familiarize, (2) Generate initial codes, (3) Search for themes, (4) Review themes, (5) Define themes, and (6) Write up the data analysis. Codes and subsequent sub-categories were generated directly from topics raised in the data. The over-arching code categories (barriers and facilitators) were developed from the research questions.

4.3.7 Trustworthiness

The quantitative study was reported based on the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [162] and the qualitative study was reported based on the Consolidated criteria for reporting qualitative research (COREQ) [161] (please see Appendices D and E, respectively). At the time of the study, the first author was an MSc student conducting in-depth interviews for the first time after training in graduate classes and workshops. The first author identifies as a female, and participants were made aware of the reason for the author to be conducting this research, their personal interest in the research topic, and PCOS status, but otherwise no significant relationship existed or was established between the author and participants. To ensure reliability and validity, the first author considered researcher bias, used the strategies of thick description, development of a coding system, checking and agreement on themes and analysis by members of the team, transparency when reporting research (as per COREQ), and demonstrating the author's interpretive lens throughout the report [152].

4.3.8 Ethical approval and consent to participate

Ethics approval for this multi-methods study was received from the University of Ottawa Research Ethics Boards (REB) in April 2018. Permission to replicate the questionnaire was granted by the authors and Oxford University Press in June 2018. All participants were voluntarily enrolled in the study with free and informed consent. Informed consent for the survey was obtained from all those agreeing to complete the survey. Participants were informed of the purpose of the study, who the investigators were, that their responses will remain confidential and accessible only to the researchers, the length of time of the survey (5-10 minutes), and that by clicking "I agree" and starting the survey, they were declaring consent to participate but could withdraw their data at any time. Participants were informed of all this via the survey welcome page which also held a link to the full implied consent form. The survey data was hosted solely on the first author's SurveyMonkey account on Canadian servers and was password-protected. No personal information was linked to survey results in any way (e.g., contact information to enter the draw). The fully de-identified dataset is kept on password-protected computers.

Interview participants were also informed that once they chose to participate, they could withdraw at any time and/or refuse to answer any questions, without suffering any negative consequences. Permission to audio-record the remote interviews was sought and obtained before data collection. All personal identifiers were removed from transcripts and in quoted texts below. Written or oral informed consent was obtained from all interview participants prior to their participation.

4.4 Results

4.4.1 Socio-demographic characteristics

Advertisement resulted in 397 women accessing the survey, out of which 296 were included in the analysis (response rate of 75%). The rest were screened out due to ineligibility. Mean age of participants was 29 years and median BMI was in the obese range (33kg/m^2; Table 4.1). The results showed that 16.9% of the sample were of average BMI, 0.7% were underweight (BMI<18.5), 18.8% were of average BMI (BMI 18.5-24.9), and 63.6% of the sample were obese (BMI≥30.0), of which 39.5% were class I (BMI 30.0-34.9, moderate), 26.4% were class II (BMI 35.0-39.9, severe), and 34.1% were class III (BMI≥40, very severe). A substantial proportion of the participants was from Ontario (58%), identified as White/Caucasian (80.1%), completed post-secondary education (67%), and were employed for wages (64.2%).

Table 4.1 Demographic characteristics of women with PCOS living in Canada (n = 296)

Demographic characteristic	Number of women (%)
Mean ± SD age in years	29 (6)
Median (interquartile range) BMI (kg/m^2)	33 (11)
Born overseas	31 (10.9)
Province of residence	
Alberta	48 (16.4)
Ontario	170 (58)
British Columbia	27 (9.2)
Quebec	11 (3.8)
Nova Scotia	10 (3.4)
Saskatchewan	10 (3.4)
Other	17 (5.8)
Marital status	
Single	105 (35.8)
Married or domestic partnership	183 (62.5)
Divorced, separated, or widowed	5 (1.6)
Ethnicity	
White/Caucasian	234 (80.1)
Asian/Pacific Islander	24 (8.2)
Black	7 (2.4)
Indigenous	6 (2.1)
Hispanic/Latino	2 (0.7)
Other	19 (6.5)
Education level	
High school diploma	35 (11.9)
Trade/technical/vocational training	27 (9.3)
Associate degree	36 (12.3)
Bachelor’s degree	98 (33.4)
Postgraduate degree	25 (8.5)

Professional degree	10 (3.4)
No formal qualification	62 (21.1)
Work status	
No paid work	35 (11.9)
Student	48 (16.4)
Employed for wages	188 (64.2)
Self-employed	22 (7.5)

4.4.2 Diagnosis Experience

The results indicate that 71.3% of respondents were diagnosed within 5 years of conducting the survey. For 34% of women, diagnosis took >2 years from first seeing a health professional about symptoms and 41% saw 3 or more health professionals before diagnosis. Most women (65.9%) reported being dissatisfied with the information provided at diagnosis. A significant proportion reported receiving no information about lifestyle management (41.9%), and of those women who did, 33.5% were dissatisfied or very dissatisfied with the information. 38.1% of women reported being dissatisfied or very dissatisfied with information given about medical therapy, and 28.1% received no information at all. Finally, 58.8% received no emotional support or counselling after diagnosis, with 27.7% of those who did being dissatisfied or very dissatisfied with it (see Table 4.2).

Table 4.2 PCOS diagnosis experience among women living in Canada (n = 296)

Perceptions of PCOS diagnosis experience	**Number of women (%)**
Time since diagnosis (years)	
≤1.0	109 (39.5)
1.1-5.0	88 (31.8)
5.1-10.0	49 (17.8)
>10.0	30 (10.9)
Time until diagnosis	
Within 6 months	133 (44.9)

Within 12 months	42 (14.2)
Within 2 years	20 (6.8)
More than 2 years	101 (34.1)
Number of health professionals seen before diagnosis	
1-2	175 (59)
3-4	102 (35)
≥5	19 (6)
Satisfaction with diagnosis experience	
Dissatisfied or very dissatisfied	111 (37.5)
Neither	65 (22)
Satisfied or very satisfied	120 (40.5)
Satisfaction with information given about PCOS	
Dissatisfied or very dissatisfied	195 (65.9)
Neither	37 (12.5)
Satisfied or very satisfied	64 (21.6)
Satisfaction with information given about lifestyle management	
Dissatisfied or very dissatisfied	99 (33.5)
Neither	33 (11.1)
Satisfied or very satisfied	40 (13.5)
This information was not mentioned	124 (41.9)
Satisfaction with information given about medical therapy	
Dissatisfied or very dissatisfied	113 (38.1)
Neither	36 (12.2)
Satisfied or very satisfied	64 (21.6)
This information was not mentioned	83 (28.1)
Satisfaction with emotional support and counselling after diagnosis	
Dissatisfied or very dissatisfied	82 (27.7)
Neither	22 (7.4)
Satisfied or very satisfied	18 (6.1)
This information was not mentioned	174 (58.8)

4.4.3 Factors associated with PCOS diagnosis experiences.

Spearman's rank-order correlations determined several statistically significant, positive correlations (all *P* values ≤ .001) between ratings of diagnosis satisfaction (see Table 4.3). Overall satisfaction with the diagnosis was associated with satisfaction with overall information received about PCOS (r_s = .454). Overall satisfaction with information provided about PCOS was associated with satisfaction with information about lifestyle management (r_s = .768), medical therapy (r_s = .618), and emotional support and counselling (r_s = .650). Associations existed between satisfaction with information on lifestyle management and medical therapy (r_s = .650), and between information on medical therapy and emotional support and counselling (r_s = .635).

Table 4.3 Spearman correlation coefficients between selected variables in the study (N = 296)

Variables	Spearman correlations				
	1	2	3	4	5
1. Satisfaction with overall diagnosis	-	0.454**	0.380**	0.346**	0.351**
2. Satisfaction with info received about PCOS		-	0.768**	0.618**	0.655**
3. Satisfaction with info about lifestyle management			-	0.650**	0.583**
4. Satisfaction with info about medical therapy				-	0.635**
5. Satisfaction with emotional support and counselling					-

** p<.001

Chi-square tests determined several correlations between demographics and diagnosis experience (see Table 4.4). Being over 30 years of age was associated with seeing 3 or more doctors (p = .030) and waiting more than 2 years before attaining a diagnosis (p = .008). Participants who saw more than 3 doctors were more likely to wait longer than 2 years for the diagnosis (p < .001) and experience decreased satisfaction with the overall diagnosis (p = .008). Finally, residing in Ontario was associated with greater satisfaction with information provided on lifestyle management compared to all other provinces (p = .028). No significant associations were found between diagnosis experience and BMI, education, employment, and ethnicity.

Not receiving information on lifestyle management was associated with also not receiving information on medical therapy ($p < .001$) and emotional support and counselling ($p < .001$) (See Table 4.5). Not receiving information on lifestyle management was associated with greater dissatisfaction with overall diagnosis ($p = .004$) and information received about PCOS ($p < .001$). Missing information on medical therapy was also associated with greater dissatisfaction with the diagnosis ($p=.033$) and information received about PCOS ($p = .001$). Finally, participants who did not receive emotional support or counselling were also more likely to be dissatisfied with the overall diagnosis ($p = .015$) and information received about PCOS ($p = .002$), suggesting that these individual factors may be important to the diagnosis experience.

Table 4.4 Chi-square results between socio-demographics and experience of diagnosis.

Variables	**Time to diagnosis**				**Number of doctors seen**				**Satisfaction with overall diagnosis**				**Satisfaction with info received on PCOS**				**Satisfaction with info received on lifestyle management**			
	<2 years n(%)	**>2** years n(%)	**Total** n(%)	**X^2; p-value**	**<3** doctors n(%)	**>3** doctors n(%)	**Total** n(%)	**X^2; p-value**	**Satisfied** n(%)	**Dissatisfied** n(%)	**Total** n(%)	**X^2; p-value**	**Satisfied** n(%)	**Dissatisfied** n(%)	**Total** n(%)	**X^2; p-value**	**Satisfied** n(%)	**Dissatisfied** n(%)	**Total** n(%)	**X^2; p-value**
Age																				
<30 years old	108 (65.1)	58 (34.9)	166 (100)	7.016; .008*	106 (63.9)	60 (36.1)	166 (100)	4.701; .030*	71 (53)	63 (47)	134 (100)	.197; .657	37 (25.5)	108 (74.5)	145 (100)	.265; .607	21 (14.9)	120 (85.1)	141 (100)	.007; .935
>30 years old	62 (49.6)	63 (50.4)	125 (100)		64 (51.2)	61 (48.8)	125 (100)		47 (50)	47 (50)	94 (100)		25 (22.7)	85 (77.3)	110 (100)		17 (14.5)	100 (85.5)	117 (100)	
Province																				
In Ontario	97 (57.1)	73 (42.9)	170 (100)	.703; .402	100 (58.8)	70 (41.2)	170 (100)	.015; .904	66 (50)	66 (50)	132 (100)	.468; .494	38 (26.2)	107 (73.8)	145 (100)	.397; .529	29 (19.5)	120 (80.5)	149 (100)	4.824; .028*
Outside Ontario	78 (61.9)	48 (38.1)	126 (100)		75 (59.5)	51 (40.5)	126 (100)		54 (54.5)	45 (45.5)	99 (100)		26 (22.8)	88 (77.2)	114 (100)		11 (9.6)	103 (90.4)	114 (100)	
Number of doctors seen																				
<3 doctors n(%)	140 (80)	35 (20)	175 (100)	77.214; <.001**	-	-	-	-	79 (59.4)	54 (40.6)	133 (100)	6.971; .008*	37 (24.2)	116 (75.8)	153 (100)	.056; .813	23 (14.6)	134 (85.4)	157 (100)	.095; .758
>3 doctors n(%)	35 (28.9)	86 (71.1)	121 (100)		-	-	-		41 (41.8)	57 (58.2)	98 (100)		27 (25.5)	79 (74.5)	106 (100)		17 (16)	89 (84)	106 (100)	

*p<0.05.
**p<0.01. No significant associations were found between ethnicity, education level, BMI, employment, and experiences of diagnosis.

Table 4.5 Chi-square results between selected variables and experience of diagnosis.

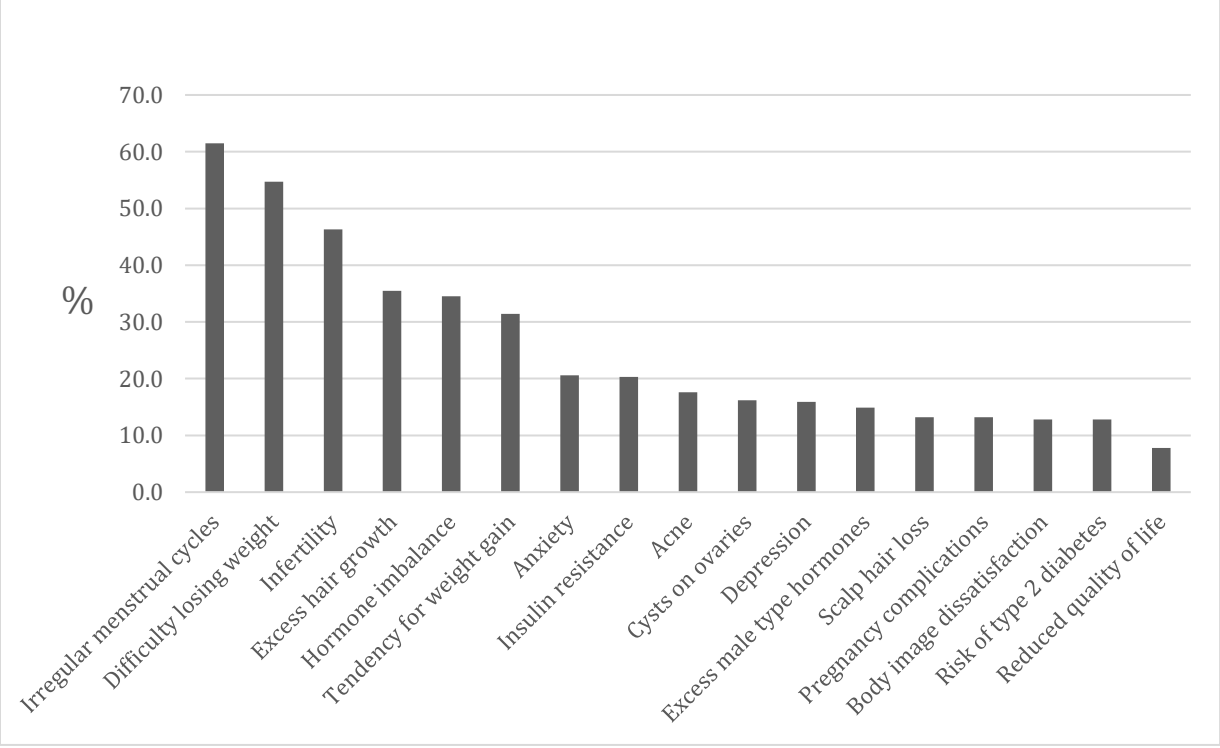
Variables	Satisfaction with overall diagnosis				Satisfaction with info received on PCOS				Received info on medical therapy				Received emotional support and counselling			
	Satisfied n(%)	**Dissatisfied** n(%)	**Total** n(%)	**X^2; p-value**	**Satisfied** n(%)	**Dissatisfied** n(%)	**Total** n(%)	**X^2; p-value**	**Yes** n(%)	**No** n(%)	**Total** n(%)	**X^2; p-value**	**Yes** n(%)	**No** n(%)	**Total** n(%)	**X^2; p-value**
Received info on LM																
Yes	82 (59.9)	55 (40.1)	137 (100)	8.430; .004**	54 (36.7	93 (63.3)	147 (100)	26.418; <.001**	152 (88.4)	20 (11.6)	172 (100)	52.972; <.001**	106 (61.6)	66 (38.4)	172 (100)	68.123; <.001**
No	38 (40.4)	56 (59.6)	94 (100)		10 (8.9)	102 (91.1)	112 (100)		62 (50)	62 (50)	124 (100)		17 (13.7)	107 (86.3)	124 (100)	
Received info on medical therapy																
Yes	94 (56.3)	73 (43.7)	167 (100)	4.547; .033*	56 (30.4)	128 (69.6)	184 (100)	11.192; .001**	-	-	-	-	116 (54.2)	98 (45.8)	214 (100)	50.911; <.001**
No	26 (40.6)	38 (59.4)	64 (100)		8 (10.7)	67 (89.3)	75 (100)		-	-	-		7 (8.5)	75 (91.5)	82 (100)	
Received emotional support & counselling																
Yes	59 (61.5)	37 (38.5)	96 (100)	5.952; .015*	36 (35.0)	67 (65.0)	103	9.640; .002**	-	-	-		-	-	-	-
No	61 (45.1	74 (54.9)	135 (100)		28 (17.9)	128 (82.1)	156 (100)		-	-	-		-	-	-	

*p<0.05.
**p<0.01. No significant associations were found with demographic variables such as age, province, ethnicity, education level, BMI, employment.

4.4.4 Key concerns about PCOS

Women were asked to select “the four key clinical features of PCOS that are most important to you.” Figure 4.1 displays top 17 concerns most selected by participants (%). Overall, irregular menstrual cycles (61.5%), difficulty losing weight (54.7%), infertility (46.3%), and excess hair growth (35.5%) were the most selected features. Hormonal and metabolic PCOS features were among the top concerns for participants. Features affecting mental health and well-being were substantially picked: anxiety (20.6%), depression (15.9%), body image dissatisfaction (12.8%), and reduced quality of life (7.8%). Other answer options included migraines (6.8%), ovarian cancer (6.1%), endometrial cancer (5.4%), improvement of symptoms after weight loss (4.7%), premenstrual syndrome (4.4%), increased cardiovascular risk factors (4.4%), and fatty liver (4.1%) (Fig. 1).

Figure 4.1. Key clinical features of PCOS most important to participants (n = 296).



4.5 Results

The interview sample of 25 participants included mostly White/Caucasian women mainly born in Canada, with a few born in the US but residing in Canada for a long period of time (please see Table 4.6 for demographic characteristics). Most participants were between the ages of 25-30, resided in Ontario, and were employed full-time. Seven participants had children, and nine participants were looking to conceive at the time of the interview. All participant names presented in this article are pseudonyms.

Table 4.6 Demographic characteristics of interview participants (n = 25)*

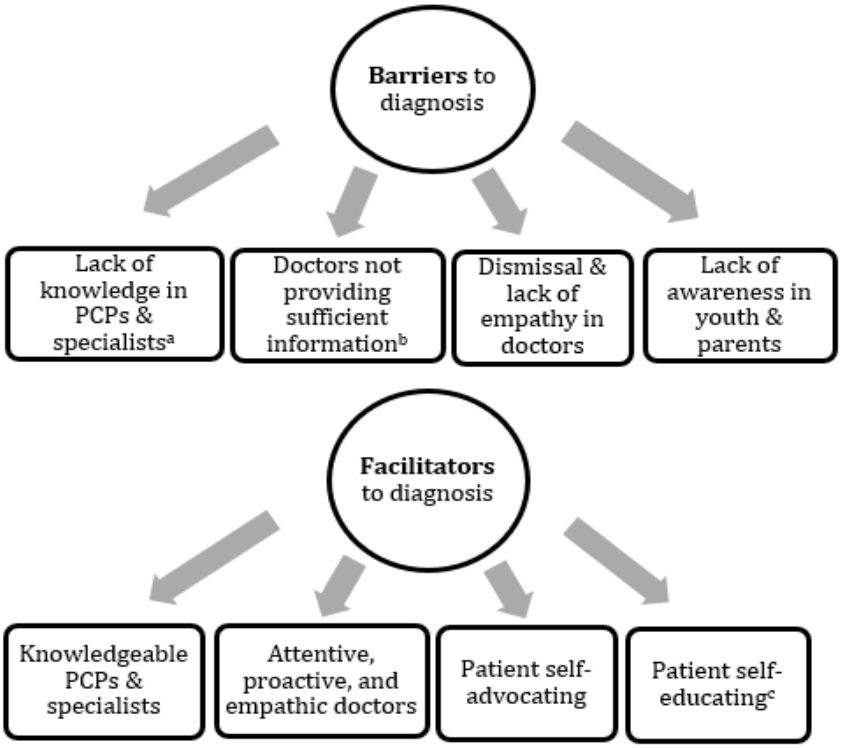
Demographic characteristic	Number of women (%)
Age group	
18-24	5 (20)
25-30	10 (40)
31-36	4 (16)
37-40	2 (8)
41-50	2 (8)
51-66	1 (4)
Province of residence	
Alberta	4 (16)
British Columbia	4 (16)
Ontario	13 (52)
Quebec	1 (4)
Ethnicity	
Black	1 (4)
East Asian	2 (8)
Middle Eastern	2 (8)
South Asian	2 (8)
White/Caucasian	18 (72)
Marital status	
Single	11 (44)
Common-law/live-in partner	5 (20)
Married	9 (36)
Education level	
Bachelor's degree	12 (48)
Master's degree	3 (12)
Trade/technical/vocational training	2 (8)
Parents or looking to conceive	

No children	18 (72)
Has children	7 (28)
Looking to conceive**	9 (36)
Pregnant	2 (8)
Work status	
No paid work	3 (12)
Student	7 (28)
Employed full-time	12 (48)
Employed part-time	1 (4)
Self-employed	2 (8)

*Note: based on information participants were comfortable divulging, not all participants are captured.
**Participants who were actively looking to conceive at the time of the interviews.

Barriers were identified as factors external or internal to participants which affected the experience of the diagnosis negatively (e.g., by delaying diagnosis or worsening the experience of the diagnosis). Facilitators were identified as factors external or internal to participants which affected participant's experience of the diagnosis positively (e.g., by quickening diagnosis or positively affecting participant experience). Figure 4.2 outlines major themes found.

Figure 4.2. Barriers and facilitators to satisfactory diagnosis experience.



[a]Sub-theme of attributing all symptoms to weight instead of potential PCOS.
[b]Sub-themes of not providing enough information on PCOS risks and mental health.
[c]Sub-themes include self-education pre- and post-diagnosis.

4.5.1 Barriers to a satisfactory diagnosis experience

4.5.1.1 Lack of knowledge in primary care physicians (PCPs)

One of the biggest barriers to a prompt and accurate diagnosis of PCOS arose when participants encountered physicians who appeared to lack sufficient knowledge of PCOS. Many participants described instances where physicians failed to identify the significance of symptoms brought up, did not order tests for their patients to rule out PCOS and/or other conditions, and even missed opportunities to refer the patient to a specialist, such as a gynecologist or endocrinologist. Participants who had physicians who lacked knowledge about PCOS would experience a lot of confusion and face delayed diagnoses, waiting months to years at a time. Of

survey respondents, 34% waited more than 2 years before attaining a diagnosis – a lack of knowledge in physicians may have explain that finding.

Josie, aged 27, recounted facing barriers with her General Practitioner (GP) in British Columbia. Josie experienced menstrual irregularities since adolescence, but her GP had not seemed concerned with any symptoms Josie would bring up. Finally, after many years of frustrating dismissals, Josie convinced her GP to refer her to a gynecologist. Josie described:

"I just had enough dealing with my women problems, whatever you want to call it, my menstrual problems, that kind of stuff. I had been trying to get my doctor to figure stuff since I was 15. 14 or 15 I knew there was something wrong because I'd never had a regular cycle since I hit puberty, started my period at 12 years old. Never had a regular cycle. I always thought it was just me, I know my mom has some sort of blood clotting disorders that she's been diagnosed with. And I thought maybe I was susceptible to blood clotting issues, you know. My doctor never really was concerned about anything, it didn't seem to me that way. Finally, when I was 24 I told her like "I just need you to send me to a gynecologist and to help me." And that's what she did. So, I got myself referred to a gynecologist at 25 actually. And then I got an IUD to help with my cycles."

Although Josie's GP was well-meaning, she appeared to have inadequate knowledge about PCOS to help with a diagnosis. Josie explained:

"I just struggled with my cycles and stuff and she never seemed concerned about anything really. I guess being on birth control, some doctors don't like women to be on that if they don't have to be. She just kind of avoided everything possible before finally referring me to a gynecologist. I don't know what the reasoning was behind it, I never really asked. She just seemed to avoid everything. Maybe she doesn't know much about PCOS."

A common sub-theme occurred within participants who were overweight – some doctors assumed that symptoms (e.g., irregular periods) were caused by excess weight and did not test for PCOS. Emma, aged 29, was diagnosed by accident after not being able to feel the strings of her IUD and going in for an ultrasound to locate the IUD. Her doctor noticed cysts on her ovaries which spurred him to diagnose her with PCOS. For years prior, Emma had experienced significant and unexplained weight gain, facial hair, and irregular periods, but when she brought up her concerns, her doctors attributed a lot of them to her weight. Emma explained:

"I gained a severe amount of weight, I gained I think... I was 115 pounds when I was 18 and by 23, I was 200 pounds. So clearly looking back at my diet it wasn't great, but it wasn't that severe of a diet shift. So, I just assumed this is what I have, this is the body I have. And it was only because I had the ultrasound for something else that they diagnosed me. Had I not had that ultrasound, I think I would still have the cysts, I just don't think they would have diagnosed me with them, they would have kind of "oh yeah you're just doing this and this" and "oh yeah you're hysterical" or whatever. "That's just how your body is, try diet and exercise." Which is funny, because as soon as I went on metformin, I lost 30 pounds."

PCOS occurs on a spectrum; some participants can be lean and still have PCOS. Doctors who misattributed their patient's weight to be the cause of symptoms may not have had enough knowledge on PCOS presentation. Lucy, aged 27, was another participant who expressed frustration at her GP delaying diagnosis due to the lack of knowledge on PCOS presentation:

"Well, this is the most common reaction was "you're overweight and that's the problem." Honestly, I feel that any time any of those symptoms were brought up, the only focus was on my weight. Rather than it being a symptom, that's the cause of all my health problems."

To sum up, a common barrier to diagnosis for participants occurred when PCPs lacked sufficient knowledge on PCOS to identify key symptoms and test for PCOS. For overweight

participants who faced this barrier, unknowledgeable PCPs posed a barrier when they overly attributed all their symptoms on weight instead of testing for PCOS.

