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Noelle Citron
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The Role of Disclosure and Social Support on Quality of Life in Women with Polycystic Ovary Syndrome (PCOS)

By

Noelle Citron

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The Role of Disclosure and Social Support on Quality of Life in Women with Polycystic Ovary Syndrome (PCOS)

By

Noelle Citron

APPROVED BY:

S. McMurphy

Department of Sociology, Anthropology and Criminology

J. Kichler

Department of Psychology

K. Soucie

Department of Psychology

September 12, 2022

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ABSTRACT

Polycystic Ovary Syndrome (PCOS) is the most common hormonal disorder in women of reproductive age, with prevalence rates up to 21%. Symptoms include ovarian cysts, menstrual irregularities, and possible infertility, as well as hirsutism, alopecia, and weight gain/obesity. These symptoms are distressing for many, and lead to psychological distress, poor body image, and reduced quality of life. They also may also cause feelings of social rejection, shame/embarrassment, and stigma which can complicate avenues for disclosure and social support, which are crucial in mitigating distress. The purpose of this qualitative study was to explore women's experiences disclosing their PCOS diagnosis to others, and to understand how disclosure experiences impact avenues of social support. Twenty-eight PCOS-diagnosed participants (age range, 19-43; *M*=28.17, *SD*=6.03) were interviewed about their experiences disclosing PCOS to others. A reflexive thematic analysis of interview transcripts was conducted. Four themes were constructed that represented how disclosure and social support intersect and unfold over time, and across contexts: *broaching PCOS with others, the building blocks of support, maintaining meaningful conversations, and dead ends*. Findings of this study highlight the complexity of PCOS disclosures and social support experiences, while also providing tangible avenues of supports to improve quality of life. This study has direct implications for future research within the field of disclosure and chronic illnesses and has the potential to inform the development of services aimed at supporting women with PCOS.

DEDICATION

This thesis is dedicated to my grandparents, Georgette, and Hanna Boutros. You both had the courage to uproot your lives and immigrate to Canada to provide better opportunities for your children and grandchildren. You have shown me that sometimes, a leap of faith pays off. Despite you both being unfamiliar with the concept of graduate school, you are always waiting with open arms, unconditional love, and many prayers to support me on this journey. I can only hope to make you both proud.

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CHAPTER 1

INTRODUCTION

For many, being diagnosed with a chronic health condition is a self-defining experience that includes a range of emotions (Berna et al., 2011). Often, we process and make meaning from these events through the conversations we have with others in our lives (McAdams, 2013; McLean, 2008). Illness-related disclosures and setbacks can be difficult to share with others; however (Greene, 2009). These disclosures require the management of risk and vulnerability on the part of the discloser. Individuals may fear stigma (Greene et al., 2003), rejection (Goffman, 1963), shame (Vagelisti et al., 2001), or the risk of social exclusion and isolation (Yoshioka & Schustack, 2001; Maman et al., 2016). Disclosure also requires an individual to find an opportunity while managing the flow of conversation (Hyman & Faries, 1992), balancing the anticipation of a positive response from the recipient/listener (Greene & Serovich, 1996), and consider past experiences of reactions to disclosure (Greene, 2009) as well as understand the social/cultural considerations of how much to share and what topics are appropriate vs. not appropriate disclose (McLean & Pasupathi, 2009).

Women with Polycystic Ovary Syndrome (PCOS), a chronic illness that upwards of 21% of women of reproductive age worldwide (Bozdag et al., 2016; March et al., 2009; Okoroh et al., 2012; Wolf et al., 2018), report that PCOS significantly disrupts their life trajectory and life plans. Symptoms of the disorder fall into three specific clusters: reproductive, metabolic/endocrine, and psychological/mental health impacts. Reproductive symptoms include polycystic ovarian morphology (PCOM), menstruation irregularities and possible infertility (Poleshuck & Woods, 2014). Women also may experience hirsutism (excess hair growth), acne, and androgenic alopecia (male-pattern baldness) as a result of reproductive hormone abnormalities (Teede et al., 2010, 2018). Obesity and insulin resistance are also prominent features of the syndrome. As a result of symptom impacts, higher rates of mental health disorders, such as anxiety, depression, poor body image, and lower quality of life have also been reported by women with PCOS in comparison to women without PCOS (Damone et al., 2018; Kogure et al., 2019; Yin et al., 2020).

Symptoms are reported by women as embarrassing and stigmatizing, and so many are reticent about broaching their PCOS with others for fear of judgment (Farkas, 2014). Menstruation and fertility are also considered taboo topics in most societies, and when female bodies do not conform to normative expectations of shape, appearance, and function (fertility/pregnancy), it can be difficult to engage with others around these topics (Farkas, 2014; Kitzinger & Willmott, 2002; Newland et al., 2019). As a result, women with PCOS regularly connect with virtual support communities for their social support needs rather than reaching out to individuals within their social networks (friends, family, etc.). While virtual communities offer benefits in ways that in-person support may not, such as accessibility, affordability, and the ability form community with others (Holbrey & Coulson 2013), many report feeling more socially isolated and defeated after visiting these websites particularly when the information on the websites perpetuated misinformation or if the information shared was predominately negative (Holbrey & Coulson; Williams et al., 2016; Soucie et al., 2021).