4.5.1.2 Physicians not providing sufficient information.

A lot of participants described needing more information at the diagnosis than they had received. They left without fully understanding the impact of PCOS, what their futures might look like, or what complications they may need to look out for. In addition, many were diagnosed but not informed about the specifics of their condition. Similarly, most survey respondents (66%) were dissatisfied with the overall information given to them about PCOS. In some cases, tests to check for insulin resistance or hyperandrogenism were not conducted, and if they were, some patients were not informed of the results of those tests.

Bianca, aged 36, was diagnosed after trying to conceive but not getting any periods after coming off birth control. Although Bianca had a great experience in finding a knowledgeable GP who quickly diagnosed her in 3 months after running some tests, she explained that missing information at the diagnosis still posed a barrier to her feeling well-equipped to deal with her condition. She reflects on how she needed more information than what she was offered:
“The most negative part of the diagnostic experience was probably the lack of answers and information. So, it was “let's do this test, let's do that test” but there wasn't a whole lot of talking it through. And with something like PCOS, I had no idea about it. I think a lot of people don't, unless they know somebody or are somebody who is dealing with it. So I think communication at the outset was lacking and I think that's probably the worst part of it because when you're dealing with the unknown when you're trying to figure this out… for me the more information the better. And I didn't feel like I was given as much as I potentially could have been.”

Many participants were not told of the full expanse of what PCOS may impact. Excerpts of the responses provided by three of the participants are as follows:

Jamila, aged 26: "Like recently I found out that insulin resistance is one of the symptoms of PCOS. But I didn't know it was related."

Fiona, aged 31: "She didn't say anything to me about the potential side effects because I don't even know if she knew about them or if she did, I don't know. She never mentioned anything."

Vanessa, aged 63: "He just said I probably couldn't have children. That was about it."

Participants who encountered physicians who provided little information to them would leave the doctor's office ill-equipped to manage their condition when they were not even fully aware of its significance. Holly, aged 29, looking back on her diagnosis, felt that the lack of information provided to her led her to not take her condition as seriously and start on management. She explained:

"So, if my doctor had communicated to me that I might have trouble having kids in the future, I might have taken it more seriously when I was first diagnosed."

Margaret, aged 33, received little information from her first GP who diagnosed her.

Margaret was able to find another GP many years later who was able to give her more information and guidance. But one thing was still missing: information about how PCOS can impact mental health. Margaret explained:

"I wish she would have maybe talked about more like the risk. I just kind of like those little satellite things that are kind of offshoots because I think that those tend to be more of the symptoms that I deal with. Like it's the higher risk for depression and anxiety and that's something that I have trouble with. Particularly the anxiety. Or like I sort of mentioned before, the tendency to binge eat because I have that problem as well. And so those were things that I didn't realize were related until I started looking into it a little bit deeper."

In fact, Margaret was not the only participant whose doctors did not touch on mental health. Many participants had doctors who not only did not offer information on the mental health impacts of PCOS, but in general never touched on mental health during visits. Survey responses indicated that many women found mental health-related impacts of PCOS concerning, such as anxiety (21%) and depression (16%). Participants often discovered the link between PCOS and mental health on their own, as Margaret did during her research. Down the line, a lack of information at the diagnosis can impact how successfully women can manage their PCOS. If a patient is presented with an incomplete picture of their condition, they can go for many years underestimating the management efforts they may need to undertake.

4.5.1.3 Dismissal & lack of empathy in physicians

Another barrier in the diagnosis experience arose when participants encountered little empathy from doctors. Feelings of being dismissed, not listened to, and talked over were prominent and led to a perception of low empathy and lack of concern from doctors. Very few survey respondents (6%) were satisfied with the emotional support or counselling provided to them. Low levels of knowledge on PCOS may have contributed to a doctor's dismissal of concerns, but the problem was compounded in many cases by apparent lack of empathy and unwillingness to really listen to and understand patient concerns. In many cases, lack of empathy and dismissiveness significantly affected doctor-patient interactions and trust levels.

Lizzie, aged 27, was 12 when she initially brought up her symptoms and concerns to her pediatrician, and each time her concerns were dismissed, leaving her at a loss. She explained:

"Just being as young as I was and not knowing what was going on, and them not even knowing how to explain it. Every time I would go into the doctors and they'd be like "nothing's wrong" I'd leave thinking "did they not tell him how bad it is? Like am I covering it up, am I imagining it

worse than it really is?" So yeah, that was the biggest thing, "well what am I doing wrong? Why does nobody want to help me?""

Lizzie was later diagnosed at age 16 when she switched doctors. Her initial GP provided little information, but mostly the lack of empathy to Lizzie's concerns at the time affected her experience and left her feeling unsupported.

Josie, aged 27, also did not receive the level of support that she would have liked from her doctor and perceived her doctor to put little effort into understanding Josie's experience. Josie explains her thoughts and feelings at the time:

"For me, I didn't really know what to do. I didn't really know what PCOS was. I had kind of questioned my doctor's like willingness to help and dig deeper into my issues. For the most part, she doesn't really dive deep into finding out why the issues are happening… With my GP, I didn't feel very supported at all. I didn't feel like she really tried very hard to figure anything out. Whether that was not enough time, maybe she didn't really suspect PCOS or… you know I'm giving her the benefit of the doubt in that situation. I didn't feel supported."

Holly's, aged 29, doctor was not knowledgeable about PCOS and who did not seem to take her seriously and dismissed Holly's concerns:

"I just felt that she didn't care - not that she didn't care because I know doctors don't necessarily always have the best bedside manner. But I felt like she didn't take me seriously and that she kind of brushed off what was going on with me."

This theme of diminished empathy and brushing off patient concerns was prevalent in many participants' experiences and a significant barrier in the experience of receiving a diagnosis. Doctors who did not take the time to truly listen to and understand patient concerns displayed a lack of empathy which left many participants unsupported during a health challenge.

4.5.1.4 Age considerations: lack of awareness in youth and parents

Patients who experienced PCOS symptoms from a young age would often recall not knowing that their symptoms were abnormal or something to be concerned about at the time. The lack of awareness and concern over early symptoms led many younger participants to underrecognize the significance of certain symptoms and not bring it up at appointments, contributing to delayed diagnosis. This lack of awareness was understandable as none of the participants (or their parental figures) recalled being educated on PCOS and women's health conditions throughout their schooling years or in mainstream media.

Margaret, aged 33, officially started to notice her symptoms and became concerned over them in her early 20s, when her periods became very irregular and she noticed unusual hair growth, which led her to reach out to health professionals. However, looking back she began experiencing odd symptoms at puberty, but recalled not being able to recognize them as concerning due to her own lack of knowledge:

"I would have been like 22 or 23-ish. I was young. I remember being young. And yeah, like I said that was kind of when I really started to notice that there was something off. And if I really sort of think back to when symptoms started, it really would have been obviously around puberty. I sort of gained a whole bunch of weight. I think I packed on like 60 pounds in a year or so. But so much of that I think got played off as just kind of being a teenager. But now kind of looking back on it, it's just like oh no, this was kind of when those symptoms really started to present themselves. I just didn't have any knowledge of it at the time."

Margaret's mom was coincidentally a nurse, but she also did not have enough knowledge to guide her daughter to the physician's office for examination. Margaret recalled:

“Yeah, I don't really know why that would have been something that didn't get brought up at the time. Particularly like my mom is a nurse, you’d think she would mention it. But I mean I don't know. Maybe she was just hoping that it wouldn't be something that affected me, kind of a thing.”

Vanessa, aged 63, had heavy, painful periods ever since puberty which she started a bit early at 11. She remembered bringing up her menstrual problems to her stepmom, but her concerns went unrecognized. Vanessa recounted the interaction:

“And she kind of just brushed it off like “whatever.” To her it was just that was the word for having really bad periods. So, I kind of felt like I was making too big of a deal about it so I let it go for about ten years. And didn't really find out what it was until I was 30.”

Many participants in general had little awareness of PCOS and other women’s health conditions before becoming diagnosed. Emma, aged 29, reflected on why PCOS might not be taken seriously:

“It's just- I feel like it's either seen as no big deal because it's very common or it's just not taken very seriously because either it's a woman's issue or it's just... there are so many other issues that are more glamorous and kind of take the forefront that people actually want to focus on. But I don't really know.”

To sum up, many participants did start having concerning symptoms early in youth, but their own lack of awareness about their symptoms and women’s health conditions in general caused a barrier to seeking medical care and achieving a diagnosis. Not being aware of PCOS and similar women’s health conditions in youth led many participants to not realize the potential significance of their symptoms and delay going in for a check-up. Similarly, the parental figures of many younger participants were not concerned about their child’s symptoms, again mostly

due to a lack of knowledge. In these cases, parents were not able to encourage their daughters to visit the doctor.

4.5.2. Facilitators to a satisfactory diagnosis experience

4.5.2.1 Knowledgeable PCPs & Specialists

One of the facilitators to the diagnosis was the availability of knowledgeable doctors who were able to quickly diagnose PCOS once the patient presented their symptoms and provide enough information about PCOS to their patient. Some doctors were able to diagnose solely based on the symptoms and some ran further tests. As the first point of contact in the healthcare system, PCPs who were knowledgeable about PCOS acted as great facilitators to a speedy diagnosis, because they did not need to refer patients out and add weeks/months of waiting time.

Pam, aged 28, was one participant who had a great experience of achieving a quick diagnosis due to having a very knowledgeable GP at her local university clinic. After coming off birth control in her late 20's she found that her period ceased to occur without it. Pam recounted:

"So, when I went to my appointment and explained that I hadn't had a period in a year, they suggested I go for some blood tests and get all my systems checked up. Just to make sure all the levels were normal in my blood… Once I brought it up, they gave me a diagnosis within 2 weeks of that first appointment."

Pam was able to find a team of physicians who identified the significance of her symptoms and were able to diagnose her. Pam appreciated the amount of information she was able to receive as well:

"They gave me a whole bunch of handouts to read about PCOS... I think it's just my personality that I wanted a lot of information. So yeah, they gave me enough information but I was just

presented with this new thing that I didn't know anything about so I just wanted to learn as much as I could so I could understand what I was up against."

In cases where PCPs had to refer patients out to see specialists (e.g., OB-GYNs, fertility doctors, endocrinologists), knowledgeable specialists were a great facilitator to diagnosis because they would be able to quickly diagnose PCOS and could provide a lot of information about PCOS at the time of diagnosis.

Josie, aged 27, had a very tough time getting her GP to take her symptoms seriously. Since the age of 14 or 15 she felt something was wrong because of her irregular cycles. Her GP *"never really was concerned about anything, it didn't seem to me that way.*" At age 24, she felt the urgency to push her GP to send her to a gynecologist. She had started to experience cystic acne and hirsutism. At age 25, Josie's experience with her gynecologist was very positive:

"And she actually was very helpful, she right away, she knew without asking me anything, she knew the physical signs of PCOS. She explained how PCOS works, basically explained all the symptoms. And she could tell by asking me questions and me telling her about my history, she just knew right away what it was that I had and diagnosed me with it. She was super helpful."

To sum up, for participants who had positive experiences with their diagnosis, some of the biggest facilitators were the availability of knowledgeable PCPs and/or specialists who could provide a quick and informative diagnosis. In cases of knowledgeable PCPs, an added benefit occurred for participants who did not have experience long wait times associated with specialist referrals. This facilitator may have factored into the 40% of survey respondents who were diagnosed within 1 year and satisfied with their overall diagnosis experience.

4.5.2.2 Attentive, Proactive, and Empathic Doctors

Another facilitator to the diagnosis was the availability of doctors who were attentive to the concerns patients brought, proactive about providing referrals or running tests, and empathic when interacting with patients. Attentive, proactive, and empathic doctors included both PCPs and specialists and a defining feature of those doctors were their ability to start acting on a patient's concern and provide them with resources so that they are diagnosed, even when these doctors alone did not have adequate knowledge to diagnose PCOS themselves and had to research and follow-up on symptoms.

Margaret, aged 33, had a long journey to her diagnosis - it took her 10 years to find the doctor who would be able to diagnose her. She brought up her symptoms with all the doctors but felt that they would just brush it off. She had *"given up on sort of getting anybody to really take it seriously."* In her early 20s she came across a doctor who acknowledged that she most likely had PCOS but did not discuss it further other than prescribing birth control. Margaret moved around a lot in her 20s and felt that every time she brought up her PCOS *"it was always just kind of accepted and nobody really questioned it or really offered any kind of support."* That is until Margaret found her latest GP.

Margaret remarked how her latest doctor *"was the first one to really highlight to me just like the importance of you know with this condition you have to be making sure that you're eating right and that you're exercising and you're at this extra risk for all of the type 2 diabetes and stuff like that."* Margaret had seen 3-4 physicians since her early 20s and only her latest GP provided her with sufficient information and ran tests. Margaret described how her GP helped her take her condition seriously:

"The information from my most recent GP that actually did the diagnosis was probably the most helpful to me based on the fact that it kind of spurred me to really look into and kind of understand something that I kind of didn't really take seriously before."

Josephine encountered many doctors on her journey to her diagnosis and perceived most to be unknowledgeable about PCOS. Although that aspect was frustrating for her, Josephine appreciated the empathy present in their interactions and felt supported regardless:

“The doctor in fact at the fertility clinic was very gentle and I have a very good impression with him. So, most of the time, health professionals I think are very good. But yes, sometimes they don't know about everything. But yeah, during my diagnostic, yes the doctor was good. And the people that I've seen in the hospital, they were very gentle, and I had a very good impression.”

To sum up, participants appreciated physicians who were able to display empathy and be attentive and proactive when addressing concerns. Even when physicians did not know much about PCOS, participants still felt supported when encountering their attentiveness, empathy, and proactiveness.

4.5.2.3 Self-Advocating

In cases where participants felt that their concerns were not taken seriously and a diagnosis was evading them, a great facilitator to the diagnosis was their own ability to self-advocate - in a sense to push to be taken seriously and to get the doctor to take their symptoms seriously and/or refer them out to a specialist. Participants had to self-advocate mostly with PCPs but some participants had to self-advocate with specialists too who were unsure of what to do. Older participants often portrayed a greater motivation to self-advocate, usually due to increasing concerns with health and aging or when pursuing conception.

Mary, aged 27, had a unique case of PCOS where her symptoms started after the birth of her first two children. Mary found that her doctors were hesitant to investigate her concerns, possibly because Mary was still breastfeeding. But Mary persisted and eventually persuaded them for a referral:

“Oh yeah, I was really really really aggressive about it. They were not - based on the blood work they were going to send me away, but I had to be. And honestly it was just because I really wanted another baby. So, I was kind of having to really advocate for myself because I knew… because they just looked at me like “okay well you're breastfeeding, so that's the reason for your issues.” Which I found in general there's a lack of knowledge for breastfeeding women and when it comes to PCOS there's some overlap there because they definitely just blamed it on “oh that's what's messing up your hormones.” Even though the hormones of breastfeeding and your period managing hormones or whatever, are not the same. So, they had a lot of confusion, I just had to really push them to kind of get that referral. The nurse that I’d seen was originally very hesitant towards referring me. Which is so crazy because if I wasn't trying to have a baby I wouldn't know to this day that I have PCOS.”

Mary was very motivated to push for herself and advocate for her concerns because she wanted to conceive again. Her efforts to self-advocate paid off and led to a diagnosis of PCOS which allowed her to take charge of her health and aid her in her quest to conceive. At the time of the interview, Mary had become pregnant after being prescribed clomiphene. Mary explained how attaining a diagnosis finally allowed her to feel less lost and out of control and helped her get pregnant again:

“The most positive part about it was that I was able to figure out what was going on with my body and that I was able to be properly treated to get pregnant because that's really what was motivating me. I started to feel really kind of lost about not having a period and not really having it in my control. So even though I wasn't really given a lot of resources, I feel like once I knew what was going on I was kind of able to advocate for myself enough to get those resources and yeah, just getting pregnant, honestly.”

Lucy, aged 49, explains that her doctors seemed to not take her concerns seriously since she had given birth twice. One of Lucy's sisters went through a remarkably similar experience getting diagnosed with PCOS and having to self-advocate. Lucy described:

"She had the same issue I did, in that it was very difficult. She had to fight for a diagnosis. Amazingly enough, like she's in her 30s now, it's only recently that she was diagnosed with PCOS even though she's known that she's had it for years. It just took them forever to admit it. And that was the same with me. They wouldn't even look at me initially and consider that I had PCOS because I already had two children."

Like Lucy, many participants shared the stories they heard about other women having to self-advocate and push to get the resources they needed for the diagnosis. Self-advocating, in cases where knowledgeable and proactive doctors were unavailable, proved to be a significant facilitator in achieving a diagnosis. Attaining a diagnosis aided participants in feeling empowered and able to take charge of their health in many ways, such as by getting them started on treatments to address their symptoms, undertake the necessary lifestyle changes, and allowing them to feel less lost and out of control about what was happening to their bodies.

4.5.2.4 Self-Education

Self-education pre- and post-diagnosis was a significant facilitator for many participants who lacked sufficient information from medical providers. Many participants benefited from a period of self-education when encountering unknowledgeable doctors who could not diagnose their symptoms. Usually frustrated with the lack of helpful information from doctors, participants started to learn more about the potential causes to their symptoms on their own. Whether it was through reading up about their symptoms online, talking to friends, or joining online mailing lists/groups, participants were able to self-educate and attain a diagnosis after presenting new

knowledge to their doctors. In other cases, participants who were able to get diagnosed but did not receive enough information from their doctors benefited from self-education post-diagnosis.

Melissa had struggled with her weight all her life, and after having her first child in her 20s she struggled to get pregnant again and her periods became increasingly irregular. She experienced many miscarriages and noticed facial hair and skin tags. Melissa's GP at the time attributed all her symptoms to her weight, instead of testing for PCOS. Melissa described:

"My GP that I had, any time I brought up any concerns about any concerns I had about my body, she would say "lose weight and you'll be fine, you're just overweight." Eventually, I just had to fire her, I didn't really feel safe with her."

Melissa's GP was unable to provide her with relevant information, so Melissa reached out to a friend with PCOS and learned more about her symptoms:

"I spoke to a girlfriend who had been diagnosed with PCOS and she suggested that I talk to my reproductive endocrinologist (RE) about the possibility that I have PCOS because of all the symptoms I had. So, when I went to see the RE, I mentioned to her that I was concerned that I may have PCOS because of my symptoms, my lack of ovulation which is kind of like the lack of periods. So, she sent me for assessing blood tests to check my insulin resistance, and she said based on my results and my symptoms, she was diagnosing with PCOS."

Due to Melissa's efforts to self-educate with the help of a friend, she learned more about what may be causing her symptoms and was able to achieve a diagnosis with an RE, despite having an unknowledgeable GP.

Bianca's, aged 36, GP was knowledgeable enough to diagnose her with PCOS quickly. The only thing lacking from her GP was sufficient information about PCOS, but Bianca was able to delve into what it meant to have PCOS with self-education.

“I mostly did a lot of online research. First, I try to see what kind of medical articles I could get my hands on to see what's going on. Especially when I was trying to conceive and what works better for women with PCOS in terms of ovulating and things like that. But I also at the beginning spent a lot of time on the Soul Cysters web site and I find that really really good as a source of information... It was a good collective source of information.”

Sources of information for participants varied, with many participants recognizing that not all information online was reliable, but still valuable to sort through because that was often the only source of information for participants to access. Self-education pre-diagnosis aided participants who were faced with unknowledgeable doctors and facilitated their journey to their diagnosis. Self-education post-diagnosis helped participants piece together and understand their condition better when they did not receive sufficient, or any, information from physicians. Many survey respondents (42%) reported receiving no information on lifestyle management and a smaller subset (28%) did not receive any information about medical therapy.

4.6 Discussion

Most interview participants expressed frustration at how few medical professionals they encountered had substantial knowledge and information about PCOS to provide, which ended up being a significant barrier in their diagnosis journeys. Survey findings included a majority (65.9%) reporting being dissatisfied with the information provided at diagnosis. A significant proportion of participants received no information about lifestyle management (41.9%), and of those who did, 33.5% were dissatisfied or very dissatisfied with the information. About a third (38.1%) of participants reported being dissatisfied or very dissatisfied with information given about medical therapy, and 28.1% received no information about medical therapy at all. These survey findings closely resemble the satisfaction scores from other surveys done on PCOS populations in Australia and internationally [12, 44].

During the interviews, numerous participants expressed leaving the doctor's office none-the-wiser about the impacts of PCOS. Participants reported not learning about the associations between PCOS and insulin resistance, weight gain, and even infertility. These sub-themes may help explain why 65.9% of survey respondents were dissatisfied or very dissatisfied with the information provided to them at the time of diagnosis. Participants tended to learn about those impacts on their own, during self-education post-diagnosis. Similar findings were reported on the gaps in information patients receive about PCOS in the doctor's office, with many recommendations to include pamphlets or other summative informational sources about PCOS so that patients can have access to credible medical information at the time of diagnosis [12, 15, 16, 18, 44, 56, 82, 98, 176].

A sub-theme was identified under the larger barrier of not receiving sufficient information: participants reported physicians not screening for or acknowledging mental health. Top key features most important to participants included several mental health-related symptoms: anxiety (20.6%), depression (15.9%), and body image dissatisfaction (12.8%). A majority (58.8%) of survey participants did not receive emotional support and counselling at the time of diagnosis, and of those who did, 27.7% were dissatisfied or very dissatisfied. Almost none of the 25 interview participants recounted their medical professionals asking about their mental health or providing information about PCOS impacts on mental health. Several participants expressed needing information from their provider on the potential mental health impacts of PCOS, such as the increased risk for eating disorders [8, 172], and anxiety and depression [9, 173, 174]. For participants with eating disorders, generic lifestyle advice to eat less and exercise more to lose weight can exacerbate disordered eating. Lifestyle therapies for PCOS may benefit from shifting focus away from body weight; use of weight-neutral, non-restrictive nutrition programming has been found effective at promoting lifestyle changes while also reducing disordered eating patterns [177, 178]. Several guidelines have been published in the last 5-10 years detailing the need for

mental health screening at the time of diagnosis [9, 171, 174]. Although previous studies and guidelines had been published to highlight the importance of mental health screening with PCOS, recent data from this study and others [12, 16, 44] suggests that so far that clinical shift does not appear to have occurred yet.

Self-advocation and self-education were particularly strong, and unexpected, themes to emerge from the data. Many participants described needing to advocate for themselves to convince their physicians that their symptoms were a) real and b) serious enough to warrant testing and/or referral. Often, participants self-advocated and self-educated concurrently; self-education sometimes informed and supported self-advocation efforts at the doctor's office. The self-advocation and self-education themes emerged from other study population in the literature [16, 18, 19, 97]. In this study population, it appeared that few participants had easy-going diagnosis experiences or the opportunity to be taken care of by knowledgeable doctors who were well-versed on PCOS and could provide ample support to patients at the time of the diagnosis. When such support was missing from doctors, participants' own efforts to self-educate (pre- and post-diagnosis) and self-advocate facilitated their efforts to attain a diagnosis that explained their symptoms.

A concerning theme within participant experiences included the large number of women experiencing their concerns and symptoms being dismissed chronically by their doctors, and feeling unheard, brushed off, and not taken seriously, leading to delayed diagnoses. This theme occurred across age groups, from women being diagnosed as adolescents, young adults, and even in adult women who started to experience symptoms after childbirth. Many participants went years having their concerns dismissed, and diagnosis delayed, until they switched doctors or began to self-advocate. For overweight participants, their concerns and symptoms were often brushed off as being due to their weight instead of potential PCOS, a finding that was also

reported by a recent qualitative study [179]. Similar findings of dismissal and lack of empathy from physicians were reported by several other studies [16, 18, 19, 82]. Some participants attributed their physician's dismissals on a lack of knowledge about PCOS; other participants felt that chronic and widespread dismissal of PCOS symptoms fell under systemic under-prioritization and unawareness of women's health. In cases with dismissive doctors, participants often benefitted from seeking counsel from another doctor, such as by changing family doctors or seeking referrals. Self-advocation was a particularly strong facilitator for participants whose concerns were brushed off. Participants would "push" to be taken seriously and continue advocating for themselves until something was done to address their concerns.

One of the biggest facilitators in patient journeys was the availability of knowledgeable PCPs who were able to diagnose patients quickly without the need for referral, allowing participants to be informed of their health status quickly and get them started on their management journeys. Chi-squares revealed that participants who saw more than 3 doctors before attaining diagnosis were more likely to wait more than 2 years for the diagnosis and be less satisfied with the overall diagnosis. Previous studies point to a widespread gap in awareness of PCOS in health professionals. Surveys of OB-GYN residents and physicians found deficiencies in knowledge of PCOS diagnostic criteria where only 55% of trainees correctly identified the 3 main Rotterdam criteria despite 85.4% reporting using the criteria to diagnose PCOS [47]. Another study found that most physicians surveyed reported not knowing which PCOS diagnostic criteria they used [45], pointing to a need for greater physician training so that the care they deliver for PCOS aligns with national and international guidelines [45, 47]. Participants may benefit the most from knowledgeable PCPs in Canada, as it can cut down wait times associated with referrals and the number of doctors they need to see before starting on treatment. Special targeting for PCP education may be needed in Canada and countries with similarly structured healthcare systems.

In terms of age considerations, a few themes occurred for participants who were diagnosed in adolescence. Reflecting, participants found a general lack of awareness of PCOS and other women's health conditions within themselves in adolescence and in parental figures. Due to lack of awareness, many adolescents with symptoms would fail to recognize the potential implications and not bring up their symptoms at doctor's offices. Youth were often not able to self-advocate compared to older participants, who emphasized the need for self-advocation at the doctor's office. Several studies found little awareness of PCOS in students internationally [180, 181] and a need for awareness programmes [182, 183]; however, more research is needed to gauge awareness levels in adolescents in Canada.

More commonly, adolescents would bring up symptoms but would encounter physicians who dismissed symptoms and were unable to diagnose. Although participants may have attributed the lack of action their physicians took to diagnose them in adolescence to lack of knowledge, physicians may be purposely delaying diagnosis avoid overdiagnosis in adolescents as PCOS symptoms often overlap with normal pubertal development, instead opting to consider them as "increased risk" as recent guidelines suggest [89]. However, with many youth reporting dismissals and a lack of information from doctors, physicians in these cases may need to ensure that they adequately communicate why they may be delaying diagnosis if that is the case. Education for youth to be able to identify potential symptoms of PCOS may be necessary, along with greater education for physicians on how to navigate providing care for adolescent populations [82].