The theoretical model that is most relevant to the current study is the Proposed Disclosure Decision-Making Model (DD-MM; Greene, 2009). The DD-MM segregates the disclosure decisions into several components. These components include assessment of information, consideration of the potential receiver, disclosure efficacy and perceived adequate efficacy (Greene, 2009). Disclosure is important in constructing and maintaining social relationships and building social support networks; however, disclosing private and sensitive health information may make one feel vulnerable (Martins et al., 2013). When disclosing PCOS to others in one's life, it is important to anticipate support from the listener. Cohen and Willis (1985) proposed one of the first models that capture the connection between social support and well-being. Their model states that social support is associated with higher well-being primarily in times of stress (Cohen & Willis, 1985). Overall, the quality and effectiveness of social support seems to be the most important factor in relation to well-being.

The purpose of this study was to capture, with the aid of semi-structured interviews, PCOS-diagnosed women's experiences of disclosure to family, friends, and others within their social networks, as well as within online support communities. I aimed to understand how, why and under what circumstances women chose to disclose their PCOS. I also sought to understand common reactions to PCOS-related disclosures and symptomology, and how women navigate and respond to those reactions from others as well as which aspects of social support are productive in buffering women from PCOS-related illness concerns. To my knowledge, the role of disclosure in fostering social support within a person's social network has never been studied within in the context of PCOS. This study bridges PCOS, which has been studied mostly within a biomedical or biological framework, into new avenues and domains of research.

This study will provide insight into how disclosure and social support unfold for women with PCOS. It will offer tangible strategies to for support that will benefit family members, friends, and allies, as well as health care providers. It will highlight productive communication strategies that begin with relaying a diagnosis to another person, to building those relationships, and maintaining those conversations over time, in ways that are productive. This project also addresses on-going stigmatization and neglect of women's health conditions, such as PCOS and aims to find solutions at multiple layers, i.e., within the individual, as part of our daily conversations with others where these disclosures happen, and within a larger sociocultural context that puts constraints on what women can and cannot disclose to others. My goal is also to contribute to a small but robust body of research on the psychosocial impacts of PCOS, while also raising awareness and education of the syndrome in Canada.

CHAPTER 2

LITERATURE REVIEW

Polycystic Ovary Syndrome (PCOS)

Nearly eighty years ago, at the meeting of the Central Association of Obstetricians and Gynecologists in 1934, Irving Freiler Stein and Michael Leventhal described seven case studies of women presenting with amenorrhea (inconsistent or irregular menstruation), bilaterally enlarged polycystic ovaries, and hyperandrogenism (excess testosterone). These clinical presentations were then published in the conference journal archives in 1935, and the syndrome was named *Stein-Leventhal syndrome* (Stein & Leventhal, 1935).

This first set of influential publications sparked many empirical investigations into the syndrome and Stein himself went on to publish over 100 articles on the topic. Interest in the syndrome increased exponentially with more than 28000 publications documented from 1930 to 1950, and more than 8000 papers were published from 1950 to the early 2000s with an additional 20,000 manuscripts published after the 2000s (an 8-fold increase in this area of investigation). While the name of the syndrome has changed to *Polycystic Ovary Syndrome* (PCOS), and its diagnosis criteria refined over the years, it has remained one of the most prevalent health conditions in women worldwide (Azziz & Adashi, 2016).

Currently, PCOS has a global prevalence of between 8% to 21% in women of reproductive age (Bozdag et al., 2016; March et al., 2009; Okoroh et al., 2012; Wolf et al., 2018) with 1.4 million Canadians estimated to have PCOS (Lujan et al., 2008). Both the National Institute of Health and the European Society for Human Reproduction and Embryology/American Society for Reproductive Medicine (ESHRE/ASRM; Azziz & Adashi, 2016) require at least *two* of the following three criteria for diagnosis: hyperandrogenism, chronic anovulation, and polycystic ovaries. The Rotterdam criteria (Rotterdam, 2004) requires all three clinical features to be present. However, the addition of polycystic ovaries has increased prevalence rates by 3-5%, which contributes to the variability in diagnosis rates seen across countries. The Androgen Excess and PCOS Society (AE-PCOS) modified the diagnostic criteria in 2016 to include polycystic ovaries on transvaginal ultrasound and amenorrhea, but not hyperandrogenism. Based on refinements in criteria across these societies, PCOS is currently divided into four phenotypic expressions: (1) hyperandrogenism, chronic anovulation, and polycystic ovarian morphology (PCOM); (2) PCOM, chronic anovulation, and no clinical signs of hyperandrogenism; (3) hyperandrogenism, chronic anovulation, and no PCOM and (4) hyperandrogenism, PCOM, and normal ovulation (see Teede et al. 2018 for a set of the most up to date evidence-based international guidelines for the four expressions).