The findings laid out in barriers and facilitators to the diagnosis experience ultimately attempt to add to a rich body of evidence to provide useable knowledge to clinicians and stakeholders and optimize clinical responses for PCOS healthcare. Many patients with PCOS do not receive adequate medical guidance and information, contributing to delayed and unsatisfactory diagnoses, as well as possible loss of trust [13]. Findings from this paper resemble previous

findings about women's experience of PCOS diagnosis from as far back as 21 years ago (at the turn of the century) [184] suggesting that although research has been conducted with this population, and recommendations have been laid out, clinical response has not yet been optimized for this population. Greater awareness and research into this population's experience with healthcare delivery is necessary to provide women with equitable healthcare.

4.6.1 Limitations and strengths

Limitations of this study include self-reported diagnosis of PCOS, potential for recall bias, and selection bias. Recall bias is possible for participants who received their diagnosis many years prior to completing the survey. Selection bias is possible due to all participants being recruited from websites and online groups, eliminating the potential to reach women with PCOS who are not as active online. The questionnaire was also only available in English and posted on English web sites, and thus, may have excluded non-English speaking populations, such as immigrant populations. Most survey and interview participants identified as Caucasian; few participants from diverse ethnic backgrounds were captured. The sample may not be representative of the general population of women with PCOS, and limited conclusions can be drawn regarding other world regions. The data gathered is largely consistent with previous research internationally and in North America [12, 44]. Member checking, where participants are given an opportunity to review findings and provide feedback, was not performed since participant contact information was not recorded and permission was not sought to save information and contact the interviewees when data analysis was complete.

With regards to the interviewer's positionality, MI shared with participants her prior knowledge about PCOS due to having friends with PCOS, her personal interest in the topic, but that she herself did not have a PCOS diagnosis. Since MI herself did not have PCOS, participants may

have felt more reserved than if they had been interviewed by someone with PCOS; however, disclosing that MI was personally connected to friends who do, may have helped participants feel more understood. As MI was a student and novice researcher, who was not involved in the healthcare profession, participants may have felt more at ease being open about their experiences navigating the healthcare system without the presence of a potential power dynamic.

Strengths of this study include involvement of qualitative research to help clarify and gather context on survey results. Previous survey-based studies were solely quantitative and may have failed to capture the richness of data from qualitative research [12, 44]. This study addressed the need for qualitative research to compliment the results of survey data [44]. Another strength of this study was the involvement of peri- and post-menopausal women whose experiences and beliefs may not be transferable from the experiences of women of reproductive age. Previous qualitative studies largely involved women under 50 years of age [15, 16, 18, 19].

4.7 Conclusion

Poor experiences with attaining diagnosis revealed numerous barriers faced by women with PCOS. There are clear opportunities for improving patient experiences: improving PCOS awareness in medical professionals (particularly at the PCP level) and in the general population, promoting the use of diagnosis guidelines and recommendations in clinical settings, and the provision of credible medical information at the time of diagnosis. Women appeared to benefit most from physicians who were knowledgeable and informative; however, attentive physicians who investigated and addressed patient concerns even with little knowledge on PCOS aided women's journey to their diagnosis. Although self-advocation aided participants greatly in their journeys, it might be time for patients with PCOS to rest easy knowing that their physicians will be healthcare advocates on their behalf.

4.7.1 Policy recommendations and future research

Participant experiences revealed that some things are amiss with PCOS healthcare delivery and clinical shifts are necessary to provide appropriate care for this complex condition. PCOS awareness, and perhaps awareness of overall women's health issues, may need greater integration in medical curriculums and resident training, in primary care especially. Advocation to relevant peak bodies, stakeholders, and professional medical societies is needed to raise awareness of the potential need for educational reform on PCOS for health professionals in Canada. Several international evidence-based guidelines and reviews [23, 25, 26, 55, 89] have been established for the diagnosis and management of PCOS which can be consulted by clinicians in practice. The guidelines inform of the necessary information to provide and of the importance of mental health screening, among other screening and testing to be done, accounting for the needs of different phenotypes and age groups of women. Evidence-based translation and education resources for physicians and women with PCOS, along with the first, evidence-based app for women with PCOS "AskPCOS," can be found at https://www.monash.edu/medicine/sphpm/mchri/pcos/resources.These translation resources were developed in conjunction with health professionals and women with PCOS.

Future research is needed to explore the experiences of women from various ethnic backgrounds accessing care for PCOS in Canada, a country with many immigrant women who may experience greater barriers to care not captured in this study. Studies are also needed to explore rural populations who were missed by this study, who live with limited access to doctors and who may also face greater barriers to care in Canada. Studies on physician populations are also needed to gauge PCOS awareness and inform education efforts. This study recruited for women with PCOS; more inclusive studies are needed for other gender identities with PCOS.

Finally, further studies are needed with women outside of reproductive age, such as peri- and post-menopausal women with PCOS whose experiences accessing care are still not fully understood.

CHAPTER 5: ARTICLE 2

“I’m usually being my own doctor”: patient experiences managing PCOS in Canada.

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5.1 Abstract

Background: PCOS is a complex, chronic condition characterized by anovulation, ovarian cysts, and hyperandrogenism and requires life-long management. To prevent risk for comorbidity, lifestyle management and pharmaceuticals such as oral contraceptives are the most common forms of treatment and should be tailored to the individual patient. The literature to date has shown PCOS patients to experience widespread dissatisfaction with the amount and quality of information they receive from providers, along with lower levels of trust in physicians. Little is known about women with PCOS in Canada, and the barriers and facilitators they face when managing PCOS, accounting for age-related considerations.

Methods: In-depth remote interviews were used to explore women's lived experiences managing PCOS and the barriers and facilitators they encounter in their management journeys. Data were analyzed using thematic analysis and interpretive description methodology.

Results: 25 in-depth, telephone interviews conducted with participants across Canada (ages 18-63) revealed several barriers to management: lack of sufficient information provision and guidance in treatment plan formation by physicians, lack of empathy, weight bias, and little consideration for mental health, along with little guidance on lifestyle management. Younger participants were affected by lack of information and concern from doctors, and older participants received little guidance on treatment options post-menopause. Facilitators to management included: social support, knowledgeable and communicative doctors, involved doctors, self-education, self-advocation, and self-experimentation with treatments.

Conclusion: Most women in this study received little support for management of PCOS from physicians who they perceived to have little knowledge and/or concern about PCOS. Loss of trust and withdrawal from seeking medical care were prominent themes, along with greater self-reliance on self-management, including self-educating and self-experimenting, without medical supervision. Key considerations are identified for the provision of care to younger and older patients with PCOS. An overall need for greater physician education was found to improve the quality of healthcare provision for this population.

Keywords: PCOS; polycystic ovary syndrome; management; age; interviews; lived experiences; barriers; facilitators

5.2 Background

Polycystic ovary syndrome (PCOS) is one of the most common endocrine disorders, affecting 8-13% of reproductive-aged women [1]. Historically seen as a gynecological and reproductive disorder, PCOS's spectrum of health consequences are increasingly recognized [11]. PCOS may present, at one end of the spectrum, with the single finding of polycystic ovaries as detected by pelvic ultrasound. At the other end of the spectrum, symptoms of insulin resistance, hyperandrogenism, alopecia, infertility, anxiety, poor self-image, and depression may co-occur and have a significant impact on quality of life [9, 56]. Many patients with PCOS develop insulin resistance, central obesity, and dyslipidemia, which places them at a higher risk of developing diabetes and other long-term complications [3, 164, 185]. An additional, often-overlooked dimension of PCOS impacts mental health: PCOS patients are likely to develop anxiety, depression, eating disorders, and body image issues [9, 170, 173, 186].

The heavier side of the spectrum of symptoms can impart a significant burden of disease. Some patients solely have irregular periods to manage and can live their daily lives relatively unhindered, while others must manage many symptoms at once such as insulin resistance, weight, hirsutism, acne, and infertility, and thus may require access to a multidisciplinary healthcare team and a variety of treatments [10, 59, 187, 188]. Symptoms and concerns are dependent on the age and needs of the patient - PCOS presentation varies across the life cycle [189, 190]. Acne may be a primary concern for a patient during adolescence, while menstrual and fertility challenges may be more concerning in adulthood, and hyperandrogenism can be tricky to manage in peri- and post-menopause [191, 192]. As symptoms of PCOS change over time, with some symptoms worsening and/or new symptoms cropping up [189, 193], access to an involved and present healthcare team who can monitor the long-term health of a patient is paramount to the success of PCOS management in the long-term [81]. Tailored and individualized treatment plans that target the patient's unique symptoms and concerns can address the unique challenges of PCOS and provide the patient with positive health outcomes [10, 23].

Lifestyle management, involving weight loss or healthy weight maintenance, remains the most effective first-line therapeutic intervention [57, 58]. Modification to diet and exercise are important to managing PCOS and reducing the associated long-term health risks. There is no evidence that patients with PCOS benefit from a specific diet; the right diet is one that is

sustainable and compatible with the patient's lifestyle and concerns [57]. Due to the unique way PCOS can present in a patient, it can be helpful to refer to a dietitian for guidance on lifestyle management [58, 60]. Pharmaceuticals such as metformin, lipid lowering agents, and oral contraceptives should be tailored to the individual patient's risk profile and treatment goals [10, 59–61]. Health professionals well-equipped with knowledge on PCOS and its treatment options and who can provide informational resources to patients along with referrals and follow-up, are vital to management of PCOS [11, 13, 45, 46].

The literature to date shows that many women feel that they do not receive sufficient information about their condition and are frustrated by the limited knowledge of PCOS they find in professionals [11, 12, 56, 98]. Many patients with PCOS experience frustration with the inconsistent approaches of health professionals with regards to both diagnosis and management of PCOS [45]. Studies of healthcare providers found that many need more knowledge on PCOS and have a limited amount of information available for patients about PCOS and its management [45–47, 64]. Little is known about patients' firsthand experiences accessing care for the management of PCOS and navigating the healthcare system in Canada.

This qualitative study explores the lived experiences of women with PCOS in Canada to better understand the meaning of that experience for them and identifies the barriers and facilitators in participants' efforts to manage their condition. The study is important for patient care in that it adds to the body of knowledge related to PCOS management, providing insight into patient perspectives on care and well-being, with the goal to inform healthcare providers in their attempts to provide care to this patient population. Experiences and needs with PCOS management are explored with consideration to age and life stage.

5.3 Methods

5.3.1 Study design

In-depth, semi-structured phone interviews with participants explored their experiences getting diagnosed and subsequently managing PCOS. As described in a prior paper, interview participants were sourced from a larger, multi-methods study which involved an online questionnaire about PCOS diagnosis experience hosted on SurveyMonkey. Respondents who indicated interest in being interviewed at the end of their questionnaires were subsequently

interviewed remotely, over the phone, on a first come first serve basis. Interviews were in-depth and lasted around 1 hour (see Appendix C for interview guide). Interviews explored women's perceptions and experiences with the diagnosis and management of PCOS, but only the themes relating to their management experience are explored in this paper.

5.3.2 Research setting

Participants were reached across Canada. Canada is a country with 38,005,238 people as of July 2020, with the 4 most populous provinces being Ontario, Quebec, British Columbia, and Alberta [159]. The three most populous provinces after Ontario (14,734,01) are Quebec (8,574,571), British Columbia (5,147,712), and Alberta (4,421,876) [159]. Phone interviews were conducted by the corresponding author in a private residential office in Ottawa, Canada.

5.3.3 Participants and recruitment[2]

A purposive convenience sample was gathered online with participants who met the inclusion criteria: age 18 years or older, reporting a medical diagnosis of PCOS, having lived in Canada since their diagnosis, and able to speak and understand English. No upper age limit was established to promote participation from older patients living with PCOS, in the peri- and post-menopausal stages of life. Recruitment posters were posted in online PCOS groups and forums (Facebook, Reddit). The PCOS Awareness Association shared the posters on their Facebook page as well. Participants who filled out questionnaires were invited to submit their contact information for follow-up interviews. Participants were interviewed in the order in which their affirmative responses and consent forms were received. Social media was used as a recruitment strategy to recruit a more diverse sample from across all Canadian provinces. Recruitment continued until preliminary analysis during data collection suggested thematic consistency across age groups and no more peri- and post-menopausal women were available to interview.

5.3.4 Data collection

25 interviews were conducted remotely over the phone by the MI between October and December 2018, averaging an hour in length and conducted in one uninterrupted meeting. The interviewer conducted all interviews over the phone in their private residential office with no one

[2] Recruitment posts included gendered, women-specific language. However, not all people with PCOS may identify as women. Due to our recruitment, we will continue to use gendered language in this publication to reflect our sample.

else present. All interviews were audio-recorded (with participant consent) and transcribed verbatim by the corresponding author. One interview was held over Skype™ due to participant preference. The participants were encouraged to share their experiences through a semi-structured interview process. Interviews were in-depth and lasted around 1 hour. The semi-structured interview guide was developed by MI based on themes and gaps identified in previous literature, and included questions such as, 'Could you describe a typical day living with PCOS?' and 'Which areas of your life are most impacted by PCOS?' (See Appendix C for interview guide). Interviews were capped at 25 once data saturation was reached and no more participants in the peri- and post-menopausal stages were available. Pseudonyms are used here and in all written documents.

5.3.5 Data analysis

The first author coded all qualitative interview data, including field notes made during and after interviews, and managed and analyzed all data in NVivo 12 (QSR International Pty Ltd. Version 12, 2018). In accordance with Thorne et al.'s (2004) [152] interpretive description methodology, an inductive analysis technique was used to analyze data. Themes were derived entirely from the data. Thorne's (2004) interpretive description approach is widely used in nursing research and does not generate new truths or theories but rather describes thematic patterns and commonalities while also accounting for individual variations and provides a product that clinicians can use as a backdrop for clinical decision-making [152]. Braun and Clarke's (2006) six key stages in the thematic analysis of qualitative data were also followed in this study: (1) Familiarize, (2) Generate initial codes, (3) Search for themes, (4) Review themes, (5) Define themes, and (6) Write up the data analysis [160]. Codes and subsequent sub-categories were generated directly from topics raised in the data. The over-arching code categories (barriers and facilitators) were developed from the research questions.

5.3.6 Trustworthiness

This study was reported based on the Consolidated criteria for reporting qualitative research (COREQ) (see Appendix E) [161]. At the time of the study, MI was a MSc student conducting in-depth interviews for the first time after training in graduate classes and workshops. MI identifies as female, and participants were made aware of the reason for the author to be conducting this research, their personal interest in the research topic, and PCOS status, but otherwise no significant relationship existed or was established between the author and participants. To ensure reliability and validity, MI considered researcher bias, used the strategies of thick

description, development of a coding system, checking and agreement on themes and analysis by members of the team, transparency when reporting research (as per COREQ), and demonstrating the author's interpretive lens throughout the report [152, 161].

5.3.7 Ethics

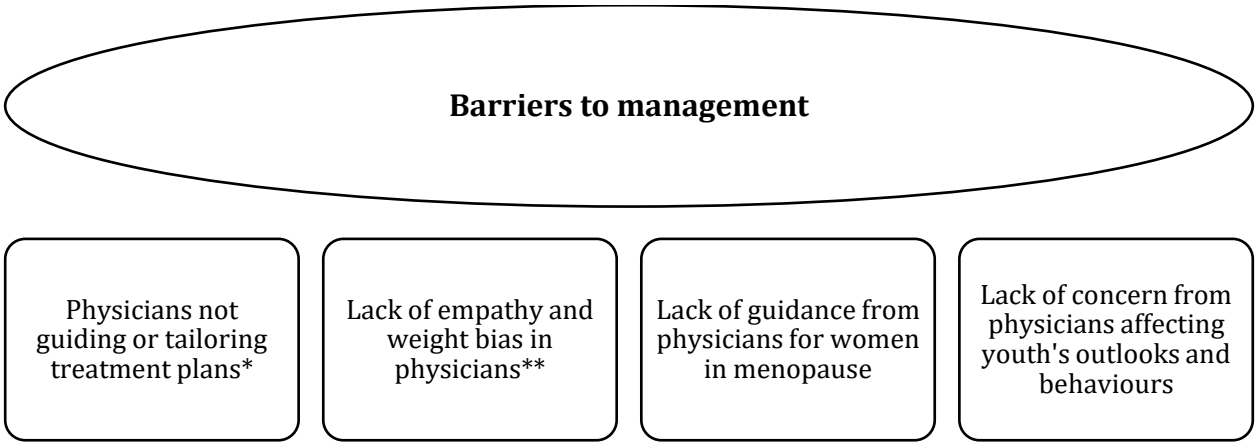
Ethics approval for the study was received from the University of Ottawa Research Ethics Boards (REB) in April 2018. Participants were voluntarily enrolled in the study with free and informed consent. Participants were informed that once they chose to participate, they could withdraw their consent and data at any time and/or refuse to answer any questions, without suffering any negative consequences. Permission to audio-record the remote interviews was sought and obtained before data collection. All personal identifiers were removed from transcripts and in quoted texts below. Written or oral informed consent was obtained from all participants prior to their participation.

5.4 Results

Recruitment resulted in 25 participants ranging in age from 18 to 63 years old, with mostly Caucasian ethnic backgrounds, along with 2 East Asian, 1 Black, 1 South Asian, and 2 Middle Eastern backgrounds. The length of time since the diagnosis of PCOS varied between 1 month to 33 years at the time of enrollment in the study. Most participants were between the ages of 25-30, 6 participants were between ages 30-40 years old, and 3 participants were above the age of 40. Most participants resided in Ontario, with a few from Alberta (n=4), British Columbia (n=4), and one from Quebec. Most participants were employed full-time, 7 were students, and 2 were stay-at-home moms. Seven participants had children, and nine participants were looking to conceive at the time of the interview.

Barriers were identified as factors external or internal to participants which affected participant experience of their PCOS management negatively (e.g., by delaying management). Facilitators were identified as factors external or internal to participants which affected participant experience of their PCOS management positively (e.g., by making them feel supported). Figures 5.1 and 5.2 below outline major themes found.

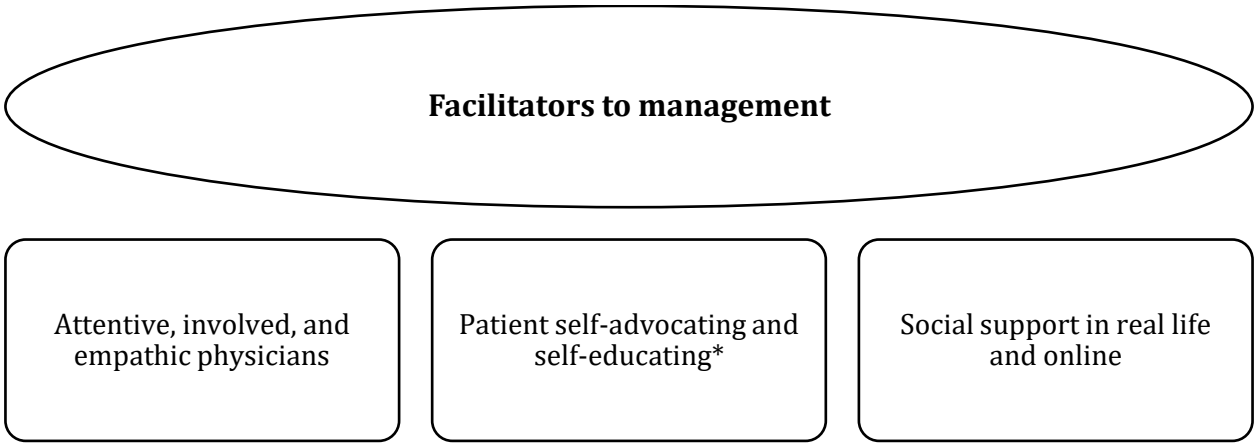
Figure 5.1 Barriers to satisfactory PCOS management experience.



*Sub-themes of physicians not guiding or providing information for lifestyle management and treatment of mental health.

**Sub-theme of participants losing trust and withdrawing from medical care.

Figure 5.2 Facilitators to a satisfactory PCOS management experience.



*Sub-theme of self-experimenting with treatments.

5.4.1 Barriers

5.4.1.1 Doctors not guiding or tailoring treatment plans

A barrier to management occurred when participants did not receive adequate guidance and support from medical professionals regarding treatment, which was especially common with primary care physicians (PCPs) uninvolved with treatment. Participants were not given enough guidance or information on treatment options or help from physicians in devising an

individualized treatment plan. The lack of information and guidance led to participants feeling unsupported by healthcare providers and needing to gather relevant information and make decisions pertaining to their treatment plans (short and long-term) on their own.

Josie, aged 27, expressed that her family doctor offered little guidance with Josie's management of PCOS. Josie felt as though she was unable to rely on her family doctor for guidance and resources like referrals:

"It's very frustrating because I usually have to basically tell her "you need to refer to me to this" or "I need to be referred to this" or "I need to see this person." I don't know why, I haven't really figured out. It seems to be like I'm usually the one googling how to deal with this. I'm usually being my own doctor."

Josie expressed that she was essentially being her own doctor and similarly to many other participants, was left to rely solely on herself to navigate her management journey.

Holly, aged 29, similarly expressed how she felt unsupported and left to her own devices in her management of PCOS, relying on her own research to know what to do next:

"I think with her understanding and knowing that I had it, I think it would have been nice to have them take a bit more interest. If that makes sense. Because I don't necessarily know what I should be watching for, or something that could be detrimental to me, that sort of thing. Whereas I would think that they do, which would have been nice. Because I mean like I don't know to check for insulin resistance. I don't know to check for my fasting glucose or whatever. But they do. Or they're supposed to."

Divya, aged 22, expressed frustration over her GP who routinely dismissed her concerns and could offer little information and guidance to help her manage her symptoms. She described a visit where she wanted to get her doctor's guidance on a keto diet she was considering and share her questions on a new birth control prescription:

"And I didn't really feel supported by my family doctor at all because I had a meeting with him about it, like just to show the birth control to ask him about it and keto. And I was gonna bring up my mental health issues but he actually cut the appointment short. So no, I really feel that I've

never really been able to voice any concerns. I've always been kind of talked over and then being kind of told and not asked like "hey, so do you have any questions? Or do you want to bring something up?""

Several participants shared that they experienced mental health challenges because of PCOS but lacked acknowledgement of mental health from their doctors. Very few participants had GPs who followed up on their mental health or discussed the mental health impacts of PCOS. Divya had a particularly distressing interaction with her doctor who she felt avoided the topic of mental health completely after she brought up her symptoms:

"But with my family doctor has always dismissed not just the PCOS but I've gone to him with other issues. I know PCOS is potentially linked to mental health issues too. I've read it. And I remember bringing these types of things up and he would just kind of shy away from it like he didn't want to deal with it. So I feel like they try to look for the path of least resistance if they can. Unless I was physically dying or something like diabetes. It's easier or maybe more of a concern to him than if there was mental health issues, or like the period issue where it's like "oh, she's not trying to get pregnant or whatever, so who cares." I don't know. It's like the path of least resistance. It's like "oh come back in six weeks and see if you still feel the same." But what if I just off myself in 6 weeks, you know? I don't know. It's like not taken seriously."

Rita, aged 38, spoke about how her GP did not have enough knowledge about PCOS to participate in her PCOS management:

"My GP is more the "I'll refer you" not the "well, let's talk about it." I feel he is not - he obviously didn't specialize in women's health but yeah he didn't really help me with that. I went back to him and said "you know my gynecologist said this and this and that" and it was more like he was just taking what I told him and then that's it. It's like processing it, he didn't really offer any solutions."

Emma, aged 29, reflected on her GP being uninvolved in her care:

"Not involved at all. It's mostly just me. She's very busy, obviously she's very overworked and she just doesn't have time. She just doesn't have time to get a treatment plan going and that type of stuff. It's just frustrating."

Few participants had access to involved doctors/PCPs in their management journeys. The theme of doctors not asking questions, not looking into concerns too deeply, not offering advice, and not offering guidance put patients into a strong disadvantage while managing PCOS. Several participants also acknowledged the gap in mental health care and physician awareness of the mental health implications with PCOS. Although few participants recalled being asked about their mental health, most noted that was something they would like their physicians to consider and address more.

5.4.1.1.1 Doctors not helping with lifestyle management

Lifestyle management is the first line of recommendation for management of PCOS. Many participants were often told to lose weight, but their doctors did not offer any specific guidelines or advice. Most participants were proactive in their lifestyle management, but most of the information guiding their lifestyle changes came from online sources. Keto diets, intermittent fasting, low-carb diets were prominent in interviews, but rarely were those diets supervised by doctors.

Lucy, aged 47, who had struggled with her weight, explained her frustration with the little1guidance from her doctors on lifestyle management:

“They just said “lose weight” which is really useless. You don't need to tell people to lose weight. None of my doctors have ever offered valuable advice. Not only with PCOS but with lifestyle or nutrition or anything, ever.”

Josephine, aged 32, has also struggled with losing weight and described feeling frustrated at not being given more dietary guidance:

“So I wanted some help for my weight but she made me blood tests and the only thing she told me that everything is normal. But she didn't help me for my weight, she just told me that she can gave me an injection of something in my intestines so I wouldn't get hungry but it wasn't the help I needed. So I search on Internet and I found about intermittent fasting and keto diets. So I started this in early July and I already lost twelve kilograms.”

Josephine ended up doing her own research and trialing intermittent fasting and keto diets, which helped her to lose weight. Divya, aged 22, was another participant who struggled with losing weight and could not get any guidance or advice from her doctor about the keto diet. She explained:

"I also asked my family doctor "can I go on the keto diet, do you recommend it?" And he's like you could go on it you can do whatever diet you want. It doesn't really matter. I basically asked if the keto diet is safe and he said "yeah, you can do whatever you want" but no one really gave me any guidelines."

Lifestyle management is one of the most important and effective treatments for PCOS; however, many participants experienced physicians to provide little guidance on dietary and lifestyle changes. Doctors who were uninvolved with guiding and following up with their patient's lifestyle management were identified as another barrier to successful PCOS management.