However, despite these improvements and the volume of research into PCOS, a lengthy and frustrating diagnosis timeframe is commonly reported by women. The data show that, regardless of participants' health care systems or country of residence, it takes 4 years on average and consultations with 2-3 providers to reach a conclusive diagnosis (Boyle & Teede, 2016; Dokras et al., 2017; Teede et al., 2014; Gibson-Helm et al., 2018; Hillman et al., 2020; Soucie et al, 2019). Studies that use qualitative methods show unsupportive provider communications as one underlying reason accounting for these delays (Hillman et al., 2020; Soucie et al., 2019). Interactions with general practitioners and specialists (e.g., endocrinologists, OBGYNs, and allied professionals, such as registered nurses, nutritionists/dietitians, ultrasound technicians, etc.) are often described by women with PCOS as curt, inattentive, cold, rude, mechanical, and unprofessional. Some women also recount that their health concerns were dismissed, their symptoms trivialized, and women who were overweight recalled many instances of discrimination on the basis of weight/obesity, poor coordinated care between general practitioners and specialists, and significant unmet needs in terms of treatment plans, and information about long-term impacts and comorbidities (Crete & Adamshick, 2011; Hillman et al. 2020; Soucie et al., 2021, Tomlinson et al., 2017; Williams et al., 2016). It is not surprising, then, that women with PCOS often report that they feel unsupported and stigmatized by the medical community.

Physiological Aspects of PCOS

PCOS has significant and widespread clinical implications across multiple life domains. Reproductive symptoms include hyperandrogenism (elevated testosterone) leading to more overt physical changes in appearance such as of hirsutism, oily skin, acne, and androgenic alopecia (De Leo et al., 2016). Hirsutism is male pattern hair growth on the body (e.g., dark or coarse hair growth on the chest, face, abdomen, or buttocks, for example), and presents in about 60% of patients (De Leo et al., 2016). Alopecia is thinning of the hair or male-pattern baldness on the scalp that results from excess androgen. Absent or irregular menstruation, polycystic ovarian morphology (small, fluid filled sacks that line the ovaries and impair ovulation), and subfertility or infertility (Teede et al., 2010) are also part of the diagnosis of PCOS. In fact, PCOS is one of the leading causes of infertility or subfertility in women (Poleshuck & Woods, 2014). Women who do become pregnant may experience complications such as miscarriage, hypertension, gestational diabetes, and pre-eclampsia, leading to more risky pregnancies (De Leo et al., 2016; Homburg, 2009;Palomba et al., 2015).

Women with PCOS are also at an elevated risk of metabolic concerns such as insulin resistance, impaired glucose regulation, type 2 diabetes and chronic inflammation (see review by Teede et al., 2010; Mahalingaiah & Diamanti-Kandarkis, 2015; Ollila et al., 2017; Broskey et al., 2018). Insulin resistance occurs when cells require above normal quantities of insulin to respond to the presence of glucose in the body, leading to the formation of both glucose intolerance and type 2 diabetes risk (De Leo et al., 2016). Insulin resistance is often associated with obesity, and 60-70% of women with PCOS are overweight or obese (De Leo et al., 2016). A popular treatment suggestion for metabolic-related concerns is a combination of medical management and weight loss through diet and exercise to reduce body fat percentage by 5-10% (Moran et al., 2010). However, with metabolic dysfunction already present, losing weight is often challenging for many women. For some, this may be an unwavering cycle; the weight loss is needed to treat metabolic concerns, but metabolic dysfunction causes the weight gain.

Women with PCOS are also at an elevated risk of other long-term comorbidities that require lifelong management, such as sleep apnea, non-alcoholic fatty liver, high cholesterol, endometrial cancer, and potential for stroke (Chandrasekaran & Sagili, 2018; Stewart & Sohrabji, 2020; Palomba et al., 2015). As mentioned above, infertility and pregnancy difficulties as well as obesity, type 2 diabetes, and general metabolic dysfunction are also higher risk in women with PCOS as compared to women without POCS (Peigné & Dewailly, 2014; Carmina et al., 2007; Moran et al., 2010; Aprindonidze et al., 2005). PCOS is thus a long-term condition that comes with long-term physical health risks, thus early diagnosis is crucial. It is also necessary for at-risk women with PCOS to be screened routinely for these potential complications during follow-up care (Peigne & Dewailly, 2014).

Psychological Aspects of PCOS

While less researched in the PCOS literature, women with PCOS also experience higher rates of mental health disorders such as depression and anxiety disorders and in severe cases, suicide attempts (Mansson et al., 2008, Yin et al, 2020). As well, they have an increased prevalence of body image problems, which are often accompanied by disordered eating behaviors and potential for eating disorders (Kogure et al., 2019, Himelein & Thatcher, 2006). In an Australian based meta-analysis by Damone et al. (2018), women with and without PCOS were compared on aspects of depression, anxiety, perceived daily stress, psychotropic medication use, and help-seeking behaviours. Participants were assessed on a variety of variables, such as demographic measures (e.g., presence of PCOS or not, Body Mass Index [BMI], fertility issues), psychological outcomes (e.g., depression, anxiety, perceived stress, mental illness diagnosis) and health seeking behaviours (e.g., psychological symptoms and seeking behaviours, psychotropic medication use). Women reporting a PCOS diagnosis exhibited an increased prevalence of anxiety and depression symptoms, perceived stress, and other major mental health illnesses (Banting et al., 2014, Yin et al., 2020). A significantly higher proportion of women with PCOS reported having used psychotropic medications and were more likely to seek help from a mental health professional in comparison to women without PCOS.

Certain mental health disorders may be more common than others in women with PCOS. Specifically, in a study by Kerchner et al. (2009), the risks and predictors of depression were explored in sixty women with PCOS. The overall prevalence of depression among women who have PCOS is 40%, with 16% of their participants suffering from Major Depressive Disorder (MDD). In addition, 23% women were taking antidepression medication. A second survey of these women revealed 56% of them suffered from mood disorders, 11% suffered from anxiety symptoms and 23% binge eating disorder. This study highlights the significant risk of mood disorders in women with PCOS, illuminating the importance of routine screening and treatment for mental health disorders in women with PCOS. In addition, psychological outcomes tend to be more severe in women with PCOS who struggle with infertility. For example, Basirat et al.

(2020) explored differences in the level of anxiety, stress coping strategies, personality traits, and social adjustment in a population of infertile women with PCOS and without PCOS. They revealed that infertile women with PCOS had higher levels of trait anxiety than the women without PCOS. As well, infertile women with PCOS were more likely to engage in problem-focused coping and seeking social support as compared to women without PCOS.

Despite the prevalence of mental health disorders in women with PCOS, physicians are only now beginning to acknowledge the presence of psychological concerns in women with PCOS (Kerchner et al., 2009). Regarding the gaps in knowledge surrounding psychological symptoms, Dorkas et al. (2017) found that practitioners (including family physicians, endocrinologists and gynecologists) were familiar with the cardiometabolic comorbidities such as insulin resistance and glucose intolerance but were unaware of the psychosocial and mental health symptoms associated with PCOS. Specifically, physicians were aware of the reduced quality of life and body image dissatisfaction but less than half were aware of the anxiety symptoms associated with this syndrome. This gap in diagnostic knowledge may explain the dissatisfaction in diagnosis and treatment in relation to mental health outcomes. Patients reported that less than half of their physicians gave information on medical management of psychological and emotional health (Dorkas et al., 2017), which emphasizes the lack of knowledge in physicians regarding the psychological comorbidities of PCOS. Additional education surrounding psychological health of women with PCOS is needed for healthcare professionals, to help increase quality of life of their patients.

Impacts on body image and femininity. Due to the widespread phenotypic expression of the disorder, many women with PCOS report stigmatization and marginalization (Kitzinger & Willmott, 2002), stemming from an inability to conform to typical feminine norms. Many of women report that symptoms such as hirsutism, acne, alopecia, and weight gain alienate them from Western norms related to body shape, size, and form (e.g., being thin and hairless), as well as gender-based expectations (e.g., fertility/pregnancy) (Farkas et al., 2014). As a result, PCOS can have profound effects on one's sense of identity and femininity (Newland, 2019). In Kitzinger and Willmott's (2002) influential study on women's experiences living with PCOS, participants reported shame and embarrassment as a result of their symptoms, often making them reluctant to broach or disclose their disorder to others (Kitzinger & Willmott, 2002). Women defined themselves as '*freaks*', '*bearded ladies'*, and '*hairy monsters'* and made many references of failing to appear as *'proper'* women. These women described 'proper' women as being those that are free from body and facial hair, have regular periods, and have the capacity to carry children. Comparing body image in women with and without PCOS, and the relationship between depression and body image, Himelein and Thatcher (2006) found that women with PCOS reported more depressive symptoms and body dissatisfaction. In addition, body dissatisfaction in women with PCOS was discovered to not originate solely from weight concerns. Instead, the participants with PCOS were expressing dissatisfaction with other body characteristics such as skin complexion, facial hair, general hair problems and overall appearance. Body dissatisfaction was most strongly associated with depressive symptoms among all women in the study.

Body image distress in women with PCOS was also evaluated in a cross-sectional study by Alur-Gupta et al. (2019). Women with PCOS were compared to a control group on three factors: body image dissatisfaction, depression, and anxiety. Overall, women with PCOS reported significantly higher body image dissatisfaction than the control group. Although women in general may have body image issues, the phenotypic features of PCOS make these body image issues more complex and harder to cope with (Alur-Gupta et al., 2019). Specifically, these overt symptoms of the disorder are often uncontrollable, and thus women cannot prevent them. Recently, Samardzic et al. (2021) explored how PCOS influences young women's (ages 18-22) conceptions of normality and abnormality and found three themes related to how young women with PCOS position themselves in relation to Western standards of femininity (e.g., being thing, hairless and able to reproduce). *Justifying abnormality* which focuses on women's experiences navigating and justifying their bodily changes. Next was *pathologizing the abnormal*, which explored the participants pathologizing of PCOS physical features that they expressed strayed from the normal boundaries of femininity and normality. The last theme was a *fear of failure in pregnancy*, which consisted of women's fears of infertility because of their PCOS, as well as concerns regarding their future relationships.