5.4.1.2 Lack of empathy and weight bias in physicians alienating participants

Many participants' interactions with their healthcare providers were marred with a feeling of not being heard, or in the case of overweight/obese participants, perceiving bias from doctors because of their weight. A lack of empathy, poor listening skills, and dismissiveness in doctors were another barrier which led to participants feeling unsupported in their management journeys.

Holly, aged 29, spoke about how a lot of doctors she encountered did not know much about PCOS but she felt more frustrated at their lack of guidance and lack of concern and empathy:

"So I should preface this. My mom is a nurse. I've grown up around the healthcare profession. I mean I don't necessarily blame them for not knowing, like there's a myriad of disease and syndromes, like I can't expect every doctor to know off the top of their head and be able to pinpoint. I think I was just frustrated at the lack of follow up, not even follow-up, but the lack of resources for me to go to. And I didn't feel like my doctor gave a hoot which was frustrating and it felt like what was the point?"

Some participants who were overweight or obese felt a bias in some of their doctors which alienated them. Zara, aged 24, spoke about how frustrated she felt when her doctor had assumed she was sedentary due to her weight, when in fact Zara was consciously incorporating physical activity into her daily life:

"Totally negative. kind of like without necessarily asking. Like I walk an hour and a half twice a day, every day. I'm not sedentary. But you just assuming is just very frustrating, especially when you're told that it's very hard for you to lose weight when you have PCOS. It's just like, oh my god, you need to talk about this better."

Josephine, aged 32, felt that her specialist did not understand her struggles with weight due to PCOS. Even when Josephine was maintaining a healthy diet, she could not lose weight easily but her specialist assumed that it was a matter of overeating. Josephine did not feel heard:

"And with the endocrinologist, she just told me the blood tests are good so you just have to lose weight. And she thought that I was eating too much. So I don't feel that they're hearing me when I talk about symptoms."

Eileen, aged 47, recounted experiencing little empathy when she was struggling with her health. She expressed feelings of being dismissed and the weight bias she perceived in her doctors:

"No I'm the type of person- I don't see a doctor until I'm really ill. So just the fact that no one is helping me, no one's listening to me, I do my own research, I try not to tell the doctors their job. I'm just like "would you help me with this? Can you give me some pointers?" And once they see that you're overweight… I think it's more to do with the fact that once you're overweight there's already a bias and I feel guilty for my obesity. I fully take responsibility for the fact that I can control it. But it would be a lot easier if I had help and by help I mean if I can get something to regulate hormones. Yes, it's very very isolating living with this."

Eileen was one of a few obese participants with PCOS who recounted disheartening experiences with her doctors displaying weight bias. Physicians who did not display enough empathy, lacked listening skills, or displayed weight bias alienated their patients, many of whom chose to no longer seek medical care and instead took care of their health on their own.

5.4.1.2.1 Loss of trust in physicians after adverse experiences

When encountering lack of empathy and/or weight bias in physicians, some participants lost trust with their doctors and stopped reaching out for help. Many participants also grew discouraged after finding that their doctors could not offer any useful information and chose to opt out from seeking care from them.

Divya, aged 22, experienced many barriers to her diagnosis due to an unknowledgeable GP who dismissed her concerns over her irregular period for years before finally offering a referral to a gynecologist. Divya had many instances when she felt unheard and dismissed by her GP, especially when looking for guidance from him. Unfortunately, her negative experiences led her to losing trust in her doctor:

“I don't like going to the doctor. I feel like every time I do they just don't care. So I stopped going to the doctor even though I got really sick earlier this month and I just like waited it through. Because I really didn't think anyone would care. And I don't know I just lost my confidence and everything, it’s kind of like “no one gives a shit, so who cares.” I don't know. And like no one will understand.”

Lucy, aged 47, had a bumpy experience reaching out for information from her doctors. She explained:

“This is one of the things I found that any of the professionals I've talked to over the years about it, including my own GP, didn't seem to know too much about it. And this was including the specialist. Their information on it is incomplete… And not just GPs but even specialists who have mismatched and incorrect information. And that's what made me realize I can't rely on any physician to have accurate information about it and I'd have to find the information on my own.”

Lucy was one of many participants who lost faith and trust in their physicians after not receiving the information they needed. Many other participants in similar situations to Lucy felt like they could not fully trust and rely on their doctors, which alienated them away from seeking medical care.

Mary, aged 27, expressed that she wanted to be able to trust and rely on her doctor, but when she was not finding the information she needed, it was hard for her to do so:

“Because it's not that I wouldn't trust my doctor if they gave me that information but they don't. So it kind of instills a lack of confidence, you know? So it's not even “who do I trust the most” it’s like “who is the only one giving me information?” Because I would trust – like if my doctor handed me a pamphlet and was like “this is PCOS, if you have any questions ask me” then I would 100 percent trust that. But then it's like they're not doing that.”

Like Mary, many participants stated that even something like a pamphlet with basic information on PCOS would have been very helpful, but very few participants described receiving pamphlets or sufficient information. Participants who did not receive enough information from doctors, or perceived little empathy and understanding in their doctors, felt that they could not trust and rely on their doctors for help. In cases where loss of trust occurred, participants chose to withdraw from seeking medical help and self-manage PCOS and do the best they could to accurately judge the credibility of information they found on their own.

5.4.1.3 Age considerations: lack of concern and info from doctors delaying management in youth

With regards to age, a few themes showed up in how younger patients and older patients experienced unique barriers to management. Patients who were diagnosed early in life, such as during adolescence, reflected that they did not fully understand the long-term implications of PCOS or the importance of management until many years after their diagnosis. This happened in participants who did not receive enough information from their doctors about PCOS implications and/or who perceived a lack of concern in their doctors which rubbed off on their own attitudes towards their condition.

Lizzie, aged 27, received little information from her doctors and reflected on how it led her to not take her symptoms seriously:

“Of course when I was 16 I thought no big deal because it was really far away, right? By when I got older, I kind of did my own research and was like “oh, this is a little more serious than was explained to me.”

Lizzie awakened to the serious nature of PCOS after doing her own research and starting management in her mid-20s, almost a decade after her diagnosis. Adolescent patients

diagnosed with PCOS may require a bit more information and more of a discussion to help them understand what PCOS might mean for them in the long-term.

Vanessa, aged 63, was diagnosed when she was 20 by a GP who gave her little information on PCOS and its management:

"So it was a doctor in Calgary but he didn't really do much. We just talked about my symptoms and then suddenly he said "you have PCOS." Didn't really do any tests at that time and I wasn't put on anything. I wasn't given any medication or anything at that time. He just said I probably couldn't have children. That was about it."

Faced with a doctor who seemed unconcerned about the diagnosis and a stepmother who was also unconcerned, Vanessa began to normalize PCOS and did not begin management:

"So I kind of felt like I was making too big of a deal about it so I let it go for about ten years. And didn't really find out what it was until I was 30… I can imagine, when you're younger you deal with some of these things the symptoms aren't gonna be as bad. When you're older whether you've got a really bad case of PCOS or mild, it probably gets worse as you get older for everybody. So the sooner you're dealing with something the better information helps with that."

Margaret, aged 33, detailed how her unconcerned GP who initially diagnosed her in her early 20s affected her attitude towards her health:

"It's kind of really funny because I even I discounted it because everybody was so casual about it, you know what I mean for so long that it really wasn't until I started seeing my GP now and she actually took it seriously and kind of treated it like it was something that actually needed to be dealt with, you know? Then I kind of clued in to like "hey somebody should have been doing something about this like 10 years ago.""

Margaret found a new GP who was surprised when Margaret off-handedly mentioned her diagnosis, and immediately began running tests to verify that Margaret indeed had PCOS. After the tests came back conclusive of PCOS, Margaret's GP began to provide Margaret with a lot of information and support - her first doctor to do so:

"And she was the first one to really highlight to me just like the importance of you know with this condition you have to be making sure that you're eating right and that you're exercising and

you're at this extra risk for all of the type 2 diabetes and stuff like that. And yeah, that's sort of been the journey from there I guess."

For younger participants, they were more likely to not fully understand the long-term implications of PCOS, and barriers like non-informative and unconcerned doctors contributed to the delay of their management journeys. When doctors were unconcerned over younger patients' symptoms, or when they did not take the time to explain the impacts and long-term nature of PCOS, it led participants to normalize their symptoms and not start on PCOS management until much later in life.

5.4.1.4 Age considerations: need for more information and guidance for women nearing menopause.

For older participants nearing menopause, a unique barrier to management arose when they had to terminate their medications due to advanced age risks. A barrier to management for aging women was having to terminate their treatments after many years (often decades) of taking them and learning to manage without them, often without any medical guidance.

At the time of the interview, Vanessa at age 63 was post-menopausal and was facing health challenges and had many unanswered questions around how PCOS will affect her post-menopause. Ten years prior, at the age of 50, she had been assessed by an endocrinologist who had to take her off the medications she was on:

"Metformin, spironolactone, and birth control of some sort, a variety. And so she had me come off of all those pills. And these last 10 years I haven't been on any medication and I'm in the process of going to see a specialist next week to see if I can find somebody that has some medication I can go back on because things have gotten quite a bit worse."

Vanessa's symptoms gradually worsened, and she had no follow-up for another check-up on how she was doing without the medication:

"But then there was no follow-up. Like I went to see the endocrinologist and then there's no follow up. They just took me off those meds and then there was no follow-up to see what's going

on or if I should be on anything or whatever. It's always up to you to figure out what you should be doing and who you should be seeing."

Vanessa at the time of the interview was still not followed up with and was doing her best to manage her symptoms with various over-the-counter supplements she was experimenting with from her own research and waiting for an appointment at a new clinic.

Eileen, aged 47, had many symptoms due to PCOS, menstrual irregularities, central obesity, and hirsutism, and thinning of her hair. Although metformin had not worked out for her due to the severe nausea she experienced, she was able to manage her symptoms with birth control for many years. But in here 40s, she had to terminate her birth control use due to advanced age risks and was unsure how to manage her symptoms going forward:

"It was that same doctor who diagnosed the PCOS who put me on birth control pills. I have no problems with PMS, I've never had side effects from birth control pills. So it was great. The only reason I'm not on this now is because I'm 47. You know, risk of stroke, etc."

Eileen has been self-experimenting with certain over-the-counter supplements: black cohosh, myoinositol, and magnesium, as well as doing her best to keep a low-carb diet. She wished that she could have access to "*just more doctors to tell people about myo-inositol or other things to regulate your hormones*" but she had not found any doctors who could guide her with alternative treatments once she was unable to be on prescription medication anymore.

To sum up, older participants in peri- and post-menopause had to terminate a lot of medications that were helping them due to advanced age risks. Unfortunately, medical doctors often left the picture at menopause and participants had to explore other options without medical guidance. Ample guidance and information must be given to older patients with PCOS to help them continue managing their symptoms with whatever means available, as PCOS symptoms may continue or worsen after menopause.

5.4.2 Facilitators

5.4.2.1 Attentive, involved, and empathic doctors who help even with little knowledge

Many participants had doctors who had little knowledge on PCOS; however, their experiences accessing care were still positive because they felt that their doctors were still able to help them

by researching and addressing their concerns. Participants identified some doctors as being very attentive, involved, and empathic despite having little knowledge of PCOS, which made the participants feel supported in their management journeys and in accessing care.

Vanessa, aged 63, felt supported by one of her previous doctors who did not know much about PCOS at that point, but listened to Vanessa's concerns and was proactive about researching and offering information:

"The first doctor I had when I came to BC, I felt supported. At that point I didn't really understand terribly much. And she also didn't looking back. But she cared enough that she sent me on these tests and she would listen to me when I'd come in and say "okay I think I should be on this drug." She would research it obviously or look it up in the drug book. But she listened to me."

Lizzie, aged 27, similarly felt supported by her GP who stayed involved in her PCOS management and researching treatment options:

"She will help, like when I come in with a situation and ask "can we figure this out?" A little while ago, it was migraines like crazy and obviously I've been on birth control for a long time and talking to other people it was like "do I need to come off this? Am I hurting myself, like can we find a solution?" She was good, I think she did a little bit of research and we kind of reconvened and she gave me options of changing birth control or taking the placebo week or an IUD altogether… She's also good with that, she'll tell if it's something she thinks I can manage without a prescription or if she feels prescription is the only way to go. There's usually a discussion and we figure it out."

Lizzie had a very communicative, back-and-forth relationship with her new GP which aided in her ability to access care and feel supported. She explained her experiences:

"But I know even just going into her and saying "you know this is what I've heard and this is what I'm thinking for this, what lines are you coming in on?" She's open to discussing, she doesn't always like my ideas, I think she thinks I just sit on google to make her life complicated. But she's pretty involved and "ok well let's think about it" or "okay we'll try it, I'll give you 2 weeks and you'll have to come back and we're evaluating this." But yeah, she's pretty good."

Participants who felt supported by their doctors felt heard, even when their doctors initially did not have the knowledge to help them. Lucy, aged 47, described her experience with her doctor:

“Yes, I felt supported. I mean before we kind of knew what was going on, I didn't feel he was fully dismissing me. I felt that he was willing to look into it and that's all I was asking for, that he would listen to me and would follow up when I asked for it. And so in that regard yes I definitely felt supported.”

Lucy felt supported by her doctor’s ability to listen to her and not dismiss her concerns. Josephine, aged 32, was another participant who felt supported by a doctor who did not know much about PCOS but despite that, Josephine felt supported by him due to his empathic attitude:

“Yes. He doesn't have a lot of answers about PCOS so I have to do my research. But for the rest, he is very supportive and also I can talk to him. So that's great.”

Many participants acknowledged that their doctors initially had very little knowledge about PCOS but participants still felt supported because their doctors would listen and take action on their behalf by researching PCOS treatment options, offering information, providing reassurance and displaying empathy.

5.4.2.2 Self-advocation & self-education

A significant facilitator to participants’ management of PCOS included their own efforts to stay involved in self-management and be their own caregivers, especially in situations where participants lacked access to knowledgeable and/or involved doctors. Self-education aided participants in the quest of understanding their condition better and finding treatment options to manage their symptoms. Self-advocating helped when participants encountered physicians who had little informational resources to provide and/or seemed hesitant to offer referrals.

Although Emma, aged 29, had symptoms from early in her life, such as significant and unexplained weight gain, facial hair, and irregular periods, her GP was unable to diagnose her when she presented her symptoms an unrelated scan revealed ovarian cysts that led her to be diagnosed with PCOS. After the diagnosis, Emma found that her doctors had little information and guidance to offer her. Emma reflected on how much she had to push to get information on PCOS management, and the importance of self-advocating and self-education:

“But I find that you really do have to advocate and that I think is the most frustrating part is that there just aren't enough doctors to give you that quality and that level of care. So you have to fill

in the gaps yourself and to go back to my earlier topic, what if I didn't have time or know how to do my own research or anything like that and I have then I had to just depend on a doctor who didn't know exactly what the best things to do were or exactly what the best treatment plan was? It could be- it would be even harder I think for someone in that situation than me who at least knows because of my university education peer reviewed articles are better than having to kind of weed out some of the very easy to find bullshit that you find online."

Emma recognized how her postsecondary education likely aided her in her self-education on PCOS when she had to weed through unreliable sources of information online. She explained how important PCOS management is throughout life but how frustrating it was for her to receive the care she needed:

"I need to be very proactive with it because time goes by very very fast and you don't want to find out that you're in your 40s and you could never get pregnant because you didn't do the correct steps in your 20s and 30s. So yeah that's, it's very frustrating. I think that especially for women's issues, it can be very frustrating to kind of feel like you don't have the availability of care that you needed."

Many participants echoed Emma's perception of women's health being underserved and underrecognized in healthcare and the general population. Emma reflected on how her symptoms had become apparent in her early 20s but with her doctors unable to diagnose and her not being able to self-advocate, she slipped through the cracks:

"I feel like without, if I am not willing to take the initiative to do it, nobody's going to do it for me. And I think that a lot of women with PCOS are either not in mental health positions- I certainly wasn't in my early 20s. I had depression, I had other issues. I was unable to advocate for myself."

Josie, aged 27, was another participant for whom self-advocating played a big facilitating role in her management journey. Josie reflected on her doctor not being proactive at offering solutions, leading Josie to self-advocate and push for to get she needed. Josie explained:

"And then my doctor does do follow-ups for my blood tests and whatever health problem I'm working on. So she's involved enough but I think it would be nice to have her a little bit more invested in my health, and wanting to figure things out. I just feel like it's kind of like pulling teeth. It would be nice for a doctor to be self-motivated that way, but some doctors aren't."

Brianna, aged 21, had a similar experience to Josie where her doctor needed that extra push to start offering information. Brianna spoke about how she was able to receive more information once she started to actively try to get more information:

“Anyways, once I finally started to go to that doctor, I started becoming more interested in it and asking about it. So that's why I was getting more information about it. I'm not sure if I would have gotten as much had I not been curious, if that makes sense. That’s a main factor.”

Lucy, aged 47, described receiving conflicting information from the doctors she had seen, which led her to emphasize how important self-advocation and self-education were for her to adequately take care of her health:

“One of the things that I've realized, I think when it comes to PCOS and a lot of conditions, I think it's crucial to be your own caregiver. You have to be proactive. You can't leave it to someone else to give you all the answers and just do what they say. You have to because there's just so much misinformation.”

Lizzie, aged 27, was diagnosed at 16 or 17 and all she remembered being told by the doctor was *“I would probably have diabetes by the time I was 40. That’s all I was really told by the doctor - by the first doctor.”* At that point, Lizzie did not know what to do with the diagnosis and being so young she did not spend much time thinking about it herself, but since the age of 20 she had become more proactive:

“Since then, I’ve had to advocate for myself at the doctor, like “no, no, no, we need to do something about this now.””

Most participants did not have fully knowledgeable and/or attentive doctors, and in those cases, a big facilitator for them were their own efforts at self-advocating and self-educating. Self-education was particularly important, even aiding in self-advocation efforts, as in the case of Mary, aged 27. She described how through self-education on PCOS, she was able to self-advocate better and get the referrals and guidance she needed:

“So even though I wasn't really given a lot of resources, I feel like once I knew what was going on I was kind of able to advocate for myself enough to get those resources.”

5.4.2.2.1 Self-experimenting with treatments.

A lot of participants experienced a lack of information from their doctors about treatment options and plans for PCOS. In those instances, self-education aided them - learning to understand their condition better and researching therapeutic options on their own, often via the internet. Often a last resort, self-experimentation was a prominent theme for participants who did not have knowledgeable and involved physicians who could provide them with treatment options.

Holly, aged 29, turned to self-experimentation with treatments after not being able to find the guidance she needed in her GP. She explained:

“If it was coming from a GP, I would definitely trust that. In my experience, the information that I've been looking for hasn't come from a GP. When I was diagnosed, I wasn't given anything. Like in that experience, that kind of leaves me with my GP knows nothing about it so I have to go and figure it out myself. So then I trust the information in all of these books and looking at kind of what the popular opinion is on certain things. Like testing out all these different supplements and then trial and error myself.”

Vanessa, aged 63, had to go off all her medications, such as birth control and spironolactone, due to contraindications with menopause. Since then, she has been trying to find alternative treatments like supplements and over-the-counter medications and consulted a naturopath. Vanessa described an instance of finding out about a new potential herb for PCOS symptoms and brought that information to her naturopath for review:

“And then I suggested - I came across this article saying that berberine is a really good herb for women with PCOS. So she put me on a supplement that has berberine. But she didn’t bring it up herself.”

Vanessa was one of the few participants who had the opportunity to consult a health professional, in this case a naturopath. While naturopaths are an option to some participants, to others they were too expensive to visit and consult on a long-term basis, due to their services not being covered under most provincial health plans.

Other participants self-experimented without the guidance of any health professional. Lucy, aged 47, started going through menopause and could not continue taking her prescriptions. She was able to find over-the-counter supplements like black cohosh and vitex to regulate her hormones through self-education:

"It was my own research on what would help. I mean some of them directly related to PCOS, some of them related to some of the symptoms. And so it was just through my own research, and mostly trial and error with the dosages."

Myo-inositol, berberine, black cohosh, vitex, among supplements like magnesium and various amino acids featured prominently in many participants' self-experimentation. Pam, aged 28, was another participant who started to experiment with myo-inositol after researching about it:

"And the other thing I'm taking is a supplement, this is just through my own research, it's myo-inositol."

Eileen, aged 43, also self-experimented with various supplements that she learned about online. She had little luck receiving the care she needed from her doctors, which led her to double down on self-education efforts to figure out treatment options:

"I even go to medical study websites and I'm constantly poring over them to see if I can find out about the latest medications or natural remedies so that they can give me a clue. You know maybe I can do this by myself."

While self-experimentation can be risky due to not having a health professional to consult and approve treatment options, for participants who did not have access to a knowledgeable and involved health professional, self-experimentation was beneficial and allowed them to take matter into their own hands. Self-experimentation featured prominently in many participants' management journeys, often as a last resort.

5.4.2.3 Social support in real life (IRL) & online

Social support came up as a common facilitator in participants' management journeys, usually in the form of participants reaching out to friends and family, or online groups, for support when dealing with challenges with health. In cases where participants did not have social support IRL, online PCOS groups served as social support and as an informational resource.

When some participants struggled with hirsutism and other outwardly manifesting PCOS symptoms, connecting with their loved ones helped them cope with their feelings. Bianca and Fiona described how social support helped them cope with hirsutism:

Bianca, aged 36: "But with my mother and my girlfriends I'm like "oh my gosh" if anybody so much is complaining a little bit about an odd hair I'm like "Guys I have to shave." Like you know it's not something pretty or feminine but I definitely have friends and family in a support sense, that I can be open and honest and reveal on those less flattering aspects."

Fiona, aged 31: "Like just trying to stay connected with people and stay on those tasks just to make sure that if I'm having a shitty day and I'm feeling hairy on my face or feeling fat that I'm not alone with that."

Many participants did not feel comfortable openly sharing about some physical symptoms like hirsutism, possibly due to some stigma surrounding those symptoms to be seen as less "feminine." Bianca and Fiona were able to find other people with whom to share about their challenging symptoms and feel less alone.

Rita, aged 38, struggled with a lot of pain due to having both PCOS and endometriosis. During challenging periods of time, her family helped her cope:

"They will never feel my pain but they always tried to understand me and they always tried to understand what I'm going through. I would call my dad at 2:00 in the morning crying my eyes out because I was in so much pain. I knew he couldn't do anything but my dad was super supportive.""'

Mary, aged 27, was able to find support and comfort in her loved ones going through her trials with conceiving and experiencing miscarriages:

"Oh yeah, for sure. My family and close friends have helped me through all of the fertility drugs and everything that's happened through this crazy, crazy year. Yeah, so they're invaluable to me."

In situations where participants did not have loved ones who they felt supported by or they just wanted to connect with others in the same boat as them, online groups were an easily accessible source of social connection. Jamila, aged 26, really benefited from the social connection and support in online platforms. She was unable to find the support in her friends who could not fully understand and relate to her experiences. Jamila explained:

"In the group that I'm reading now, people have the same issues which I know and it's so nice, the group is actually what I find support in now. I really enjoy reading it and being able to

connect with the people. Before that I did not have any support. I'm actually feeling much better now. I was actually really depressed about it. I didn't have a way out to speak to anyone. No one would actually understand it. So now with that group, it's definitely much better. It's nice to talk to someone who would actually be able to talk back and explain it. Who would have similar things, unlike my friends who didn't know much about it. They would listen but they really didn't have the proper answers or didn't know what to say. I could see they were really uncomfortable about it sometimes as well."

Some participants used online groups as sources of information and advice in addition to social support. Divya, aged 22, explained how she views the subreddit she frequents as an online support group with potential to find important information on PCOS management:

"Having basically a support group - like I consider Reddit a support group because it's like a bunch of people, it's a kind of like group type forum discussing their issues and what their doctors recommend or what they've come across in research. So a support group in a sense has been helpful. And from that, what they say I put into looking at studies about what they're saying."

Vanessa, aged 63, also participates in online support groups but she has not been able to find a lot of relevant information there for women like her who are undergoing or have undergone menopause. To Vanessa, online groups function more for social support than as information-havens for her age group:

"It's more a support group, I haven't found a lot of information on there. And the one that I belong to, I find that I'm more for saying and giving advice than I am getting anything, because it tends to be younger people."

Social support was an important facilitator to almost all participants' management journeys. Social connection and support were found in close friends and family, as well as online with other women with PCOS. Connection with others with similar lived experiences helped to encourage participants when they were faced with challenges managing PCOS.

5.5 Discussion

A prominent barrier in management journeys of PCOS occurred when participants did not receive sufficient information from doctors. Key areas where more information and guidance were needed included: lifestyle management, treatment options/plans in the short- and long-

term, and PCOS implications and risks (e.g. risk for type II diabetes or mental illness), and details about test results and status of their health (e.g. hormone test, insulin sensitivity test). Many participants in this study were frustrated by how little information they were able to receive from their physicians, which added to the growing body of evidence of high rates of frustration in women with PCOS with the amount of information they receive [12–16, 19, 56, 81, 98, 144, 194]. Participants in this study were also frustrated by inconsistent information, attitudes, and approaches to management in health professionals. Inconsistent approaches to the diagnosis and management of PCOS have been previously found in physicians, contributing to frustrations for patients [18, 45, 46, 48, 64, 145]. Knowledge gaps around the diagnosis and treatment of PCOS were also found in residents in training [47]. The lack of clear information about PCOS led many participants to lose trust in their medical professionals and opt out of consulting their doctors for medical advice in the future (for both PCOS and unrelated concerns). A study by Lin et al. (2018) found that women with PCOS were more likely to have greater distrust in their PCP's opinion, have more arguments with their healthcare providers, and feel that their doctors spent less effort to treat PCOS concerns [13]. Patient beliefs about their healthcare providers and their trust levels can dictate treatment adherence levels and be used as an assessment of the quality of care received [195–197]. Overall, participants who received little information from their physicians began to lose trust in their physicians and/or delay starting management for PCOS due to misinformed and/or incomplete understanding about their condition.

Many participants wanted to implement lifestyle changes to manage their symptoms better, such irregular menses, fertility struggles, and insulin resistance, but did not receive enough concrete guidance from physicians on lifestyle management. Participants were often told to lose weight but not given guidance as to how to go about it or were referred to dietitians or nutritionists. Several other studies similarly report women with PCOS not being given information on lifestyle management [13, 144, 148]. There is wide variation across studies of physicians regarding how frequently lifestyle management is recommended by doctors [11, 45], and previous studies found low referral rates to dietitians from PCPs [60, 198]. Recommendations exist for doctors to provide information on lifestyle management and/or referrals to dietitians as necessary to patients [10, 46, 58]. Adherence to the recommended diet and activity levels can be challenging for patients yet needed to for PCOS management [199]. A 47.1% attrition rate was found among lifestyle modifications trials for women with PCOS in a recent review [61]. Previously, women identified support from health professionals, including

dietitians, as facilitators to weight management [149]. Yet most attempts to manage lifestyle appear to be self-initiated and maintained [60, 148, 149]. This study adds to the body of evidence that greater information on lifestyle management from physicians is needed for some patients with PCOS. Health education, along with individualized treatment plans, can support patient motivation to implement lifestyle changes and prevent health risks associated with PCOS [21].

Other experiences which led to loss of trust and withdrawal from seeking medical care included when participants perceived a lack of empathy and concern in their physicians. Many participants experienced a lack of empathy and concern in doctors when explaining symptoms or seeking care for symptoms, a theme which was found in many other studies [16, 18, 82, 141, 144]. Experiencing a lack of empathy in physicians often resulted in participants distancing themselves from their physicians and solely relying on self-management. Lack of concern in doctors over symptoms particularly affected younger patients who grew to lose concern over their symptoms and delay managing their symptoms for several years, realizing too late the importance of early surveillance and management. Another alienating encounter occurred for some participants who were overweight or obese who perceived weight bias in physicians. Some participants felt that their physicians investigated symptoms less, pinned the cause of symptoms on weight instead of exploring patient concerns, and assumed the state of the participant's lifestyle modification. Curiously, many participants who struggled losing weight and perceived a weight bias described their doctors not offering any guidance on lifestyle management. Weight bias is common and can have adverse health consequences, especially for patients struggling with eating disorders, as many with PCOS do [8, 200]. Participant experiences indicate that overweight and obese patients with PCOS may experience additional barriers as compared to lean patients with PCOS.

The theme of not being followed up with, not being asked questions, and not being given guidance on overall treatment plans was prominent in many participant journeys. Most participants interviewed were siloed from professional medical input while managing a life-long, complex condition. There were many experiences of physicians remaining uninvolved with the decision-making and tailoring of treatment plans. Many participants described being diagnosed with PCOS without adequate explanation, prescribed birth control and being sent on their way. Previous studies reported similar findings of participants lacking guidance and long-term support on the management of fertility and needing a comprehensive treatment plan from doctors [15, 18, 141, 143, 144, 144]. Long-term individualized treatment of patients with PCOS is needed to

minimize risk for comorbidity [10, 187, 21]. Shared decision making is important to future health and wellbeing in chronic illnesses like PCOS; the provider must provide comprehensive information about treatments which are tailored for the individual patient [98, 201, 202]. Many participants also described being unaware of the full state of their health because their physicians did not order tests to screen for various PCOS implications, such as diabetes, dyslipidemia, and even hyperandrogenism. Screening for diabetes, dyslipidemia, and hypertension is recommended in several guidelines [10, 26, 163]; however, surveys on physician practices show inconsistencies on screening practices for PCOS within specialties [203, 204]. It was especially concerning to find that many participants lacked access to a PCP involved with PCOS management. As PCPs are the only doctors a patient sees consistently on a long-term basis, those who were uninvolved with PCOS management added a significant barrier to management for participants. Most adverse participant experiences with regards to this barrier revolved around PCPs, like GPs. A lack of knowledge on PCOS may have contributed to doctors not knowing which information or guidance to provide, indicating a need to investigate and address gaps in knowledge in PCPs.

A sub-theme of doctors being unavailable for treatment guidance in many participants' management journeys included a lack of provision of care for mental health. Women with PCOS are a high-risk population for anxiety, depression, eating disorders, and poor body image [19, 205–207]. Health-related quality of life (HRQoL) is lower in women with PCOS compared to women without PCOS, with mental distress being the strongest contributing factor to lower HRQoL levels [146]. Women who were more likely to face attrition in lifestyle change trials had higher depressive scores at baseline [147]. Screening for these conditions is recommended by numerous guidelines to improve well-being, ability to successfully implement and sustain lifestyle changes, and manage PCOS [10, 61, 207].

In terms of age considerations, younger and older participants with PCOS faced unique barriers to management. When younger participants were diagnosed in adolescence or young adulthood by physicians who did not sufficiently inform them about PCOS, or seemed unconcerned about their symptoms, they were more likely to carry a low level of knowledge and concern about PCOS. After some time had passed, participants began taking concern about their health and realized how little they understood about PCOS and the need for management. Previous studies found that adolescents with PCOS can struggle with coping with their condition and required more guidance from physicians than they had received for their management of PCOS [82, 141, 208]. It is understandable for younger patients to not have a full grasp on the long-term

nature of PCOS and the potential severity of its implications. Extra effort to communicate pertinent information on PCOS may be necessary for younger patients, so they can come away with all the facts necessary to make educated choices in the short- and long-term.

Older participants managing PCOS also described receiving little information and guidance about PCOS management. Health risks and symptoms with PCOS persist post-menopause [209], but due to contraindications with hormonal therapy, women nearing menopause are taken off prescriptions like birth control [210]. Participants who were peri- and post-menopausal described still dealing with symptoms such as hirsutism, high triglycerides, and hot flashes. Women with PCOS in their 40s and older have a higher prevalence of hypertension and triglycerides [211] and are more likely to have insulin resistance compared to women without PCOS [212]. Due to health risks with most hormonal therapies in later age, all participants who were peri- or post-menopausal self-experimented with natural therapies, such as herbal medicines, mostly without the oversight of a medical practitioner. Older participants stated that they would have liked advice and guidance from their physicians but noted that their doctors had very little information to provide, leaving them with the need to figure out treatments on their own. Special consideration is needed from doctors to follow-up with and guide older participants in post-menopause.

A significant facilitator for positive experiences in management journeys was the availability of knowledgeable and communicative doctors. Participants felt supported and enriched by doctors who they felt were knowledgeable about PCOS and had a lot of information about PCOS to provide. Participants who received support from medical professionals in their management journeys valued the information and guidance they were able to receive. Patient perceptions of the quality of health information on PCOS has been found to be associated with HRQoL [56]. Information-giving is important, increased knowledge of PCOS empowers patients and is associated with better lifestyle practices and improved healthcare satisfaction [21]. Even doctors who lacked significant knowledge about PCOS but who were willing to investigate and address patient concerns were a resource for participants. Healthcare providers can benefit from understanding patient information needs and information-seeking behaviours in that they can more effectively meet patient expectations, facilitate quality information exchange, and achieve better health outcomes [213].

Important facilitators to the management journey for many participants lacking access to knowledgeable or involved doctors were self-advocation, self-education, and social support.

Self-advocation aided participants when they encountered physicians who had little knowledge of what to do or were hesitant to get involved with PCOS management; participants often had to advocate to get certain referrals to specialists or for their PCPs to investigate concerns more. Self-education featured prominently for participants who received little information and guidance from their medical providers. Self-advocation and self-education themes for women with PCOS were found in a few other studies [16, 18, 19]. Participants who self-educated relied on the internet to better understand PCOS and potential treatments. Sources of information online included: anecdotal information in online groups, various PCOS websites, blogs, and videos. Few participants recalled accessing any information from websites of various PCOS organizations, similarly to the findings of another study [15]. The use of the Internet as a primary source of information for women with PCOS is widely reported [15, 19, 98, 144, 151, 214]. Although a few participants had access to credible, peer-reviewed journals, due to school or work, most participants had to find their own way when sifting through information online. Although all participants acknowledged how information online can be unreliable; however, they had nowhere else to turn to and began to self-educate without the direction of a medical professional.

Self-education led to self-experimentation with treatments for some participants. Many participants began to self-experiment and devise their own treatment plans when lacking guidance from a physician. Some participants were either too hesitant to rely on medical therapies for long, preferred natural therapies, or were unable to continue taking medication due to contraindications (such as during menopause). Participants experimented with various over-the-counter supplements and herbal medicines including vitex, acupuncture, myo-inositol, black cohosh, magnesium, zinc, often without the supervision of healthcare professionals. The use of complementary medicine by women with PCOS may have increased in recent years, with nearly three of out four women reporting the use of CM in one study [110]. While some data suggests that herbal medicines can have therapeutic benefits [115], consensus on the efficacy of herbal medicines is not well-established [215, 216]. While many participants remarked that they would have liked to have medical professionals oversee their self-devised treatment plans, for many it was not an option as they lacked access to an involved and knowledgeable physician. Finally, social connection and support was an indispensable facilitator to many participant journeys, supporting previous findings [19, 143, 150]. Whether it was bonding with a friend who also had PCOS, or exchanging anecdotes and advice with other online users, social connection helped

participants cope with unpleasant symptoms and stay motivated and informed in their management journeys despite the lack of support from their healthcare system.

A lot of PCOS management entails daily self-care and self-management by patients. Effective management of chronic illnesses, such as PCOS, is complex and requires day-to-day self-management by patients. Self-management has multiple components: engaging in health-promoting activities, monitoring health status and making care decisions, interacting with healthcare providers, and adhering to treatment recommendations [217]. Many participants were committed daily to managing PCOS but received little recommendations or input from healthcare providers. Few participants in this study experienced doctors who they could rely on for information and resources in their management journeys, leaving them needing to self-educate and self-experiment. Greater support is needed for patients with PCOS from healthcare providers, especially to minimize risk for treatment non-adherence [143].

With so many participants lacking doctors with reliable information and guidance on PCOS management, it becomes important to emphasize the need for greater physician education on PCOS. Participant experiences in this study point to a widespread gap in knowledge on PCOS management in Canadian physicians, particularly PCPs, which left many participants with less trust in physicians. There is a need for health education for physicians to ensure delivery of consistent care for PCOs which is informed by evidence-based guidelines. Greater efforts need to be made by physicians to extend resources (such as reliable information, individualized treatment plans, referrals) to patients with PCOS, particularly with regards to lifestyle management and mental health. Physicians also need to be aware of the importance of information provision for patients in adolescence and young adulthood and the importance of follow-up for patients in peri- and post-menopause.

It is important to consider that due to the recruitment strategy employed in this study, many participants were recruited from online groups which consisted of engaged and proactive women who were invested in self-education and self-management. The study sample also largely consisted of women with a bachelor-level education who may be more aware of what information can be classified as reliable and unreliable online. Patients with more barriers to education, who may not have access to the same resources, are likely to experience even greater disconnects to reliable information on PCOS management and may suffer greater health consequences when lacking access to knowledgeable, communicative, involved, and concerned physicians. Participants were also engaged in their communities in real life and/or

online, forging social connections which helped them cope with their condition and gain some advice. It is important to consider the multitude of women with PCOS who may not have as much social capital and thus be less able to cope when lacking appropriate guidance from physicians. The study may not have reached patients with PCOS who may be less empowered and less invested in their management journeys, which underlines the importance of education for doctors on PCOS management and the importance of providing reliable medical information.

5.5.1 Limitations & Strengths

Limitations of the study include selections bias due to all participants being recruited from websites and online groups, eliminating the potential to reach women with PCOS who are not as active online. Most participants identified as Caucasian; few participants from diverse ethnic backgrounds were captured. The sample may not be representative of the general population of women with PCOS, and limited conclusions can be drawn regarding other world regions. Member checking, where participants are given an opportunity to review findings and provide feedback, was not performed since participant contact information was not recorded and permission was not sought to save information and contact the interviewees when data analysis was complete. A strength of this study included the involvement of peri- and post-menopausal women whose experiences and beliefs may not be transferable from the experiences of women of reproductive age. Previous qualitative studies largely involved women under 50 years of age [15, 16, 18, 19]. The use of remote telephone and Skype interviews allowed participants to feel comfortable and save financial and time costs by interviewing from their preferred location. Overall, this study addresses a gap in Canadian data on women's experiences with PCOS, and brings forth important insights to the pits and peaks in management journeys of women of a diverse range of ages.

5.6 Conclusion

Analysis of 25 in-depth interviews revealed several barriers and facilitators participants encountered in their management journeys. Overall, healthcare providers should be sure to address patient needs, and maintain patient trust, by providing ample information about PCOS and its implications on health, including the biopsychosocial, as well as guiding and individualizing treatment plans for women of all ages with PCOS. Guidance should include lifestyle management, including referrals to allied health professionals. PCOS manifestations vary across individuals and age; having long-term support and involvement from health professionals is key to helping women cope with a life-long condition like PCOS.

Follow-up from physicians on peri- and post-menopausal women's management of PCOS is needed to ensure that this age group of patients is not neglected. Younger patients may need ample information at the outset so that they can understand the various implications of PCOS and how to best mitigate those risks and not delay management. While self-advocation and self-education were prominent facilitators for women's management journeys, almost all participants preferred that their healthcare professionals were more involved and proactive in their management journeys. Education for healthcare professionals, especially PCPs, on evidence-based management of PCOS may be needed.

5.6.1 Policy recommendations

Participant experiences in this study, along with countless similar findings previously illustrated in the literature, reveal that clinical shifts are necessary to provide appropriate care for this complex, lifelong condition. Several international evidence-based guidelines and reviews [10, 23, 26, 55, 61] have been established for the diagnosis and management of PCOS which can be consulted by clinicians in practice. The guidelines inform of the necessary information to provide and the importance of screening and long-term follow-up, accounting for the individual needs and risk profiles of the patients. PCOS awareness may need greater integration in Canadian medical curriculums for all specializations, but especially in primary care.

5.6.2 Future research

Future research is needed to explore the experiences of women from various ethnic backgrounds accessing care for PCOS in Canada, a country with many immigrant women who may experience greater barriers to care not captured in this study. Most women in this study were largely Caucasian, little is known about lived experiences of immigrant/minority women in Canada accessing care for PCOS and the barriers and facilitators which may exist in their unique experiences. Individuals with PCOS who may not identify as women may also have unique needs in management which were not captured by this study. Studies are also needed to explore rural populations who were missed by this study, who live with limited access to doctors and who may also face greater barriers to care in Canada. Studies on physician populations are also needed to gauge PCOS awareness and inform education efforts. Finally, further studies are needed with women outside of reproductive age, such as peri- and post-menopausal women with PCOS whose experiences accessing are still not fully understood, particularly if they do not often access the Internet for information-seeking. Knowledge levels in

physicians on the needs of peri- and post-menopausal women managing PCOS have not yet been explored.

CHAPTER 6: ARTICLE 3

"What can be done to improve PCOS healthcare?": Insights from semi-structured interviews with women in Canada

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6.1 Abstract

Background: Polycystic ovary syndrome (PCOS) is a common and perplexing condition affecting metabolic, reproductive, cardiovascular, and psychological health in women. Previous studies point to widespread dissatisfaction and frustration in women with the information and care they receive. Studies have found delays with the diagnosis of PCOS and gaps in knowledge in physicians regarding the diagnosis and management of PCOS. Little has been heard from women regarding what they think can be improved with PCOS care, especially in Canada. This qualitative study explores women's experiences navigating the healthcare system and their insights on what could be improved based on their lived experiences.
Methods: In-depth, semi-structured, interviews held over the phone and analyzed using thematic analysis and interpretive description methodology.
Results: Twenty-five in-depth interviews conducted with participants across Canada (ages 18-63) revealed three overall areas in need of improvement. First, women emphasized a need for greater knowledge and awareness of PCOS in primary care physicians (PCPs) as well as the need for the medical community to prioritize women's health. Second, participants advocated for greater PCOS awareness and de-stigmatization in the general community and in women and girls, and any individuals with female reproductive systems. Third, participants brought up several needed resources, such as the need for more PCOS research to be funded and undertaken, more PCOS specialists and experts to be available, credible doctor-provided information (e.g., pamphlets, websites), and age-specific support groups and mental health supports to be available. Participants were generally unaware of existing PCOS organizations and brought up the need for established PCOS organizations to aid in the training and retraining of doctors and local awareness-building in communities.
Conclusions: As PCPs are often the gatekeepers to the healthcare system, greater training is needed for them to be more comfortable providing diagnoses and guiding management for PCOS. Greater awareness and de-stigmatization in the general community is needed so women can identify symptoms as they present themselves and have access to support from those around them. Overall, PCOS appears to be significantly overlooked and under-prioritized, both in the Canadian healthcare system and general community.

Keywords: PCOS; polycystic ovary syndrome; interviews; lived experiences; improvement; reform; health care; health services

6.2 Background

Polycystic ovary syndrome (PCOS) is a condition affecting 8-13% of women of reproductive age [1]. As a complex and multifaceted condition, PCOS impacts women's health and well-being in a multitude of ways. Women with PCOS often struggle with menstrual irregularity [4], infertility [5], body image issues [41], eating disorders [8], hirsutism [6], acne [7], and anxiety and depression [9]. Insulin resistance, central obesity, and dyslipidemia are also prevalent and can place women at a higher risk for developing type II diabetes and cardiovascular disease [2, 3].

PCOS is diagnosed most often with the Rotterdam criteria when 2 out of 3 of the following features are present with the exclusion of other conditions: polycystic ovaries on ultrasound, biochemical/clinical hyperandrogenism, and oligo-amenorrhea [175]. First-line treatments for PCOS include lifestyle management and oral contraceptive pills [89, 101]. Lifestyle management, involving weight loss or healthy weight maintenance, remains the most effective first-line therapeutic intervention [58, 218].

PCOS is a confounding condition, for both patients and clinicians, and the evidence suggests that women may not be receiving the quality care they need. With no known cause or conclusive treatments or cure, PCOS can be hard for health professionals to manage and understand. There appears to be widespread gaps in knowledge and inconsistent approaches among residents and physicians on the diagnosis and management of PCOS [45–49]. A recent study with physicians revealed some difficulty and confusion with PCOS care, as the spectrum of PCOS presentation can make it hard to determine appropriate diagnosis and management [51].

Surveys and interviews with women have reported similar salient findings: women are dissatisfied with the information provided to them by physicians, face delays in diagnoses, and are frustrated with the levels of knowledge and effort their physicians have in addressing their concerns [11–16]. Some women lose overall trust with their physicians [13, 17]. Mental health impacts of PCOS are often unaddressed in doctor's visits [16, 62, 63] and women describe being discounted or brushed off by physicians [13, 16–19].

With such high rates of dissatisfaction and frustration in women with PCOS, along with gaps in knowledge and confusion in physicians, it becomes important to gather insights from this

population on what can be improved in PCOS healthcare provision, based on their lived experiences. This study describes findings from in-depth interviews with women to improve the care they receive for PCOS and ultimately, their quality of life. Although this study has recruited women with PCOS in Canada to interview, the insights gathered may be transferrable to women accessing care in other countries.

6.3 Methods

6.3.1 Study design

In-depth, semi-structured phone interviews with participants explored their experiences getting diagnosed with and managing PCOS, as well as their thoughts on how to improve PCOS healthcare based on their experiences. Interview participants were sourced from a larger, multi-methods study involving an online questionnaire about PCOS diagnosis experiences hosted on SurveyMonkey. Respondents who indicated interest in being interviewed at the end of their questionnaires were subsequently interviewed remotely, over the phone, on a first come first serve basis. Interviews were in-depth and lasted around 1 hour (see Appendix C for interview guide). Only the themes related to participants' views on how to improve PCOS healthcare are explored in this paper.

6.3.2 Research setting

Survey respondents and interviewees participated from across Canada. Canada is a country with 38,005,238 people as of July 2020, with the 4 most populous provinces being Ontario, Quebec, British Columbia, and Alberta [159]. The three most populous provinces after Ontario (14,734,01) are Quebec (8,574,571), British Columbia (5,147,712), and Alberta (4,421,876) [159]. Interviews were conducted by the first author in a private residential office in Ottawa, Canada with no one else present.

6.3.3 Participants and recruitment[3]

A purposive convenience sample was gathered online with participants who met the inclusion criteria: age 18 years or older, reporting a medical diagnosis of PCOS, having lived in Canada

[3] Recruitment posts included gendered, women-specific language. However, not all people with PCOS may identify as women. Due to our recruitment, we will continue to use gendered language in this publication to reflect our sample.

since their diagnosis, and able to speak and understand English. No upper age limit was established to promote participation from older patients living with PCOS, in the peri- and post-menopausal stages of life. Participants were recruited through posts on PCOS groups on Facebook, Reddit, and online PCOS forums. Social media was used as a recruitment strategy to reach a wider sample from across all Canadian provinces. The survey was advertised entirely online by the first author posting a short paragraph about the purpose of the study along with a recruitment poster and a link to the survey on SurveyMonkey. The PCOS Awareness Association also helped with recruitment by doing a one-time re-post on their Facebook page with the study's recruitment poster and the survey link. Participants who filled out questionnaires were invited to submit their contact information for follow-up interviews. Participants were interviewed in the order in which their affirmative responses and consent forms were received. Recruitment continued until preliminary analysis during data collection suggested thematic consistency across age groups and no more peri- and post-menopausal women were available to interview. Recruitment took place between April and December of 2018.

6.3.4 Data collection

Twenty-five interviews were conducted remotely over the phone by the MI between October and December 2018, averaging an hour in length and conducted in one uninterrupted meeting. All interviews were audio-recorded (with participant consent) and transcribed verbatim by the first author. One interview was held over Skype™ due to participant preference. The participants were encouraged to share their experiences through a semi-structured interview process. The semi-structured interview guide was developed by MI based on themes and gaps identified in previous literature, and included questions such as, 'Could you describe a typical day living with PCOS?' and 'Are there any resources you wish were there for you?' (See Appendix C for interview guide). Pseudonyms are used here and in all written documents.

6.3.5 Data analysis

MI coded all qualitative interview data, including field notes made during and after interviews, and managed all data in NVivo 12 (QSR International Pty Ltd. Version 12, 2018). In accordance with Thorne et al.'s (2004) [152] interpretive description methodology, an inductive analysis technique was used to analyze data. Themes were derived entirely from the data. Thorne's (2004) [152] interpretive description approach is widely used in nursing research and does not generate new truths or theories but rather describes thematic patterns and commonalities while also accounting for individual variations and provides a product that clinicians can use as a

backdrop for clinical decision-making. Braun and Clarke's (2006) [160] six key stages in the thematic analysis of qualitative data were also followed in this study: (1) Familiarize, (2) Generate initial codes, (3) Search for themes, (4) Review themes, (5) Define themes, and (6) Write up the data analysis. Codes, subsequent sub-categories, and over-arching themes were generated directly from topics raised in the data.

6.3.6 Trustworthiness

This study was reported based on the Consolidated criteria for reporting qualitative research (COREQ) (see Appendix E) [161]. At the time of the study, MI was a MSc student conducting in-depth interviews for the first time after training in graduate classes and workshops. MI identifies as female, and participants were made aware of the reason for the author to be conducting this research, their personal interest in the research topic, and PCOS status, but otherwise no significant relationship existed or was established between the author and participants. To ensure reliability and validity, MI considered researcher bias, used the strategies of thick description, development of a coding system, checking and agreement on themes and analysis by members of the team, transparency when reporting research (as per COREQ), and demonstrating the author's interpretive lens throughout the report [152, 161].

6.3.7 Ethical approval

Ethics approval for the study was received from the University of Ottawa Research Ethics Boards (REB) in April 2018. Participants were voluntarily enrolled in the study with free and informed consent. Participants were informed that once they chose to participate, they could withdraw their consent and data at any time and/or refuse to answer any questions, without suffering any negative consequences. Written or oral informed consent was obtained from all participants prior to their participation. Permission to audio-record the remote interviews was sought and obtained before data collection. All personal identifiers were removed from transcripts and in quoted texts below.

6.4 Results

The interview sample of 25 participants included mostly White/Caucasian women born in Canada (see Table 6.1 for demographic characteristics). Most participants were between the ages of 25-30, resided in Ontario, and were employed full-time. Seven participants had children,

and nine participants were looking to conceive at the time of the interview. All participant names below are pseudonyms.

Table 6.1 Demographic characteristics of interview participants (n = 25)

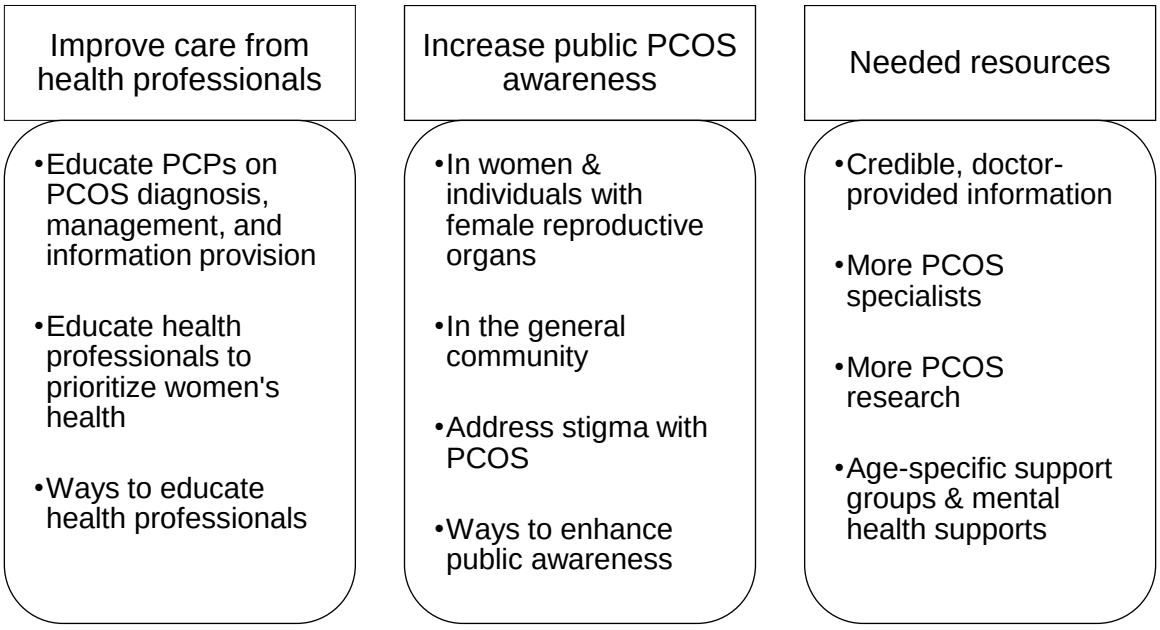
Demographic characteristic	Number of women (%)
Age group	
18-24	5 (20)
25-30	10 (40)
31-36	4 (16)
37-40	2 (8)
41-50	2 (8)
51-66	1 (4)
Province	
Alberta	4 (16)
British Columbia	4 (16)
Ontario	13 (52)
Quebec	1 (4)
Ethnicity	
Black	1 (4)
East Asian	2 (8)
Middle Eastern	2 (8)
South Asian	2 (8)
White/Caucasian	18 (72)
Marital status	
Single	11 (44)
Common-law/live-in partner	5 (2 0)
Married	9 (36)
Education	
Bachelor’s degree	12 (48)
Master’s degree	3 (12)
Trade/technical/vocational training	2 (8)
Employment	

No paid work	3 (12)
Student	7 (28)
Employed full-time	12 (48)
Employed part-time	1 (4)
Parental status	
No children	18 (72)
Has children	7 (28)
Looking to conceive	9 (36)
Pregnant	2 (8)

*Note: based on information participants were comfortable divulging, not all participants are captured.