Impacts on quality of life. Compared to other long-term conditions (e.g., diabetes, heart disease), previous studies have demonstrated that PCOS has a more significant negative impact on quality of life and health-related quality of life (e.g., physical, or emotional limitations due to PCOS), particularly in terms of poorer life satisfaction, than women without PCOS and weight-matched controls (Ching et al., 2007, Jones et al., 2010). In fact, Coffey et al. (2006) argues that PCOS has more of a substantial impact on women's quality of life than other chronic health conditions, including epilepsy, asthma, arthritis, and chronic pain syndromes. Furthermore, Nasiri-Amiri et al. (2016) found that PCOS symptom concerns, particularly concerns about hirsutism and infertility, were associated with a greater perception of family-related tension, poor self-perceptions, and impaired interpersonal/social functioning in a sample of women from Iran. However, it should be noted that these findings were not compared to other racial or ethnic groups and thus should be interpreted with caution.

In examining PCOS-diagnosed woman's quality of life, Williams et al. (2015) asked participants to describe a typical day living with PCOS, and how they have dealt with symptoms in a semi-structured interview. Thematic analysis on the interview transcripts generated four themes: *change to life plans, co-morbidities, support*, and *identity*. Several participants reported major changes to their life plans, particularly in terms of starting a family based on the ever-changing symptoms of PCOS. Other participants reported having to live with other physical (e.g., migraines, irritable bowel syndrome, hypothyroidism) and mental health (e.g., depression, anxiety) challenges. Some participants also reported frustration over lack of support from healthcare providers and instead turned to educating themselves through the internet or online support groups, which some women found to be helpful to reduce social isolation, and others found these interactions made them feel worse. Women also reported that their diagnosis threatened their 'feminine identity' (the ability to reproduce and remain thin and hairless) and felt as though it was unfair that they had PCOS.

In a follow up study capturing a "snapshot" of what it is like to live with PCOS using photovoice methodology, Williams et al. (2016) asked participants to photograph anything that they felt impacted their quality of life, and then to write a diary entry to accompany each photograph they took. Thematic analysis of the diaries generated three major themes: *control, perception,* and *support.* The first theme, control, was centered around participants need to control their PCOS as well as their PCOS controlling them. The second theme, perception, was subdivided into two subthemes: *feminine identity* and *positive outlook.* Some of the participants felt their feminine identity was threatened because of their symptoms, often using masculine language to refer to themselves. Finally, the support theme was separated into three categories based on source: *the health care system, education,* and *relationships*. Frustration and a lack of support with the healthcare system was mentioned by some participants, which led these women to self-educate using books and the internet (e.g., social media sites, PCOS support groups, online conferences).

Similarly, through the use of focus groups and semi-structured interviews, Ee et al. (2020) found that women diagnosed with PCOS and overweight/obesity in Australia discussed their syndrome as a "*whole package deal*", manifesting with a multitude of symptoms. They discussed their desire to treat all aspects of the disorder and reported a lack of control over the many forms it presents. Again, women often reported a lengthy diagnosis process and a lack of information given by their healthcare providers. Many women felt isolated and had negative experiences on online forums but expressed a heightened need for peer/social support. As a result, living with PCOS can generate a significant amount of anxiety about the future as well as a subsequent need to reach out for social support, but many women worried that their friends and family would not understand their diagnosis.

Social support was most often found in PCOS-specific virtual communities, which had both strengths and drawbacks. For example, while PCOS support communities can be an empowering context for many women (e.g., sharing diagnoses, and tips for advocating, etc.), some interactions were negative. For example, participants reported that some websites perpetuated misinformation about PCOS, and others described feeling like their symptoms were mild compared to the more severe symptoms being discussed virtually. This research exploring the complexity of online communities is consistent with past research findings (Holbrey & Coulson, 2013; Soucie, et al., 2021; Williams et al., 2015). For instance, Holbrey and Coulson (2013) reported five empowering themes related to online PCOS communities: *connecting with others who understand, accessing information and advice, building confidence in interaction* *with health professionals*, *facilitating treatment-related decision making* and *improved adjustment and management*, and two disempowering themes: *reading about the negative experience of others* and *feeling like an outsider.* Overall, then, online support groups appeared to offer a variety of benefits by providing women with PCOS an opportunity to share their own experiences, learn tools for advocacy, and connect with others, which are helpful in learning to manage and cope with PCOS. However, those who use online support groups regularly should be wary of the drawbacks of relying on virtual avenues of support.