Several themes emerged on how to improve PCOS healthcare. The main over-arching themes of areas of improvement include: (1) improvement of care provision from healthcare professionals, (2) promotion of public PCOS awareness, and (3) provision of several needed resources. Participant-identified strategies on how to bring about education reform for the public and medical community are also discussed. For a breakdown of the themes and sub-themes, please see Figure 6.1.

Figure 6.1. Themes and sub-themes on how to improve PCOS healthcare.



6.4.1 Improve Care from Health Professionals

6.4.1.1 Educate PCPs on PCOS diagnosis, management, & information provision

One of the main topics participants highlighted was the need to improve PCOS healthcare by improving knowledge in primary care physicians (PCPs) so that they can be more involved in care provision. Participants often began their diagnosis and management journeys with their PCPs, whose level of knowledge on what to do with their symptoms greatly influenced participant experiences. Many participants described instances of PCPs brushing off concerns, not providing referrals, and not ordering tests to investigate patient concerns. Participants reflected that PCPs, as first points of contact to the healthcare system, greatly determined the speed at which a patient could be diagnosed and the breadth of resources available to them.

Mary, aged 27, had a long journey to her diagnosis and believed that increased knowledge at the PCP level would quicken the diagnosis process and avoid the potential to accrue greater costs by reducing the need for referrals. Mary also discussed that PCOS is a prevalent condition in women and warrants knowledge at the PCP level:

“So it's not this kind of rush to get like - it's not like you have to get a referral to get this diagnosis. Because really the frequency that it happens, it shouldn't be something where you need to wait for a specialist to get the first step of care. And that's kind of what it is right know. And if you can't get an endocrinologist for whatever reason. And I know in Canada we're fortunate to have covered healthcare. But in the States or somewhere where these things cost a lot of money then you might not ever get a diagnosis if you can’t afford to go to those specialists. So there's definitely something wrong when your general practitioner can't at least take the first steps to help you with your diagnosis.”

Many participants noted that GPs were not fully aware of the spectrum of presentation of PCOS. Melissa’s experiences led her to remark that GPs needed to be educated on how PCOS can manifest differently in individuals, including how it can present in lean and overweight patients:

“I think that more education for doctors, not every person who has PCOS has the exact same symptoms all the time. You know, they think that I'm a bigger girl who has PCOS but my friend who is 115 pounds soaking wet, she has cysts all the time. I barely ever get cysts. There's so many things that it can or cannot be for any one individual, and I guess that makes it harder to diagnose. But I just wish they knew more about it. Because it seems really widespread.”

Many participants’ PCPs were generally uninvolved with PCOS management. Brianna, aged 21, wanted more access to knowledgeable PCPs who could work alongside specialists in management of PCOS. She explains how important GPs are in healthcare delivery and the benefits of them working with specialists in the field to provide the best possible care:

“It’s just also someone who actually knows your particular issue. They have all your methods and they have all the records of your issues. They see things that specialists don’t because they don't know your personal situation. So maybe a combination of doctors who know their situation and the doctors who are reading in this field.”

Some participants wanted PCPs to know how important information provision at the diagnosis is to them. Many participants were diagnosed without receiving enough information on what PCOS is and what it may impact in their lives. Patricia, aged 29, remarked that GPs needed to be educated on PCOS and be trained to provide information to the patient at the time of diagnosis:

“Because I guess they're usually the frontline people, make sure that they are aware of side effects and make it a point to tell them that you know “when you diagnose someone you should be giving these facts and these things as they go about their diagnosis.” I don’t know, maybe have a pamphlet or something that they can hand out so they can go over the effects and their treatment options and things like that.”

It was important for participants to receive information from their physicians instead of having to search online to educate themselves. Participants expressed that although they wanted to trust their doctors, most lost trust due to the lack of information and/or involvement from their physicians. Mary, aged 27, expressed that she wanted to be able to trust and rely on her doctor, but when she was not finding the information she needed, it was hard for her to do so:

“Because it's not that I wouldn't trust my doctor if they gave me that information but they don't. So it kind of instills a lack of confidence, you know? So it's not even “who do I trust the most” it’s like “who is the only one giving me information?” Because I would trust – like if my doctor

handed me a pamphlet and was like "this is PCOS, if you have any questions ask me" then I would 100 percent trust that. But then it's like they're not doing that."
To sum up, education for PCPs on the diagnosis and management of PCOS was emphasized by participants so that they can be more greatly involved in care provision. Most participants were not able to receive enough information and guidance from their PCPs on what PCOS entails (its implications and risks) and what treatments options are available to them. When encountering unknowledgeable or uninvolved physicians, participants often lost trust and some opted out of seeking medical care.

6.4.1.2 Educate health professionals to prioritize women's health

Most participants felt that women's health was not prioritized or taken seriously by the medical community, and PCOS being a women's health issue, it was predictably also not taken seriously. Participants wanted the medical community to realize that they had been overlooking women's health and thus, impacting healthcare delivery for PCOS and other conditions like it. As Mary, aged 27, put it, "*I feel like in general women's health has been neglected and this is just kind of like one of the issues that goes along with that*."

Margaret, aged 33, explained how hard it can be to access the care you need for a women's health condition. She explained:

"I mean I don't think that that's just confined to PCOS. I think that that's something that you can probably say about women's health in general. I know I heard so many stories from so many of my other girlfriends and not strictly PCOS-related but sort of with chronic conditions that they dealt with, that it's like a fight really to find somebody. It seems like when you're a woman that it's that uphill battle of getting somebody to take you seriously. So I think that that's probably definitely a factor. I mean I know it's certainly a factor in women's health care overall and I think that it's probably even more of a mitigating factor when you're talking about conditions that specifically are kind of women's health issues, you know."

Emma, aged 29, was another participant who felt that PCOS was not prioritized by the medical and research community. She felt that if she had developed cysts anywhere else, they would probably have been taken more seriously:

“I still don't feel like I have the same access to health care that certain other people would with a similar diagnosis that isn't female fertility related. You know I feel like if I had an abnormal growth anywhere else it would be dealt with a lot more seriously.”

Emma felt a lot of frustration at the lack of access to quality care she, and many other women, chronically experienced in their management journeys. She identified a systemic nature to the under prioritization of women’s health:

“So yeah that's, it's very frustrating. I think that especially for women's issues, it can be very frustrating to kind of feel like you don't have the availability of care that you needed… I think there are both institutional reasons and the fact that it isn't very studied, so I would say all of them would be institutional with the female... You know it's just not as big of a priority.”

Abigail spoke about how often patients with PCOS push for a diagnosis and for their concerns to be taken seriously:

“And you know probably not all deal with it in the same way because the symptoms are spread across the board for it. So I just think maybe more knowledge for all the doctors that it is, you know, an actual thing. Because I know some people go untreated for years and their doctors are like “no, you don’t have anything, nothing is wrong with you” and then all of a sudden, they have it. I’ve read a lot that people have to advocate that they have something and that their doctors have to keep testing them for stuff because some say “no you don't have anything, nothing is wrong with you, no.””

To recap, participants identified multiple ways to enhance healthcare delivery from health professionals. First, PCPs need greater education about PCOS to better be able to diagnose and treat it, to provide referrals and stay involved with the patient’s team of healthcare professionals, and to know which information to provide the patient to properly equip them to understand and manage their condition. Finally, the medical community in general need to be made aware of the under-recognition of PCOS, to prioritize women’s health, and take patient concerns seriously and not brush off potential key symptoms.

6.4.1.3 Ways to increase physician knowledge

Health education reform for medical professionals is no small feat and will likely require adequate funding and effort. Participants identified several ways to educate medical

professionals: conferences on PCOS that health professionals can attend and learn from, similarly seminars/webinars to inform doctors, and to have a reputable PCOS organization to oversee the education efforts and disseminate newly generated research on PCOS to doctors to learn from.

Divya, aged 22, identified conferences as a potential source of information and education for doctors:

"Maybe like a workshop or conference that talks about the prevalence in women and what the symptoms are and how they could help if there is any research."

Fiona, aged 31, was reflecting on wanting a seminar for herself and her doctor to attend so that they both could get the most reliable, and newest, information about PCOS:

"I wish that like there was a seminar or something. And also I wish there was like a doctor seminar so that my actual doctor could take a class on it or go to an information session or read some case studies or I don't know. Because I know that people learn from other doctors. So I wish my personal doctor could go to that. Or have the opportunity to see stuff."

Fiona pointed out an important insight: people learn from doctors. If doctors had a way to be educated about PCOS, they would be in a better position to care for their patients and impart the right information to their patients.

Some participants wanted a reputable PCOS organization to exist which could provide information, research, and education for doctors. Lucy, aged 47, hoped for a PCOS organization to exist to help train and educate physicians so that they can stay up-to-date on best practices:

"Well if there was some sort of organization that provided that information on a regular basis, where professionals who had to work with women who have PCOS, and there are a lot of them out there, the GPs and specialists who are required to take this ongoing training and to be updated so that their information was valid and up to date. I think that would be a positive thing."

Despite the need for them, there are not many well-established PCOS organizations that host a lot of educational and awareness-building events and activities in Canada. Very few participants recalled visiting the websites of PCOS organizations and finding relevant information.

6.4.2 Increase public awareness of PCOS

6.4.2.1 In women & individuals with female reproductive systems

Although the medical profession could use a lot more education about PCOS, participants also acknowledged that PCOS awareness in women is very low. Many participants identified a need for greater education and awareness on common women's health conditions like PCOS. Drawing from their own experiences and what they wished was different in their journeys, participants reflected that greater awareness of PCOS might have allowed them to achieve a diagnosis sooner and start managing symptoms.

Lily, aged 18, reflected on how little discourse there is on PCOS and other women's health conditions. She explained:

"And not everyone knows about it. But I do feel like, in terms of health and sexual education, we can definitely start talking about these things. And hopefully people will be more educated and be likely to seek medical help if they actually do experience symptoms."

Rita, aged 38, spoke about how women's health education can empower women to recognize concerning symptoms and seek care:

"I think that if more females were educated on things like this that could occur to them in the future. Like when they're just learning about sex ed or whatever it is about that age. They should also learn that these are the things that you can encounter as you're going through your motions and your hormones and when you're in your whatever age group is for this PCOS. It would help them prepare for it. I don't know if they could prevent it, but they can be proactive. Those who aren't looking after themselves can maybe change their lifestyle, educate themselves."

Josephine, aged 32, remarked how little knowledge her circle of friends, and herself, had of PCOS. Josephine reflected that maybe she might have been diagnosed with PCOS sooner had she been aware of it:

"To speak more about it because I read that a lot of women have PCOS. It was one of the first reason for infertility for example. But when I discovered I had PCOS I talked about it with some

friends around me but nobody ever heard about it. And I think if I've heard about it before maybe I would have discovered that I have PCOS a long time ago because of my weight, acne, and my periods. And I wouldn't have waited so many years to have answers. And I think there was a lot of women who have PCOS and they don't know about it."

Fiona, aged 31, discussed how PCOS awareness had not grown significantly in the last decade:

"So I think just more awareness really. I mean 10 years ago it was a little bit different than it is now. But even now nobody knows."

Fiona's point about PCOS awareness not increasingly over the last decade was echoed by many participants. Older participants recalled no one knowing about PCOS when they were younger and getting diagnosed, and younger participants also described how little the people around them knew about PCOS.

6.4.2.2 In the general community

Another benefit to building general community awareness of PCOS is the ability to make women with PCOS feel less isolated and alone. One of the most common descriptors participants used to explain having PCOS was "isolating/alone". If the general community had a greater awareness of PCOS and other women's health conditions, women with these conditions may feel less isolated and alone and be able to find sources of support around them. Most participants had little to no real-life friends who were aware of PCOS, despite it being a relatively common condition, which made participants feel more isolated dealing with their condition on their own.

Lily, aged 18, felt hesitant to open up about her diagnosis and once she did, she found that none of her friends understood what it was or were aware of it:

"At first, I didn't really talk about it or tell anybody other than my parents, but yeah now that like I've talked about it more with people my own age… A lot of people don't really know what PCOS is, and there are a lot of misconceptions about it, I guess. And just about other menstrual problems that come along with it. There was just not a lot of conversation about it, I guess."

Lily's friends were supportive but had a lot of questions, which made Lily realize how little she and the people around her were educated on PCOS and women's health conditions:

“In terms of telling my close friends. A lot of them had no idea what PCOS was. Like what does that even mean? It sounds kind of scary because like does that mean I have cysts on my ovaries? I guess I got a lot of questions about it. And I feel like their reactions have been - obviously my friends are very supportive but like there’s a lot of questions. I didn’t know anything about PCOS until I was diagnosed with it. It’s not something that’s taught in schools I guess.”

Pam encountered people around her to not be concerned about or aware of PCOS, she describes it as being a lonely experience:

“I think it’s an education thing, people aren’t that concerned about it. It’s probably just because they don’t know about it. PCOS takes so many forms and it can be so severe or not so bad, and I feel fortunate that I’m not struggling with diabetes as a result of PCOS. It could be so much worse. It has been definitely a lonely experience.”

Divya, aged 22, reflected a lot on societal lack of awareness of PCOS and the potential drawbacks it can have on women, making them feel more isolated and misunderstood. She explains:

“I can understand people saying like “oh no one really even knows what it is, and they have no empathy in the public for it.” Because actually like you see online a lot… like there’s that one obese model or something, Whitney or someone from “My 600 pound life.” But she has PCOS. And everyone makes fun of her for her weight. They don't actually think that it's harder to lose weight on PCOS. So I see a lot of that, and that kind of sucks too where everyone's like “oh you people use PCOS to hide behind their weight issues” but it's like it's actually harder because of our insulin issues but no one really knows that. So that's another thing.”

Divya referred to PCOS being linked to various mental illnesses and eating disorders and thought that societal unawareness may contribute to greater stigma around those aspects of PCOS:

“I know a lot of people with PCOS have problems with binge eating or eating disorders or mental health like depression symptoms. Either due to their symptoms or just like the societal like no help at all for what they're dealing with.”

Awareness of PCOS and other women's health conditions was identified as important in general physical and sexual education. If the general community were more aware, women would be more likely to spot concerning symptoms and access care promptly, parents would know to take their children in to the doctor, and people would be able to support one another with understanding.

6.4.2.3 Address the stigma with PCOS

With greater awareness on PCOS, it is important to also address the existing stigma with PCOS and its symptoms. A lot of participants reflected on there being a stigma around PCOS (and potentially women's health in general) when they noticed themselves feeling shameful about talking about their symptoms openly, or they noticed others around them not discussing PCOS openly. Many PCOS symptoms like acne, excess hair, weight gain are currently perceived as undesirable and less feminine in women, which introduce stigma into having this condition. There does appear to be a real stigma with women's health that needs to be lessened as awareness of the condition is established.

A lot of participants found themselves hesitant to openly share their diagnosis and symptoms - and were often not sure why. Lily, aged 18, described her thoughts:

"I guess there's a stigma around it - you don't really want to tell people and I feel like just in general there's a stigma around periods. But yeah, I still don't feel 100% comfortable telling my friends about it. And not everyone knows about it."

Patricia, aged 29, detailed how she experienced unwanted facial hair and has experienced people around her making fun of others with facial hair, leading her to keep her symptoms to herself:

"I am someone who is terrified of waxing so I just shave it daily which is sort of embarrassing but you deal with that. Some are cool with that. And then some other people who don't shave their faces or take care of the hair, which I'm totally fine with them doing whatever they like. But I do have some good friends that I haven't really shared that portion of my symptoms with them. And to hear them kind of make fun of other people with it, it's always like "well it's not always their fault.""

PCOS symptoms like hirsutism and weight gain are typically ridiculed and deemed undesirable in women by society's current standards, which contributed to women keeping their symptoms to themselves, as Patricia did. Josephine, aged 32, also found it difficult to share her physical symptoms with others due to the stigma, and felt shame about her symptoms:

"Not much. With my partner, but yes it's kind of difficult to speak about acne, weight, and hot flashes because it's not very… These are things you don't want people to know about it… But I don't feel very confident to speak about. Because it's hard and shameful I think."

Pam, aged 28, consciously chose to speak out about her condition, in hopes to lessen the stigma and increase awareness:

"It's been the most surprising part of it. The statistics are like, I mean it varies, but say 1 in 10 women have PCOS. And I think because it's related to the sex organs, there's a bit of shame about it or secrecy… It's a private thing, people don't talk about it. But I've been really vocal about it because I think the odds are 1 in 10 women have it, like some of my friends might have it, they just never talked about it because they never felt comfortable. And it can be very isolating dealing with PCOS… But a lot of people have struggles like PCOS but feel shy talking about them for whatever reason."

Pam brings up feeling isolated having PCOS and attributes some of the cause to stigma barring women from feeling comfortable and accepting of themselves and discussing their condition openly. She was one participant who actively tried to break the stigma by being vocal about her symptoms.

6.4.2.4 Ways to enhance public PCOS awareness

Participants identified several strategies to improve public awareness of PCOS and stimulate discourse. One way was to revise sexual education curriculums so that young people can learn about common women's health disorders like PCOS and later be better equipped to recognize symptoms if they arise. Another way was to fund PCOS organizations or other awareness organizations to host community outreach events, like local runs or fundraisers, to raise awareness locally for PCOS.

Lily, aged 18, was diagnosed in adolescence and did not recall learning about PCOS or women's health conditions in health class until enrolling in her undergraduate degree in a health

discipline. Lily reflected that a lot of her friends who are not in her program probably lack her level of awareness of PCOS and youth may benefit from being exposed to PCOS and similar conditions earlier in school:

"I would definitely like to see things like PCOS, endometriosis, things that are not just what a normal regular period should be like but maybe like how abnormalities are. Like what to do if you're experiencing symptoms like the irregular menstrual cycle I guess. Yeah, I'm very fortunate to be in a program where I know about a lot of these symptoms, so I know a lot of my friends probably wouldn't have gone to OBGYNs, or probably would just thought it was something normal. So being integrated in sex ed or in elementary schools especially. During that time we're first experiencing health class."

Brianna, aged 21, found that many people had misconceptions about PCOS which are not being corrected because no one talks about women's health in general. Brianna thought that greater education on PCOS, for example in sex ed classes, may help reduce the stigma:

"Actually, it'll be really good to learn about this in high school. In high school we had the you know "these are STDs" and stuff like that but I don't actually remember hearing about these types of problems in high school. So I never really thought about that. But yeah, just to cover like "these are the problems" because I think there still might be kind of a stigma on people who have a hard time. People should know about that."

Josie, aged 27, identified a need for awareness and health promotion at the local level, perhaps by an established PCOS organization. She explained:

"I think the idea of having a more local group advocating for PCOS education or something like that. I know there's fairs and festivals and different events that we have locally that could include a little booth for PCOS. I think just getting into the community, having people who can share what they know, share resources that they've been given or found, yeah. I think starting at the local level is helpful."

Divya, aged 22, reflected that a lot of awareness-building activities are already established for some women's health conditions, and that something similar can be established to raise awareness about PCOS:

“Like I feel there’s a lot of awareness on breast cancer, and fundraisers and everything around campuses, packages of food, and pens, and whatever you like to see. There’s no types of things for PCOS. You always hear about those other diseases but I’ve never really seen a PCOS-centered, like “this is a run for women with PCOS.” Even though I feel like it’s 1 in 10, like many women have it now. So it's not uncommon, it's not like a niche to say “let's do a PCOS-targeted type of fundraiser.””

Raising PCOS awareness in the community was a very prominent theme raised by all participants. To sum up, raising awareness is important to help women take charge of their own health, to break the stigma surrounding women’s health, and to have less women feel isolated when living with PCOS. Some strategies to increase general awareness of PCOS included: reform to sexual education curriculums and a need for organizations to host local events to raise awareness.

6.4.3 Participant-Identified Needed Resources

6.4.3.1 Need for credible, doctor-provided information about PCOS

Most participants described not receiving enough information from their doctors at the time of their diagnosis or afterwards. While many participants took matters into their own hands and found self-education to be a great help when missing information from their doctors, they also recognized the risks of only having online, non-validated, information to rely on. A significant participant-identified need was for credible, doctor-approved informational sources – for example, information that their doctors could direct them to (e.g. accredited websites with info on PCOS) or pamphlets that the doctors could directly provide them during visits. Reliable information on PCOS and its management was a missing resource for almost all participants.

Mary, aged 27, was not able to collect much information from her PCP or the specialist she had seen. When reflecting on which resources were missing for her, she identified pamphlets as a needed resource:

“I mean honestly, you know like when you go into a doctor's office and they'll have a little pamphlet like “this is diabetes” or whatever type of thing, you know? They always have like a

medical pamphlet. I feel like there needs to be something where they can just hand you and be like "here's some basic information.""

Holly, aged 29, was another participant who wanted to have access to pamphlets. She describes how she did not learn about various PCOS implications until after she did her own research:

"But I mean if the doctors could just have a pamphlet or direct people to these sorts of things, that would be great… Even like a pamphlet, it's just understanding that like irregular menstruation is not the only thing that happens. You can have weight gain, you can have insulin resistance, you'll have cystic acne, and that sort of thing. Not just by doing all my own research I'm finding out all these different things."

Although pamphlets were commonly mentioned, many participants just wanted any source of credible information that doctors could refer them to. Josie shared:

"It would just be nice to be able to find information online and then also from a doctor. It'd be nice if my doctor could have a little pamphlet or have the knowledge of PCOS. Even be able to suggest other places to find information."

Lily, aged 18, came from a Chinese background and had trouble explaining PCOS and its treatment to her parents. She described a need for multilingual informational sources, like multilingual pamphlets for example:

"With my parents, I guess there's a slight language barrier as they speak Chinese and I speak English primarily. My Chinese isn't amazing… I found it really difficult to have the conversation with them because of the language barrier. I would definitely have appreciated multi-language resources. Really, the only resources I found were in English. But I'm not sure if that's because I only speak in English, I can only read in English. It would be extremely beneficial if I had those resources for languages."

To sum up, a reliable, doctor-provided information source is needed for participants to learn more about their condition and how to manage it. Take-home reading material, in multilingual formats, is needed so that even if the doctor does not have much time for a sit-down, the

patients can learn on their own time from a reliable source. Participants often had to solely rely on finding their own information online with potentially unreliable sources.

6.4.3.2 Need for more PCOS specialists

Another resource that participants wished they could have access to were doctors who were specialized in PCOS. A lot of participants had positive experiences with fertility specialists, who cared for many patients with PCOS with regards to fertility. Surprisingly, experiences with seeking care from gynecologists and endocrinologists varied. Some participants found that their specialists they were referred out to, like endocrinologists and gynecologists, were knowledgeable about PCOS and could help answer questions, while other participants came across specialists who had little more knowledge about PCOS than their PCPs.

Josephine, aged 32, was one participant who was not able to benefit much from seeing her endocrinologist, making her want for more specialization in PCOS:

"I wish, yes, it would be very helpful if there was a list of doctors and specialists as specialized in PCOS. Because the endocrinologist I've seen wasn't specialized in PCOS and she didn't help me. So if we had a list of specialists it would be very helpful because I would know that if I want answers, I would just have to go see this person. I think it would be the most important thing."

Sally, aged 30, similarly was referred out many times but found that few gynecologists had enough PCOS knowledge, she explains:

"And it's super frustrating that you're being sent around in circles, and I think that's what my problem was. Like, I'm in Calgary and I found that it's a huge problem here. There's only a couple of gynecologists in Calgary that actually specialize in PCOS and endometriosis. And that's disgusting, there needs to be more."

Emma, aged 29, was diagnosed by accident during an unrelated ultrasound for her IUD. Her PCP was not knowledgeable on PCOS, and Emma had to take sole charge of her treatment plan and self-educate. Emma hoped that clinics could open that specialize in PCOS, so that she could have access to experts before necessarily trying to conceive:

“There are no clinics they send you to when you're diagnosed with PCOS where they're like this is a clinic where they have actual experts in this topic that you can meet with. I feel like if I had something wrong with another aspect of my health like I was going to see my lungs or my stomach or whatever it would be like sending you to a specialist who specializes in that… and it would be very nice if there was like "oh there's this PCOS clinic and you can be referred to this and then they will do things like look at your hormone levels and they will know to ask those questions." That would be very very helpful because it would give you the ability to manage your body and your disorder by letting you refer to experts without having to start from square one… So I think that it would be very nice if there were more specialists in reproductive health issues that you could see well before you were actively trying to get pregnant.”

Although some women were able to find incredibly knowledgeable fertility specialists, they only had access to fertility specialists for the duration of their pregnancy. Women who are not looking to conceive did not have similar access to similarly specialized doctors.