Chronic Illness Disclosures

Being diagnosed with a chronic illness is a self-defining event for many people (Berna et al., 2011). A major way in which individuals process and come to terms with important events is by sharing them with others (McAdams, 2013; McLean, 2008). Illness disclosures, experiences, and setbacks can be difficult to share with others, however (Pals, 2006). Often, disclosing sensitive health information can be an anxiety-provoking situation for many as it requires the management of both risk and vulnerability on the part of the discloser. Individuals may fear of stigma (Greene et al., 2003), rejection (Goffman, 1963), shame (Vagelisti et al., 2001), or the risk of social exclusion (Yoshioka & Schustack, 2001; Maman et al., 2016). Disclosure also requires an individual to find an opportunity while managing the flow of conversation (Hyman & Faries, 1992), balance the anticipation of a positive response from the recipient/listener (Greene & Serovich, 1996), consider past experiences of poor reactions to disclosure (Greene, 2009), as well as understand the social/cultural considerations of how much to share/what is appropriate disclose to others (McLean et al., 2009).

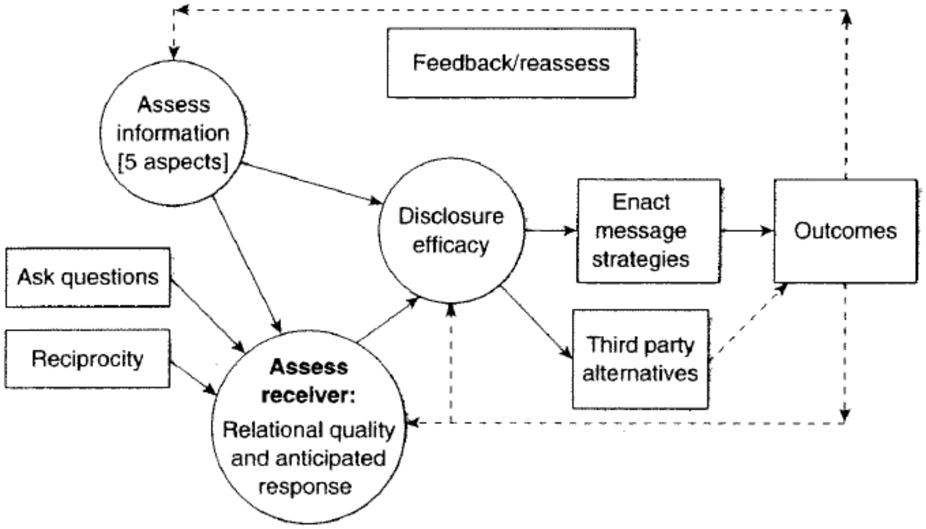
Health Disclosure Decision-Making

Many disclosure decision-making models have previously been proposed that capture the interplay between the discloser and the recipient as well as positive and negative listener aspects (Omarzu, 2000, Greene et al., 2003; Afifi & Caughlin, 2006; Derlega et al., 2004); however, a strong integrative model that encompasses multiple theories is the *Proposed Disclosure Decision-Making Model* (DD-MM; see Figure 1; Greene, 2009). The DD-MM is the most relevant model for the current study research as it focuses specifically on illness aspects (e.g., medication management) and the disclosure experience exclusively in the context of those with chronic illness. It is most pertinent to the disclosure of PCOS, since PCOS is a chronic illness that requires management, and it segregates the disclosure decision making process into several components. These components include *assessment of information* (e.g., considering the stigma around the diagnosis), *consideration of the potential receiver* (e.g., will the receiver handle the information well?), *disclosure efficacy* (e.g., how well can the discloser describe the disorder?) and *perceived adequate efficacy* (e.g., did the disclosure effectively explain the disorder?) (Greene, 2009).

It is important to note that the DD-MM is based on interpersonal contexts, such as face-to-face interactions, and does not include large group disclosures. As such, the DD-MM is suited best for interpersonal relationships (Greene, 2009). In addition, the DD-MM differs from other disclosure models as its focus is on health-related disclosures, which makes it relevant for our research topic. Although the DD-MM integrates many information management models, it must be noted that some parts of the disclosure process are spontaneous and others are more cautiously planned (Omarzu, 2000) and thus some parts of the disclosure process may face interruptions and unpredictability.

Figure 1

The Disclosure Decision-Making Model (DD-MM)



Note. This model was produced by Greene (2009), illustrating steps of the DD-MM. From Greene, K. (2009). *An integrated model of health disclosure decision-making.* In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty, information management, and disclosure decisions: Theories and applications* (p. 226–253). Routledge/Taylor & Francis Group.

Step 1: Assessment of Information. The first step in the DD-MM model is assessment of information about the diagnosis, including the stigma, preparation, prognosis, symptoms, and relevance to others. Stigma surrounding the illness is considered as disclosure involves both vulnerability and risk (Greene, 2009). When information, such as a diagnosis, is viewed as stigmatized, the risk in disclosing is elevated, and there may be more pressure to conceal (Goffman, 1963). However, Greene (2009) argued that if a person has a good relationship with the recipient, they will likely be more willing to disclose even if the information is stigmatized. Next is preparation, which addresses the discloser's own expectations prior to receiving the information (Greene, 2009). If the person was prepared to receive a diagnosis, they may have more time to prepare to disclose it. More time for planning may lead to more success in the disclosure process, whereas less time to plan may result in immediate disclosure to relieve distress (Greene & Berger, 1997). In women with PCOS, their symptoms may indicate and prepare them for a potential diagnosis. As a result, preparation for the diagnosis and disclosure is influenced by relational quality and anticipated outcome. Targets of disclosure tend to be those that we have a good relationship with and anticipate a positive response from (Greene, 2009). It is also important to consider the prognosis of the diagnosis. The prognosis of different diseases varies greatly, and the intrusiveness of the disease may change by disease stage. PCOS may affect each woman differently, and thus the prognosis will vary based on the individual. Goldsmith et al. (2007) propose that disclosure may rely on the current disease features (i.e., symptoms). Individuals may reappraise a decision to disclose based on the stage of their diagnosis and thus can choose to abort their disclosure process. In addition, visible symptoms may vary throughout progression of a disease. As a result, noticeable symptoms may affect the timing of the disclosure, as receivers may start asking about the illness (Greene, 2009). Some may feel that the disclosure process is forced on them as their health status declines (Vallerand et al., 2005). The last step in assessing the decision to disclose is the diagnosis' relevance to others. Mainly, if the diagnosis affects others (i.e., infertility from PCOS would also affect a partner), people may feel that others have a right to know (Greene, 2009). Overall, many aspects go into assessing diagnosis information and these aspects are all important considerations for disclosure decisions.

***Step 2: Assessing the Receiver*.** The next step in the DD-MM model is assessing the receiver (Greene, 2009). Two specific receiver variables are taken into consideration: relational quality and anticipated response (Greene, 2009). According to Afifi and Olson (2005), the closer the discloser feels to the receiver (i.e., relational quality), the more likely they will anticipate a positive response. Individuals will likely have varying types of intimacy with close others in their lives, and as a result will selectively choose who to share their information with (e.g., choosing to share a PCOS diagnosis with a romantic partner). The receivers' anticipated reaction(e.g., an empathetic reaction versus a negative one) is also heavily considered by the discloser (Greene, 2009), before choosing to disclose their information (Babrow, 2001). If the disclosure occurs and a rejecting response is given from the receiver, it will decrease the likelihood of future disclosures to that receiver (Greene, 2009). As a result, the discloser will need to anticipate a positive response (e.g., empathy toward their situation) before willing to disclose their diagnosis (Greene & Serovich, 1996).

Step 3: Disclosure Efficacy**.** The third step proposed by the DD-MM is disclosure efficacy. Before an individual can disclose, they must consider their confidence in being able to successfully relay a health diagnosis to others (Greene, 2009). Some people may even practice their disclosure strategies with a trusted person (Greene et al., 2003), to prepare details such as time, phrasing, and location, to maximize the confidence in their disclosure skills. However, decreased relational quality and anticipated negative responses may lead to decreased disclosure efficacy (Greene, 2009). To ensure strong disclosure efficacy, individuals should aim to practice their disclosure strategies as well as choose recipients based on strong relational quality and positive anticipated response.

Interruptions to Disclosure. Finally, it is important to consider that disclosure is nonlinear and interruptions to one's disclosure is unpredictable. There are two common conversational events that may disrupt one's disclosure: questions and reciprocity (Greene, 2009). While disclosing, the receiver asking anticipatory questions may interrupt the original disclosure plan. Questions by a receiver prior to a disclosure are not necessarily negative as even a general anticipatory question can open an opportunity for the individual to spontaneously disclose (Petronio et al., 1996), and may allow the discloser to feel as though they have permission to disclose. The other disruption to disclosure is reciprocity. Reciprocity occurs when someone receives equivalent disclosure from a close other during the disclosure process. Reciprocity is most common when the topic is shared (i.e., both sharing a health diagnosis like PCOS; Dindia, 2000). Sharing a health diagnosis may also increase the likelihood of an empathetic response (Dindia, 2000). Overall, then, there are many considerations that are made by an individual before a decision is made to disclose their health diagnosis to others. Although these considerations may vary based on the disclosure context (e.g., disclosing spontaneously or out of necessity), the DD-MM integrates many past studies regarding factors that may impact health disclosure decisions, audience reactions to disclosures as well as interruptions to disclosures (see Petronio et al.,1996 and Babrow, 2001 for a comprehensive overview of the disclosure decision making process).

Disclosure and Chronic Illness

Previous literature (Kaushansky et al., 2017; Joachim & Acorn, 2000), has illustrated that individuals with appearance-altering conditions, like PCOS, may experience stigma and attempt to conceal their illness. Sharratt et al. (2020) explored the disclosure experiences of adults with stigmatized characteristics due to a visible condition. A qualitative approach was taken, and semi-structured interviews were conducted. Thematic analysis of the interviews uncovered a variety of themes. The first theme was remaining invisible, which pertained to participants desire to avoid their differences being seen by others. Most participants reported attempts to cover their illnesses using clothes, makeup, behaviours etc., which allowed them to exert control over who was informed of their differences. Another theme was enacting agentic versus autonomous disclosures.