6.4.3.3 Need for more PCOS research

Participants described many unknowns with their condition. After a while of self-educating themselves on PCOS, they would find themselves hitting the same old information as before, with no new research enlightening them about their condition. This was especially true for participants who were reaching menopause or had already gone through it. A need was brought up to fund more research on PCOS and its treatments, and how it can impact women throughout the lifespan.

Jamila, aged 26, described her frustrations with the lack of research on PCOS:

“But I really wish that someone would actually be able to find some cure for it. And to do more funding to find more research on it. On the Internet, it's the same thing that I keep finding being repeated but hardly much new things are there. So that's the frustrating part, not being able to find an answer.”

Bianca, aged 36, found PCOS management hard to navigate because of all the unknowns:

“It's tricky because there's still a lot of unknowns. So I think more research, I think more medical testing.”

Margaret, aged 33, found that there is a lack of research done in women's health, and PCOS has not had any new research and developments coming out that she recalls reading about, and brings up the lack of one good informational source:

"I guess you can kind of say that that's true for any sort of women's health care issue is that there's not really a whole lot of research or inquiry kind of really being done. So honestly aside from sort of google searching and looking into things that my doctors were bringing up to me, there isn't any sort of 1 real specific resource that I'm kind of looking into. There isn't anywhere that I can think of that's really on the cutting edge of PCOS, you know what I mean?"

Due to the risk associated with some PCOS medications and menopause, older participants had to terminate all medications they had been on (for decades) to manage their condition. Participants did not know how to navigate management of symptoms post-menopause without their previous medications, finding very little information online and with doctors. Lucy, aged 47, was frustrated with the lack of research on managing PCOS with menopause. Her doctors had confirmed that she had started menopause but could not explain the odd changes in symptoms Lucy had been experiencing, such as her periods more regular and her immunity worsening. Lucy reflected on the lack of research on PCOS and menopause:

"I have tried to see if there's any research out there on it and there is virtually nothing on PCOS and menopause or perimenopause. Yeah I think I mentioned that to you already, the main focus seems to be on fertility right? Like "let's just see if you can get pregnant" and that's the main thing. So I mean when you're trying to have babies it's obviously going to be uppermost in people's minds. But what we forget is this isn't a condition that goes away. It stays with you. And the little research I have found is that "oh yeah symptoms get worse when you go into menopause" and suddenly you're dealing with even more severe - you know how they say diabetes and heart disease are a problem when you have PCOS, well it even ups that much more when you are in menopause."

To sum up, participants wanted more research to come out about PCOS treatment options to help them understand and manage their condition better. Especially with regards to treatment options for women with PCOS in peri- and post-menopause.

6.4.3.4 Need for age-specific support groups & mental health supports

Many participants described feeling isolated having PCOS due to the lack of public awareness around it. Participants identified the need to interact with someone else who has PCOS, someone in the same boat, for a source of support. Local support groups were a service that many women wanted to be provided by either organizations or health providers. Specifically, support groups which would include women in a similar life stage with similar treatment goals. Some participants also wished that counsellors or doctors could be present at the support groups to provide professional advice and learn from patient experiences.

Jamila, aged 26, wanted a local support to have access to social support and get support with treatments & lifestyle management:

“Like I never found any support groups like that - maybe online but nothing local. How come? Because it's so common but no one created one... It will definitely help when you can reach people, being able to actually physically talk to more people about it would help. Maybe a group on how many people can do it together, like for example people can do treatments together like you know specific diets or work out with them. That would help.”

Social support and connection are not the only benefits of support groups. Support groups also function as information havens for treatment options. Having a doctor leading the support group, as Jamila suggests, can help ensure that credible information is discussed. Divya, aged 22, suggested a local support group to attend that her doctor could refer her to, and which could be led by an organization:

“I want to say a support group would be really cool. If you got diagnosed and then your doctors talk to you about your diagnosis and say “by the way, if you want a support group, we have this.” I don't know if the doctor should run it or something like a kind of foundation could run that. If there's a foundation and then they go to every gynecologist in Canada. It's like a support group in your local area for PCOS. And then they kind of get everyone together someplace, that would be pretty cool.”

Older participants stressed the need to have age-specific support groups, because women at different stages in their life would be concerned over different things. Vanessa, aged 63, had already undergone menopause and is searching for treatment options to manage her PCOS symptoms. She remarked:

“I think it would need to be age appropriate first. Like I wouldn't want to hang out with a bunch of 20-year olds. I think their needs are different. Their focus is different. But yeah I would like something like that.”

Lucy, aged 47, remarked that having access to a counsellor adjacent to a support group could help her address the mental health impacts of PCOS:

“I would have appreciated a support group and even counselors who had an understanding at least of PCOS to talk to. I think that probably would have helped the most.”

To sum up, many participants identified a need for local support groups to be put in place to help them feel less isolated and have access to social connection, social support, and even informational support. Having a doctor or counsellor present to facilitate discussions can also help establish the support group as a safe space and credible resource for information.

6.5 Discussion

Although participants perceived a lack of knowledge and information provision in physicians across specialties, when asked to identify how PCOS healthcare can be improved, almost all emphasized greater knowledge at the PCP level. Although several participants had frustrating encounters with specialists, most had more challenging experiences with their GPs who they felt needed to know more about how PCOS is diagnosed and managed. Many participants argued that for a condition as common as PCOS, knowledge at the PCP level was needed to address their health concerns more efficiently. Participants especially emphasized that PCPs need to be more aware of the spectrum of PCOS presentation – the spectrum of presentation is a challenge for many women and physicians with regards to management [51]. Participants believed that a knowledgeable and well-versed PCP could speed up diagnoses for patients by avoiding the need for referrals to specialists and help them garner easier access to whichever resources they needed throughout their management journeys.

A recent qualitative study has recommended for PCPs to be more involved with PCOS management [63]. In participants’ experiences, PCPs were often siloed from the rest of the healthcare team and were mostly uninvolved with PCOS management. Several participants wanted their PCPs to stay up-to-date and involved with specialists overseeing their care, to ensure that they have a physician on board who is aware of their complete medical history. Little is known about levels of knowledge of PCOS in primary care. Most studies pointing to

significant gaps in knowledge in physicians have examined obstetrician-gynecology and endocrinology residents and physicians, finding many not knowing which PCOS diagnostic criteria they used or being unable to correctly identify diagnostic criteria [45, 47, 49]. A 2018 study found that women had greater levels of distrust in their PCP's opinion and felt that they spent less effort treating their PCOS concerns [13], and another study found that women received little information about long-term PCOS implications from their GPs [62].

With so many participants lacking PCPs who can diagnose, provide information, and guide or follow-up with PCOS management, it becomes important for future studies to examine gaps in knowledge in PCPs in Canada and other countries. Training and re-training of PCPs may be necessary. Participant-identified ways to educate and raise awareness in physicians included the involvement of established PCOS organizations, or professional societies, who could provide up-to-date training or informational packets for physicians. Webinars, expert panels, and conferences were identified as ways to engage physicians – some participants preferred them being open to the public so that they could also attend and pick up useful information. A few articles and guidelines have been published in recent years guiding management of PCOS in primary care [55, 219] and international guidelines recommend healthcare delivery for PCOS in primary care as it is well-placed to diagnose and coordinate interdisciplinary care for patients [89]. A recent study on pediatric PCPs caring for PCOS found variability in beliefs around ability to diagnose and manage PCOS [220], suggesting that wider dissemination of guidelines may be needed to train PCPs who may not be confident enough to diagnose and treat PCOS.

When participants received insufficient information from their doctors (e.g., not having the implications of PCOS explained to them), they often went online to search up their condition and understand it better. Participants recalled reading through health information sites like WebMD, ClinicalTrials.gov, and online groups with anecdotes from other women with PCOS. Women with PCOS often turn to online sources for information [15, 19, 98, 151], although online information PCOS is largely unaccredited at and commercially derived [221]. Although online information often answered many questions for participants, most felt that they could not completely rely on what they read and wished that they could have access to credible, doctor-provided information. Whether that be a pamphlet at the doctor's office or accredited websites the doctor could share, evidence-based information was a strong need to come up for participants.

Prior studies have also reported a need for evidence-based information in women with PCOS [12–14, 221–223]. A recent study has found that PCOS-related Google searches have steadily increased over the years [223]. Pamphlets were a resource that participants thought that doctors could quickly provide to participants, saving time for the doctor and providing participants with take-home material that they could digest after any shock from the diagnosis wear off. One participant of Chinese background hoped that as informational sources are developed, multilingual versions become available so that she and other multicultural patients can share what they learn with family members. Ethnicity and education level need to be accounted for when designing informational resources for women [224].

Almost all participants who had access to fertility specialists and clinics along their journeys had positive experiences accessing information and care from them. Perhaps due to the greater exposure to patients with PCOS attempting to conceive, fertility specialists appeared to have the most knowledge about PCOS and provided pamphlets and/or directed participants to their clinic's web page on PCOS. Experiences with gynecologists and endocrinologists varied. Although fertility specialists appeared to be highly knowledgeable, they were only available to participants who were trying to conceive. Numerous participants expressed the need for more physicians to specialize in or take interest in PCOS, as well as for more PCOS-centric clinics to open. Very few participants had visited or heard of a nearby PCOS clinic or PCOS expert to contact. There are few established multidisciplinary PCOS treatment clinics globally; however, studies are coming out to support the merit of a multi-practice approach and the need for more of these clinics [188]. In Canada, there are a few PCOS clinics including the Polycystic Ovarian Syndrome Clinic in the Women's College Hospital and the Endocrine and PCOS Clinic, both located in Toronto. PCOS experts may be far and few in between; telemedicine and other types of digital consultations with specialists may be possible options to provide women with access to more experts [17].

A lot of participants felt brushed off and not taken seriously by their doctors when bringing up symptoms, which happened most often in visits with their GPs but also with specialists. Women recalled hearing stories about others with PCOS also not being taken seriously by doctors until symptoms escalated or years had passed. Participants identified a need for educational reform for physicians to include an emphasis on taking women's health seriously to account for a potential under-prioritization of women's health. Previous studies have found that women with PCOS feel discounted by their physicians [13, 16–19]. One study found incongruences with

what women with PCOS reported to be their biggest symptoms of concern versus what physicians perceived to be concerning for patients (e.g., pain was the most common concern for patients which clinicians did not consider to be important) [225]. Health professionals may need to take greater care to understand and investigate patient concerns, especially when dealing with perplexing and under-researched conditions like PCOS.

Many participants were unsatisfied with their treatments, either due to their inefficacy at completely managing symptoms or because participants preferred a natural approach. Some participants were also frustrated at there being no cure for PCOS and the number of unanswerable questions around PCOS. A recent qualitative study also reported frustration in women around the lack of treatment options offered and unanswered questions about management [51]. Participants would search online and discover trials of emerging therapies and express frustration that they were not able to receive much information about emerging therapies from their physicians or participate in local trials in Canada. Further, participants could not find an accessible source that was on the “cutting edge” of PCOS research. A general need came up for more PCOS research to explore therapies and to be open and accessible for women to read and/or participate in. So far, causes and conclusive treatments of PCOS remain unknown. A recent study estimates that PCOS receives less than 0.01% of national funding in the U.S. and may be underfunded considering its prevalence, economic burden, metabolic morbidity, and impact on quality of life [226].

Participants often described relying on online communities and/or friends and family for support when dealing with challenges relating to PCOS. None of the participants had attended a support group past being involved in some PCOS groups online; however, many noted that a local support group would be a beneficial resource to have. Identified benefits to support groups included finding others with PCOS to connect with, learning from and being motivated by other women’s treatment strategies, and sharing a safe space with others with similar lived experiences. Older participants communicated that health concerns and lived experiences with PCOS varied with age and that they would benefit most from attending age-specific support groups with others in similar situations. Having been involved in various online support groups, older participants noted that most other users were concerned with fertility and conception which was no longer a priority or concern for older participants – they were mostly concerned with how to balance their hormones and take care of their metabolic health.

Previous qualitative studies have also showed that women have a need for social support and connection with other women with PCOS [15, 141, 227, 228] and support groups often enable women to do just that, whether that be online or locally [15, 17, 19, 150, 151]. A study evaluating the effectiveness of a nurse-led support group left participants feeling more empowered in self-management and benefitting from informational exchanges [133]. The 2018 International Evidence-Based Guideline for PCOS acknowledges that PCOS support groups could be a key resource for addressing current gaps in information provision [89]. Few studies have examined the needs of older participants with PCOS and age-specific support groups. More research is needed to better understand the specific information and socio-emotional needs of women of different age groups with PCOS.

Several participants specified the need for physicians or counsellors to attend or lead the support groups to have an opportunity to reach out for professional guidance and allow health professionals to learn from the patients as well. Most participants noted that their physicians did not discuss the mental health implications of PCOS, such as the increased risk for depression, anxiety, and disordered eating [8, 173]. Some participants did struggle with mental illnesses and disordered eating, but almost none had an open line of communication about those symptoms with their doctors. Mental health-related symptoms of PCOS need to be addressed more by health professionals [25, 62, 63, 89, 207].

Several participants noted that having counsellors with an understanding of the links between mental health and PCOS may be a beneficial resource for them, particularly at support groups to better lend a safe space for women to access support for their symptoms. A previous study on group counselling for women with PCOS found that participants grew in motivation from the supportive environment and the follow-up exercise sessions, which led to significant post-intervention reductions in weight and BMI [134]. Partnerships between support groups, health professionals, and academics have been proposed to be used to strengthen the information provided in support groups; however, more research is needed to assess which benefits such partnerships can provide for women [132].

A distinct theme came up in participants across all age groups on the need for greater PCOS awareness – in the general community and in women, girls, and individuals with female reproductive systems. Participants puzzled over why almost no one around them knew anything about PCOS, including why they themselves knew little about PCOS when their symptoms first started. Greater awareness of PCOS could allow women and girls to better understand their

symptoms and know when and how to check up on them. Recent studies have found lower levels of awareness of PCOS in young women and the public, urging for a need for greater awareness programs to be implemented [180–183, 229]. Studies on Canadian youth and public are needed to gauge awareness levels across socioeconomic strata and urban/rural regions.

Participants also stressed that the general community needed to be made more aware of conditions like PCOS so that they can be of support; the most common descriptors used by participants to describe their lives with PCOS were “isolating” and “alone.” Several other studies have also found women feeling isolated and alone having PCOS [17, 19, 43, 63, 133]. Participants wanted greater general awareness so that women and girls with PCOS can get support and understanding for their lived experiences. Raising awareness in the general community could facilitate a reduction in the current stigma around PCOS [142]. Participants rarely found themselves being open about their symptoms, described feeling a sense of stigma within themselves and in those around them, especially around the “unfeminine” or “undesirable” aspects of PCOS, similarly to participants in other studies [14, 17, 142, 230].

Some participants recalled seeing ill-informed and stigmatizing comments made about PCOS and similar conditions online. Very few participants saw representation of PCOS in popular media; however, they appreciated when women with PCOS in the public eye spoke about it and raised awareness. A study on media depiction of PCOS in magazines found that PCOS symptoms were largely presented as a hindrance to women’s roles as wives and mothers, and primarily portray white women with PCOS [231]. More research into how PCOS is portrayed in popular media is needed, as well as efforts to ensure that an accurate, unstigmatized, and diverse view is presented.

Women’s health overall was perceived by participants to be shrouded in unnecessary mystery. The ways in which participants thought to bring about greater awareness of the condition included revisions to sexual education curriculums to include a brief overview of PCOS and other common women’s health conditions, and for PCOS organizations to organize local events and fundraisers to build up awareness. Almost none of the participants recalled hearing much about local Canadian or American PCOS organizations – an opportunity exists for PCOS organizations to scale in their reach and advocacy efforts, with appropriate funding.

6.5.1 Limitations, strengths, and positionality

Limitations of the study include selections bias due to all participants being recruited from websites and online groups, eliminating the potential to reach women with PCOS who are not as active online. Most interview participants identified as Caucasian; few participants from diverse ethnic backgrounds were captured. Little understanding can be drawn about how PCOS healthcare can be improved for individuals with different social identities who may have unique experiences and need culturally- and/or gender-sensitive health care services [232]. Member checking, where participants are given an opportunity to review findings and provide feedback, was not performed since participant contact information was not recorded and permission was not sought to save information and contact the interviewees when data analysis was complete.

Strengths of this study include the involvement of peri- and post-menopausal women whose experiences and beliefs may not be transferable to the experiences of women of reproductive age. The use of remote phone and Skype interviews allowed participants to feel comfortable and save financial and time costs by interviewing from their preferred locations. Overall, this study addresses an important gap in the literature on women's experiences with PCOS healthcare in Canada and their perspectives on what can be overall improved based on their lived experiences.

With regards to the interviewer's positionality, MI had shared with participants her prior knowledge of PCOS due to having friends with PCOS, but that she herself did not have a PCOS diagnosis. Participants may have felt more reserved with MI than if they had been interviewed by someone with PCOS; however, disclosing that MI was personally connected to friends with PCOS, may have helped participants feel more understood. As MI was a student and novice researcher, who was not involved in the healthcare profession, participants may have felt more at ease being open about their experiences navigating the healthcare system without the presence of a potential power dynamic.

6.6 Conclusion

Women identified a range of improvements that can be made to PCOS healthcare in Canada, and possibly other regions of the world. Adequate knowledge and awareness of PCOS diagnosis, management, and biopsychosocial aspects in PCPs is necessary for timely diagnosis and meaningful treatment plans. Our findings support prior recommendations to provide women with evidence-based information on PCOS features and management, in pamphlet form or as a list of credible web sites, and contact details of PCOS support groups as necessary [12, 98, 144]. Referral to support groups may be important for some patients to reduce feelings of

isolation and connect women to a community where experiences and information can be shared. Women also identified a need for greater awareness and de-stigmatization of PCOS for the general community, and greater prioritization of women's health in the medical community. Finally, increased funding may be needed for furthering research on PCOS and the organizational efforts to raise awareness and train physicians.

6.6.1 Policy recommendations and future research

Participant experiences revealed that some things are amiss with PCOS healthcare delivery and clinical shifts are necessary to provide appropriate care for this population. To address gaps in knowledge and awareness, professional societies should provide relevant educational materials that can be easily accessible to patients and physicians. Residency programs for endocrinologists, Ob-Gyn's, and general practitioners may need to improve clinical training in PCOS and examine for systemic under-prioritization of women's health.

International evidence-based guidelines and reviews [25, 55, 89, 219, 233] have been established for the diagnosis and management of PCOS which can be consulted by clinicians in practice. The guidelines inform of the necessary information to provide and of the importance of mental health screening, among other screening and testing to be done, accounting for the needs of different phenotypes and age groups of women. Evidence-based translation and education resources for physicians and women with PCOS, along with the first, evidence-based app for women with PCOS "AskPCOS," can be found at https://www.monash.edu/medicine/sphpm/mchri/pcos/resources. Greater dissemination of these evidence-based guidelines may be necessary to promote best practices.

Efforts are needed to raise awareness for PCOS in the general and medical communities in Canada. Several advocacy and policy efforts have been successfully undertaken across the world. The PCOS Challenge, an American advocacy group, has designated the month of September as the "Polycystic Ovary Syndrome Awareness Month" [20]. Greater advances have been made in Australia, where The Federal National Women's Health Strategy 2020-2030 aims to raise PCOS awareness in the general and medical communities, and PCOS has been integrated into the 2017-2020 key priorities for women's sexual and reproductive health [20].

Studies examining knowledge levels and practice patterns in Canadian PCPs are needed to address the gap in the literature. Future research should explore the role of age-specific support groups in the management of PCOS and the benefits of health professional-led support groups. A list of current international English-speaking PCOS online support groups is made available by Avery et al. 2020. Most participants in this study lived in urban regions – research is needed to explore rural communities with potentially greater barriers to care. More research is needed to understand the lived experiences and needed healthcare services for individuals of various social identities and backgrounds; there is a lack of research in culturally- and gender-sensitive standards of care for PCOS [232]. Studies analyzing media content on PCOS can help researchers, patients, and stakeholders address stigma and engage with the media to increase public awareness of PCOS [232]. Finally, more research is needed to examine whether PCOS-related research is underfunded in Canada; policy changes may be warranted to address inadequate funding.

CHAPTER 7 – INTEGRATED DISCUSSION AND CONCLUSIONS

7.1 Significance of findings

There are several key takeaways from this thesis's findings that provide important insights into the experiences that women with PCOS have in Canada. The purpose of this thesis was to explore women's experiences with accessing healthcare for PCOS in Canada, especially accounting for age considerations where possible, and to identify gaps in care provision. Paper 1 focused on experiences with diagnosis; surveys and follow-up interviews highlighted women's frustrations with how little information they were able to receive from physicians and delays in diagnoses originating from a possible lack in knowledge in physicians. Paper 2 focused on experiences with management, which revealed that women largely received little guidance from physicians in long-term management of PCOS and had to rely on self-education and self-experimentation to address symptoms and concerns. Paper 3 gleaned insights from women on how to improve PCOS healthcare, based on their lived experiences in Canada. Women emphasized a need for educational reform in the medical community, greater awareness of PCOS in the general community, a need for local support groups, access to doctor-provided information, and a need for further research on PCOS treatments.

Several age-specific themes in experiences and needs came up from the findings of the first two papers. Younger participants with PCOS (i.e., adolescents and young adults) were more likely to be influenced by physicians' attitudes on their conditions, were less likely than older women to self-advocate, and were largely unaware of PCOS and the significance of symptoms prior to their diagnosis. Unconcerned physicians influenced younger participants to not take their symptoms seriously, which delayed diagnosis and management. Sometimes adolescents received a prompt diagnosis but insufficient information, which led them to delay management as they did not fully understand what PCOS meant for them in terms of long-term implications. Physicians need to be encouraged to provide ample information to younger patients who either have PCOS or are at risk for PCOS. Parental figures rarely had any knowledge on what to do with their children's symptoms and were largely unaware of PCOS – greater awareness in the general community can help parents of girls with PCOS get diagnosed and start treatment sooner. Participants suggested that awareness of PCOS and related conditions should be introduced to adolescents during sexual education and/or health classes so that they are better prepared to notice symptoms such as menstrual irregularity and consult their physicians.

Older participants with PCOS (i.e., nearing, in, or past menopause) received little information and guidance from physicians on what to expect and how to manage symptoms without medical therapy. Peri- and post-menopausal participants were most involved in self-experimentation to manage hormonal irregularities, hirsutism, hot flashes, and issues with digestion without the guidance of medical professionals. Many women expressed a lot of confusion over their symptoms in later age; they were unsure whether their symptoms were linked to menopause or having had PCOS or both. They were also frustrated with the lack of research on PCOS in post-menopause. Indeed, there is little research on how women with PCOS are impacted by menopause and few current guidelines provide comprehensive recommendations on PCOS management post-menopause. The most worrying finding for this age group was the lack of follow-up from physicians after women terminated medications due to contraindications with age. Women were essentially left to their own devices to cope and experiment with various supplements without medical supervision. Further research on women in this life stage is needed to better understand their needs and therapeutic options. Physicians should be encouraged to follow-up with post-menopausal women with PCOS and oversee their treatments.

Many participants learned about important PCOS implications on their own. Survey findings showed 65.9% of women were dissatisfied with the information provided to them about PCOS and 41.9% had received no information on lifestyle management. A significant reliance on the Internet was widespread across participants in this study. Participants described being aware of the potential for misinformation and the unreliability of online sources; however, due to the lack of doctor-provided information they had no choice but to partake in self-education using online sources available to them. Patients often turn towards the Internet when they feel a lack of patient-centered communication with their healthcare providers [213]. Most women in this study relied on various websites they could find with Google searches and anecdotes from other women online. Some participants sought out online information created by health professionals, such as physicians or naturopaths. They listened to podcasts, watched YouTube videos, and browsed Instagram to gather insights. A few women also read through books on PCOS and women's health. While self-education was an important facilitator in their journeys, almost all participants expressed that they would have liked access to a knowledgeable physician whom they could trust for appropriate guidance and information. Studies have found a general lack of high quality health information online about PCOS and concluded that official organizational bodies would benefit patients by publishing evidence-based knowledge online [214, 221].

Experiences with unhelpful, uninformative, and/or unempathetic professionals led to loss of trust and alienation in numerous participants. Participants would opt out of seeing their medical professionals for future visits, even ones that would be unrelated to PCOS. Such loss of trust can have long-term impacts on health outcomes. Physicians need to be educated on the diagnosis and management of PCOS and the importance of information-giving, and stay engaged in long-term follow-up as guidelines suggest [89]. Ways in which doctors could provide more information include distributing pamphlets during visits which could save time for both the doctor and patient and allow any patients with initial shell shock to digest information at their own pace at home. Doctor-provided websites were also identified as an option, to enable women to read information online that has been verified or endorsed by a medical professional.

Self-advocation and self-education were prominent facilitators in women's experiences in both diagnosis and management of their PCOS. In diagnosis experiences, self-advocation enabled women to push for a diagnosis when physicians were hesitant or unknowledgeable. Self-advocation was an important facilitator in experiences with management when women did not receive the information they needed from doctors or had to push for referrals to specialists. In the third paper, women emphasized the desire for greater PCOS awareness in women and girls, so that they may recognize symptoms and be enabled to advocate for themselves should it be necessary. Self-advocation came up less often in younger participants; women in their 20s and 30s most exhibited self-advocation as they were more motivated to find an answer to their ailments, especially when it came to fertility.

Self-education often led to self-experimentation for participants with physicians who were not engaged with PCOS management. Participants who self-experimented often had more complex symptoms that were not resolved with birth control or metformin or were hesitant to rely on medications long-term. Women with hirsutism, for example, tried spearmint tea. Participants who were concerned with hormonal imbalances, especially in peri- and post-menopause, used Vitex (chasteberry), inositol, and black cohosh to manage symptoms. Participants who self-experimented rarely learned of these alternative therapies from their physicians or allied health professionals, such as naturopaths. Very few participants consulted naturopaths on such treatments, often due to the costs of seeing a naturopath. Self-experimentation was largely based on participants' own research and trial and error; few women felt comfortable going to their doctor for advice and/or had little confidence that they would be find much insight from their doctors. It is important for physicians to have greater education on PCOS so that they may be able to oversee and guide treatment plans for women. Women may find it overwhelming to

coordinate care for all their potential symptoms. It is incredibly important in patient-centered care for primary care providers and specialists to help direct the treatment plans for women with PCOS and ensure they have access to adequate resources [89, 189]. Resources may include informational needs about their condition or treatment plan, access to referrals to specialists and allied health professionals, and support groups.

Social support appeared as a common facilitator in women's journeys with the diagnosis and management of PCOS. Communal knowledge and support from online PCOS groups, such as groups on Facebook, helped women gather information from anecdotes and find a safe space to connect to others with shared lived experiences. Participants also described relying on friends and family for support when dealing with challenges related to PCOS, such as experiencing pain or feeling unmotivated or down. Most participants did not have loved ones who were aware of PCOS or could relate to their experiences. Participants often felt alone and isolated due to the under-recognized and stigmatized nature of their condition. The need for greater awareness in the general community tied to these experiences in that participants thought that with greater awareness in friends and family, more women with PCOS would feel less alone. Social support was an important source of motivation and comfort for women, online and in real life. Participants identified a need for more local support-groups, ideally led by health professionals, where patients can gather credible information and draw support from others with similar lived experiences and in a similar geographic setting.

Human beings do not exist in a social vacuum, but rather depend on others throughout their lives and derive meaning from social structures around them [189]. An adolescent or adult woman with PCOS on her self-care journey depends on her immediate social circle, her healthcare professionals, and her community [189]. When living with a syndrome that is underrecognized in the general and medical community alike, it can be hard to find social support structures in place to guide women on the life-long management they have to maintain. Social and psychosocial resources like support groups (local or online) can be of paramount importance in a woman's self-care journey. Support groups expose women to others living in a similar narrative to them, which can make them feel less alone and more supported [132, 133]. Age-specific support groups were especially important to older participants as their priorities and concerns changed with age. Older participants described often feeling left out of the conversation in online groups and not being able to draw many insights for how to manage their symptoms and concerns in their age group.

Women in this study faced mental health challenges and eating disorders; however, very few of those challenges were investigated or acknowledged by doctors. Almost all participants found out about the links between PCOS and mental health by themselves, such as the increased risk for anxiety and depression. Survey respondents found anxiety (20.6%), depression (15.9%), and body image dissatisfaction (12.8%) to be their most concerning symptoms; however, very few participants were screened for mental health or discussed such matters with their doctors. Several participants expressed needing information from their provider on the mental health impacts of PCOS. Mental health-related symptoms of PCOS need to be addressed more by health professionals. Several participants noted that having counsellors with an understanding of the links between mental health and PCOS may be a beneficial resource to have at support groups to better lend a safe space for women.

In paper 3, women identified a need for more PCOS experts and/or PCOS clinics so that they may benefit from expert opinion and have access to a multidisciplinary group of health professionals who are well-versed on PCOS. Studies of multidisciplinary PCOS clinics found that women and adolescents benefitted from same-day access to multiple healthcare professionals (e.g., psychologists, endocrinologists, nutritionists) [234, 235]. Women confirmed that they did perceive the clinic staff to be knowledgeable about PCOS and were generally satisfied except for the lack of social group support [235]. A barrier to entry to the clinic involved lack of knowledge of the clinic's existence by patient and their primary healthcare provider, as well as financial constraints [235]. Access to a multidisciplinary health care team in such clinics can help ensure that women's complex concerns and symptoms are adequate addressed. The extent to which different healthcare professionals work together affects the quality of healthcare they provide to patients [236].

A need for greater advocacy for PCOS came up throughout the 3 papers. When asked how to improve PCOS healthcare, education and awareness-raising were a priority for most participants. PCOS organizations can be positioned as a great source for PCOS advocacy as they could supply physicians with information packets, organize webinars or conferences for physicians and the public to attend, and organize local fundraisers to raise awareness at the local level across Canada. Considering PCOS is the most common endocrine disorder in women's health, the lack of healthcare practitioner awareness of PCOS and how to appropriately diagnose it is worrying and warrants investigation. Furthermore, the perceived lack of empathy in practitioners from patients is another sign that PCOS may not be fully understood in the medical community. Greater awareness is needed to reform healthcare practices for

PCOS to ensure women are diagnosed in timely manner and are informed about the comorbidities associated with PCOS. PCOS has been deemed by healthcare professionals and patients alike as a misnomer because it appears to place emphasis on the 'polycystic' feature of PCOS [237]. Changing the name of the syndrome from PCOS to a name that is more representative of the wide range of implications of the syndrome may aid in greater understanding of the significance of this condition.

A theme to come up in paper 3 describes the need for education for physicians to take women's health more seriously. Participants of all ages described being brushed off by some of their doctors before attaining their diagnosis and while seeking care for symptoms. Participants often did not know why their physicians brushed off their concerns or failed to take them seriously. Drawing from their own experiences being dismissed by physicians, and from the stories they heard from other women in similar positions, participants emphasized the need for greater recognition of PCOS and women's health overall. Stigma may play a factor in women's health being unrecognized in both physicians and the general community. Participants perceived stigma in others, the media, and within themselves around certain physically presenting PCOS symptoms, such as hirsutism and acne. There was almost no open discussion around PCOS in their circles, and "embarrassing" symptoms such as facial hair were taken care of in private. Revisions to sexual education curriculums and greater advocation by PCOS organizations can help break stigma and raise awareness about women's health conditions.

Overall, most participants expressed frustration with how little guidance and information their physicians could provide them. Improving physician knowledge of PCOS and teaching them about the importance of information-provision is of the utmost importance, particularly in PCPs. For a condition as common as PCOS appears to be, greater physician awareness is necessary, particularly at the PCP level, as participants emphasized. PCPs in Canada are the first point of contact to the healthcare system and act as gatekeepers for further resources such as referrals, their level of knowledge on PCOS can greatly determine patient experience and long-term health outcomes.

7.2 Limitations

Limitations of this study include participants' self-reported diagnosis of PCOS, the potential for recall bias, and selection bias. Recall bias is possible for participants who received their diagnosis many years prior to completing the survey. Selection bias is possible due to all participants being recruited from websites and online groups, eliminating the potential to reach

women with PCOS who are not as active online and may be less socially supported and/or invested in management. The questionnaire was also only available in English and posted on English web sites, and thus, may have excluded non-English speaking populations, including Francophone individuals in Canada. Only one woman residing in Quebec was captured. Most survey and interview participants identified as Caucasian; few participants from diverse ethnic backgrounds were captured. The sample may not be representative of the general population of women with PCOS, and limited conclusions can be drawn regarding other world regions. Further, few women in the peri- and post-menopausal stages of life were captured, likely due to recruitment taking place in online spaces where most users are younger [ref]. Member checking was not performed since permission was not sought to save information and contact participants upon completion of data analysis.

7.3 Recommendations for policymakers

Most regulated healthcare professionals, such as physicians and nurse practitioners, are responsible for quality improvement and system reform in Canada [66]. Physicians are responsible for the medical education of future physicians and as such are positioned as the perfect partners in healthcare reform [66]. The recent research on PCOS suggesting a lack of empathy and knowledge of PCOS in physicians is worrying because primary healthcare in Canada is almost solely based on physician knowledge and contribution. Patients with PCOS, as taxpayers and citizens, expect and deserve equitable access to healthcare [66].

Further investigation into the practices and knowledge levels of physicians in Canada is warranted following the results of this thesis. Amendments to medical school curriculums and resident training may be needed to ensure that PCOS (and similar women's health conditions) are adequately covered in general practice and specialized training. Recent international evidence-based recommendations exist for best practices in the diagnosis, management, and information provision for PCOS [89]. Those should be widely disseminated and referred to when training/re-training physicians.

Awareness of PCOS in the public is lacking. Few participants followed or were aware of PCOS organizations in Canada but wanted established organizations and professional societies to be involved in education and awareness-raising, for both the medical and general communities. Greater funding may need to be allocated to existing PCOS organizations or to establishing an organization which can build advocacy for PCOS.

Revisions to sexual education and health curriculums in elementary and secondary schools may be needed to ensure that girls (and individuals with female reproductive systems overall) are adequately equipped to recognize symptoms. Health and physical education curriculums are provincially regulated in Canada and determined by the local ministries of education; there is an absence of a common curriculum in Canada [238]. Advocacy from PCOS organizations and professional bodies may help include PCOS and other women's health conditions in such curriculums across Canada.

7.4 Recommendations for researchers and future studies

Numerous areas in need of further research emerged from this thesis. First, there is a need to capture more diverse sociocultural voices in Canada. Individuals with various ethnic backgrounds and social identities may have unique barriers and facilitators when seeking care for PCOS and have unique perspectives to provide on what can be improved.

Further research with older women with PCOS, nearing menopause or post-menopause, is needed to better capture their unique challenges and what resources are missing for them. Most research studies on PCOS symptoms across the life course were cross-sectional in design. Cross-sectional studies are more resource-efficient than longitudinal studies because they take place over a shorter period and can host large sample sizes. Longitudinal designs are often more expensive but may be more valuable in studies exploring differences in PCOS symptomology across the life span. It would be valuable to follow adolescents diagnosed with PCOS as they age and regularly track changes in symptoms, comorbidities, and fluctuations in self-reported quality of life. Follow-up should extend well into post-menopause to help us better understand the implications of PCOS in older age.

Research targeting women in rural Canadian settings may unearth important findings as women in these settings may have greater barriers to accessing care from physicians. Little information also exists on how socioeconomic status may influence the trajectory of a woman's life with PCOS. Research is also needed to explore low socioeconomic and medically underserved populations.

Women unearthed significant stigma around PCOS; analysis of popular media and online content may be needed to better understand the information (or misinformation) that spreads about PCOS. Some women in this study who were overweight or obese experienced potential weight bias with health providers who misattributed all symptoms to their weight; weight bias may need to be examined in patient-provider interactions.

Studies on interventions to improve care are needed for this population. Resources like pamphlets, support groups, and PCOS clinics have been identified as important to these participants; however, further studies need to examine the effectiveness of such resources at improving patient experiences.

Finally, studies examining the practices, knowledge, and attitudes of various physicians with regards to PCOS are needed to determine the gaps in knowledge present. Perspectives from physicians in Canada can further inform how to improve PCOS healthcare and what resources can be feasibly extended to patients to better address their needs.

7.5 Conclusions

Overall, the results from this thesis point to several areas in need of further investigation and improvement in PCOS healthcare. Women in this study overall lacked the support they required from their medical professionals to care for and understand their condition. The prominent experiences with self-advocation, self-education, and self-experimentation, along with perceiving a lack of empathy and dismissals from physicians, provide evidence for a need of training or re-training of physicians in Canada. Patients with PCOS should not have to rely entirely on their own facilities to make sense of and manage a long-term, complex condition such as PCOS. There is a need for more research into PCOS – research into PCOS treatments, into best practices for diagnosis and treatment, patient experiences and needs accounting for age and sociocultural diversity, and physicians' practices and knowledge levels. There is also a need for greater PCOS awareness, advocacy, and prioritization. Women's experiences in this study bore great resemblance to experiences reported recently in other countries and as far back as 20 years ago, suggesting that the work is not yet done to ensure that this patient population has equitable access to quality healthcare.

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APPENDICES

Appendix A: Ethics certificate for thesis

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-02-18-359
Titre du projet / Project Title	A Study of Women's Experiences with Polycystic Ovary Syndrome Diagnosis and Management with Available Healthcare Resources
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	13/04/2018
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	12/04/2019

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Najmiyya ISMAYILOVA	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Chercheur Principal / Principal Investigator
Sanni YAYA	École de développement international et mondialisation / School of International Development and Global Studies	Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments

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Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Le Comité d'éthique de la recherche (CÉR) de l'Université d'Ottawa, opérant conformément à l'*Énoncé de politique des Trois conseils* (2014) et toutes autres lois et tous règlements applicables, a examiné et approuvé la demande d'éthique du projet de recherche ci-nommé.

L'approbation est valide pour la durée indiquée plus haut et est sujette aux conditions énumérées dans la section intitulée "Conditions Spéciales ou Commentaires". Le formulaire « Renouvellement ou Fermeture de Projet » doit être complété quatre semaines avant la date d'échéance indiquée ci-haut afin de demander un renouvellement de cette approbation éthique ou afin de fermer le dossier.

Toutes modifications apportées au projet doivent être approuvées par le CÉR avant leur mise en place, sauf si le participant doit être retiré en raison d'un danger immédiat ou s'il s'agit d'un changement ayant trait à des éléments administratifs ou logistiques du projet. Les chercheurs doivent aviser le CÉR dans les plus brefs délais de tout changement pouvant augmenter le niveau de risque aux participants ou pouvant affecter considérablement le déroulement du projet, rapporter tout évènement imprévu ou indésirable et soumettre toute nouvelle information pouvant nuire à la conduite du projet ou à la sécurité des participants.

The University of Ottawa Research Ethics Board, which operates in accordance with the *Tri-Council Policy Statement* (2014) and other applicable laws and regulations, has examined and approved the ethics application for the above-named research project.

Ethics approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special Conditions or Comments". The "Renewal/Project Closure" form must be completedfour weeks before the above-referenced expiry date to request a renewal of this ethics approval or closure of the file.

Any changes made to the project must be approved by the REB before being implemented, except when necessary to remove participants from immediate endangerment or when the modification(s) only pertain to administrative or logistical components of the project. Investigators must also promptly alert the REB of any changes that increase the risk to participant(s), any changes that considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project or the safety of the participant(s).

Germain ZONGO
Responsable d'éthique en recherche / Protocol Officer
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences sociales et humanités / Social Sciences and Humanities Research Ethics Board**

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Appendix B: Permission to replicate survey from Oxford University Press

OXFORD UNIVERSITY PRESS LICENSE
TERMS AND CONDITIONS

Aug 25, 2021

This Agreement between Ms. Miya Ismayilova ("You") and Oxford University Press ("Oxford University Press") consists of your license details and the terms and conditions provided by Oxford University Press and Copyright Clearance Center.

The publisher has provided special terms related to this request that can be found at the end of the Publisher's Terms and Conditions.

License Number	4366760301791
License date	Jun 12, 2018
Licensed Content Publisher	Oxford University Press
Licensed Content Publication	The Journal of Clinical Endocrinology & Metabolism
Licensed Content Title	Delayed Diagnosis and a Lack of Information Associated With Dissatisfaction in Women With Polycystic Ovary Syndrome
Licensed Content Author	Gibson-Helm, Melanie; Teede, Helena
Licensed Content Date	Dec 1, 2016
Licensed Content Volume	102
Licensed Content Issue	2

Appendix C: Interview guide

1. Introductions

Experiences with diagnosis:

2. When did you first learn about PCOS?

3. Could you tell me about how you came to be diagnosed with PCOS? (from when you first noticed something wrong)

4. Could you tell me about the treatment(s) your physician recommended for you?

5. What have been the positive aspects of your diagnostic experience?

6. What have been the negative aspects of your diagnostic experience?

7. Could you tell me about your impressions of the healthcare system at the time you were diagnosed?

8. How did the diagnostic process affect your quality of life?

PCOS management - daily life:

9. Can you describe a typical day in your life?

10. How do you generally manage each of your symptoms on a day-to-day basis?

11. How do you feel your PCOS symptoms impact your quality of life on a day-to-day basis?

12. How satisfied are you with your prescribed treatment(s)?

13. How do you feel about your treatment plan in the long-term?

14. How involved has your physician(s) been in your management of symptoms?

15. Have you discontinued any treatments or services for any reason?

16. Are there any treatments or services you've heard about and wanted to try?

17. Where do you go to learn more about PCOS and new developments?

Ways healthcare services for PCOS can be improved:

18. Could you tell me about any healthcare resources you personally use which have helped you on your journey?

19. Where did you hear about the resources you are using now?

20. Who or what do you trust most when looking for new information on PCOS healthcare?

21. Are there any resources you wish were there for you?

22. Could you tell me about any resources you might be aware of but have chosen not to use?

23. What do you think could be done to improve PCOS healthcare?

24. Is there anything else you would like to add?

Conclusions:

25. Is there anything I should have asked about but did not?

26. Do you have any questions for me?

Appendix D: CHERRIES checklist (for article 1)

Checklist for Reporting Results of Internet E-Surveys (CHERRIES)*

Item Category/Checklist Item	*Explanation*	*Section*
Design		
Describe survey design	The target population were women over the age of 18, with a self-declared PCOS diagnosis made by a medical professional in Canada, and who have resided in Canada since their diagnosis. The sample was a convenience sample drawn from online PCOS groups on Facebook, Reddit, and various PCOS online forums.	Methods
IRB (Institutional Review Board) approval and informed consent process		
IRB approval	Ethics approval for this study was received from the University of Ottawa Research Ethics Boards (REB) in April 2018.	Methods
Informed consent	Informed consent for the survey was obtained from all those agreeing to complete the survey. The participants were informed of the purpose of the study, who the investigators were, that their responses will remain confidential and accessible only to the researchers, the length of time of the survey, and that by clicking "I agree" and starting the survey, they were declaring consent to participate but could withdraw their data at any time. Participants were informed of all this via the survey welcome page which also held a link to the full implied consent form.	Methods
Data protection	The survey data was hosted solely on the first author's SurveyMonkey account on Canadian servers and was password-protected. No personal information was linked to survey results in any way (e.g., contact information to enter the draw). The fully de-identified dataset is kept on password-protected computers.	Methods
Development and pre-testing		
Development and testing	The survey was drawn from a previous study by Gibson-Helm et al. (2017) which was developed with input from a multidisciplinary expert advisory group and piloted with women with PCOS. Permission to replicate the survey was granted by the authors and publisher in June 2018. The survey was modified by the first author to include eligibility questions about participants being diagnosed and residing in Canada. The first author tested the survey for functionality before fielding. No pilot testing was performed.	Methods
Recruitment process and description of the sample having access to the questionnaire		
Open survey versus closed survey	This was an open survey hosted on SurveyMonkey.	Methods

Contact mode	Contact mode was online via advertisement posts made in PCOS groups on Facebook and Reddit and online PCOS forums.	Methods
Advertising the survey	The survey was advertised entirely online by the first author posting a short paragraph about themselves and the purpose of the study along with a recruitment poster and a link to the survey on SurveyMonkey. The same post was posted by the first author in PCOS groups on Facebook and Reddit, along with several PCOS online forums found by searching Google. The PCOS Awareness Association also helped with recruitment by doing a one-time re-post on their Facebook page with the study's recruitment poster and the survey link.	Methods
Survey administration		
Web/E-mail	SurveyMonkey survey (web-based)	Methods
Context	SurveyMonkey is a website for constructing, storing, and analyzing online surveys. The administrator can design the length, the kind of information provided and the type of questions & answers. The website appearance is neutral and not influential on the sample.	Methods
Mandatory/voluntary	A voluntary survey.	Methods
Incentives	Participants were informed during advertising and on the survey welcome page that if interested, they could enter a draw to win 1 of 3 CAD$25 Amazon e-gift cards which would be sent out by email.	Methods
Time/Date	They survey was advertised, and data was collected across April-December 2018. Advertisement posts were made in the online groups in April, October, and December 2018.	Methods
Randomization of items or questionnaires	No randomization of items was used.	N/A
Adaptive questioning	Adaptive questioning was used via SurveyMonkey's logic tool. Relevant survey items were displayed based on previous responses (e.g., only those who had seen multiple physicians were asked how many they saw).	Methods
Number of Items	There was a total of 25 items, with the maximum number of items being 8 per page.	Methods
Number of screens (pages)	5 pages, and a progress bar was shown at the bottom of the page.	Methods
Completeness check	All items (except for the screening questions at the start to determine eligibility) were voluntary and skippable. None of the items had "don't know/none of the above" options; questions on satisfaction had "neither" as an option.	Methods
Review step	Participants had the option throughout the survey to use the "Back" and "Next" buttons to review answers.	Methods
Response rates		
Unique site visitor	Only participants or visitors completing at least the first page (agree to consent) and proceeding to the next page were counted. Thus, calculation of views or participation rates was not possible.	N/A

View rate (Ratio of unique survey visitors/unique site visitors)	Only participants or visitors completing at least the first page (agree to consent) and proceeding to the next page were counted. Thus, calculation of views or participation rates was not possible.	N/A
Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors)	Only participants or visitors completing at least the first page (agree to consent) and proceeding to the next page were counted. Thus, calculation of views or participation rates was not possible.	N/A
Completion rate (Ratio of users who finished the survey/users who agreed to participate)	296/397: 75% completion rate	Results
Preventing multiple entries from the same individual		
Cookies used	Only one participation per device was possible using SurveyMonkey's multiple responses option which used cookies to assign a unique user identifier to each browser.	Methods
IP check	IP addresses were not stored to ensure participant anonymity.	N/A
Log file analysis	Not used.	N/A
Registration	The survey was open, no registration was needed for entry to the survey. Participants accessed the survey by opening a link.	N/A
Analysis		
Handling of incomplete questionnaires	Incomplete responses were analyzed if the mandatory eligibility questions were completed. Answers in the demographics question that were obviously false (e.g., weight/height incorrectly inputted) were excluded.	Methods
Questionnaires submitted with an atypical timestamp	No respondents were removed from the survey for completing items too quickly	N/A
Statistical correction	No weighting scheme was used for the analysis of results.	N/A

* Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res 2004;6:e34.

Appendix E: COREQ checklist (for articles 1, 2, and 3)

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported in Section
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	**Which author/s conducted the interview or focus group?** Miya Ismayilova conducted all interviews.	Methods
2. Credentials	**What were the researcher's credentials? E.g. PhD, MD** The authors' credentials are as follows: - Miya Ismayilova, HBSc -Sanni Yaya, PhD	N/A
3. Occupation	**What was their occupation at the time of the study?** MI : Master's student SY: Professor	Methods
4. Gender	**Was the researcher male or female?** MI: Female SY: Male	Methods
5. Experience and training	**What experience or training did the researcher have?** MI: quantitative and qualitative research training. SY: quantitative and qualitative training and extensive experience in global maternal and child health, including sexual and reproductive health care.	Methods
Relationship with participants		
6. Relationship established	**Was a relationship established prior to study commencement?**	Methods

	No prior relationships was established	
7. Participant knowledge of the interviewer	**What did the participants know about the researcher? e.g. personal goals, reasons for doing the research.** Participants knew about the reason MI was conducting this research, their person interest in PCOS, and PCOS status	Methods, Discussion
8. Interviewer characteristics	**What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic** MI's reasons and interest in the research topic was reported	Methods, Discussion
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	**What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis** This study uses Thorne et al.'s (2004) interpretive description methodology, which is widely used in nursing research and does not generate new truths or theories but rather describes thematic patterns and commonalities while also accounting for individual variations and provides a product that clinicians can use as a backdrop for clinical decision-making.	Methods
Participant selection		
10. Sampling	**How were participants selected? e.g. purposive, convenience, consecutive, snowball** Participants were selected in a purposive convenience sample online in various PCOS groups and forums, along with the help of the PCOS Awareness Association who posted the recruitment poster on their Facebook page.	Methods
11. Method of approach	**How were participants approached? e.g. face-to-face, telephone, mail, email**	Methods

	Participants were reached out to via email, and later by telephone when interviewed.	
12. Sample size	**How many participants were in the study?** A total of 25 participants.	Methods
13. Non-participation	**How many people refused to participate or dropped out? Reasons**? None	N/A
Setting		
14. Setting of data collection	**Where was the data collected? e.g. home, clinic, workplace** Data collection took place at home where the interviewer was when interviewing.	Methods
15. Presence of non-participants	**Was anyone else present besides the participants and researchers?** No one was present except for participants and MI who was interviewing.	Methods
16. Description of sample	**What are the important characteristics of the sample? e.g. demographic data** Participants ranged in age from 18 to 63 years old, with mostly Caucasian backgrounds. The length of time since the diagnosis of PCOS varied between 1 month to 33 years at the time of enrollment in the study. Most participants resided in Ontario, with a few from Alberta (n=4), British Columbia (n=4), and one from Quebec. Most participants were employed full-time, 7 were students, and 2 were stay-at-home moms. Seven participants had children, and nine participants were looking to conceive at the time of the interview.	Results
Data collection		
17. Interview guide	**Were questions, prompts, guides provided by the authors? Was it pilot tested?** The interview guide was provided (see Appendix C), it was not pilot tested.	Methods
18. Repeat interviews	**Were repeat inter views carried out? If yes, how many?**	N/A

	Repeat interviews were not carried out.	
19. Audio/visual recording	**Did the research use audio or visual recording to collect the data?** Interviews over the phone were recorded (only audio data was collected).	Methods
20. Field notes	**Were field notes made during and/or after the interview or focus group?** Yes, reflective notes were made MI during and after all interviews.	Methods
21. Duration	**What was the duration of the inter views or focus group?** Interviews lasted an average of 1 hour.	Methods
22. Data saturation	**Was data saturation discussed?** Yes. Interviews were capped at 25 once data saturation was reached and no more participants in the peri- and post-menopausal stages were available.	Methods
23. Transcripts returned	**Were transcripts returned to participants for comment and/or correction?** Transcripts were not returned to participants for comment/correction.	Discussion
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	**How many data coders coded the data?** MI coded all data.	Methods
25. Description of the coding tree	**Did authors provide a description of the coding tree?** Yes. The transcript was read and coded based on identified similarities and patterns in the data. Codes, sub-categories, and over-arching code categories were generated directly from transcripts.	Methods
26. Derivation of themes	**Were themes identified in advance or derived from the data?** Themes were derived from the data.	Methods

27. Software	**What software, if applicable, was used to manage the data?** NVivo 12	Methods
28. Participant checking	**Did participants provide feedback on the findings?** No, it was not possible due to not asking permission to save their contact information and contact them for member-checking.	Discussion
Reporting		
29. Quotations presented	**Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number** Yes, quotes were used and identified.	Results
30. Data and findings consistent	**Was there consistency between the data presented and the findings?** Yes.	Results
31. Clarity of major themes	**Were major themes clearly presented in the findings?** Yes, we organized the findings by major themes.	Results
32. Clarity of minor themes	**Is there a description of diverse cases or discussion of minor themes?** Yes, we discussed minor themes in the manuscript and situated them within the broader literature.	Results, Discussion