Agentic state disclosures were those that were not initiated by the participants but rather arose from another person, circumstance or by necessity. One participant, who has an alopecia diagnosis, reported that she often discloses her diagnosis to intimate partners in fear of her wig falling off (Sharatt et al., 2020). *Autonomous disclosures* were those that resulted from more conscious deliberation and were under the control of the discloser. One participant reported she felt the need to unburden herself and be honest with others, and therefore planned disclosure of her diagnosis. Finally, the last theme was *preparing for and controlling the disclosure situations.* Practical preparations included planning the timing, location, and privacy of their disclosure. In addition, participants reported emotionally preparing themselves for the potential reactions of the recipient. These findings are in line with some of the considerations of the DD-MM model (Greene, 2009), and give insight into the steps one may take when deciding to disclose their illness.

Disclosure and Adolescence. The decision to disclose may be burdensome on those with chronic illnesses in general, but especially for those in the adolescent developmental period, as it is a time of growth and transition. Kaushansky et al. (2017) set out to examine why and how adolescents living with chronic illnesses chose to share their diagnosis with others; specifically, adolescents with either invisible or visible chronic illnesses. A qualitative approach was taken, with adolescent participants living with either an invisible or visible chronic illness. The interview was semi-structured with questions encompassing the following: who participants disclosed to, motivation behind why they disclosed, content of their disclosure and barriers to disclosure. Analysis of interview transcripts revealed that family members were the most common individuals that were targets of disclosure. In addition, not many participants chose to disclose to peers. The hesitancy to disclose to peers likely stemmed from the stigma surrounding their diagnoses, and not wanting to appear different than those around them. The participants motive behind choosing family members as the recipient included having an emotionally based connection with them, their medical involvement with the diagnosis and their demonstrated interest in the discloser. Additionally, the hesitancy to disclose to peers may stem from wanting to conform with others. Illness related disclosures may disrupt regular adolescent conformity as the adolescent may risk social rejection, potential stigmatization, or discrimination (Kaushansky et al., 2017). The overall decision to disclose, regardless of target audience, was influenced by the anticipated response of the participant, the visibility of their condition, practical needs, and a decision that disclosure is warranted.

Kaushanky et al. (2017) provided important insight into the effect visibility of the condition may have on disclosure and revealed that the differential expression of various disorders may influence disclosure considerations for adolescents. More specifically, Barned et al. (2016) aimed to explore disclosure decisions among adolescents with inflammatory bowel disease (IBD), as IBD is an “invisible” chronic illness, meaning their symptoms were able to be hidden. Analysis of the interview transcripts revealed multiple themes. First, *the decision to disclose or conceal*, with most participants stating that their default was to choose to conceal their illness or to be strategic in who they chose to tell and only disclosing when necessary. Participants who chose to disclose their diagnosis did so with people whom that they trusted and had known for a long time. Another major theme that emerged was *when to disclose their illness*. Participants reported wanting to make sure they had adequate knowledge about their illness to explain it to others accurately. The knowledge participants aimed to have encompassed illness symptoms, quality of life and side effects of treatment. Others reported considering the current severity of their illness before disclosing it. Specifically, considering adverse outcomes of their diagnosis and if disclosing their illness would help with symptom management. Barned et al. (2017) highlighted an important finding that other studies have yet to acknowledge: individuals wanting proper information about their diagnosis prior to disclosing. When individuals have the relevant information, they will be able to correctly relay their diagnosis to others and answer questions that others may have. Seldom has other chronic illness literature outlined this finding.

Disclosure and Women's Health Disorders

The literature on disclosure of PCOS is limited and thus we draw upon literature on similar women's health disorders as a guide. Specifically, disorders such as endometriosis have similar symptoms as PCOS, such as fatigue, pelvic pain, and subfertility (a delay in conceiving) (Krsmanovic & Dean, 2021). In addition, women experiencing infertility also may have similar experiences as those with PCOS, as in some cases PCOS causes infertility. Women with endometriosis have a myriad of symptoms that may affect physical and psychological health as well as social and personal relationships (Morandi et al., 2014). Krsmanovic and Dean (2021) sought to investigate how women with endometriosis disclose their disorder at work. The study took a qualitative approach, and asked women questions about their experience with endometriosis, their thoughts about diagnosis disclosure, communication about the diagnosis and the impact of workplace environment on communication about the disorder. The first theme that emerged was how *frequently communication of endometriosis at work* occurs. Some participants reported never discussing their disorder at work whereas others discussed their endometriosis monthly, usually based on their menstrual cycle. However, most of the participants described communicating about their disorder only when symptoms flare up. The next theme that emerged is participants *level of openness*: closed off, ambivalent or very open. Participants that were closed off preferred to keep their disorder to themselves and avoided expressing their pain. Those that were ambivalent toward discussing their endometriosis reported disclosing due to a need to explain severe pain. Those that were very open about their disorder discussed their endometriosis freely with coworkers and superiors. Another prominent theme was the *type of content* shared. Participants disclosed anywhere from “a little” information to “openly disclosing” detailed information. Participants preferred conversational partners were assessed using the listeners personal characteristics, such as their gender, as well as their closeness and comfort level with this individual. Most participants reported feeling the most comfortable discussing their disorder with a female conversation partner. Overall, the most important aspects that went into a disclosure decision were severity of illness, level of openness, type of content to be shared and preferred conversational partners, as well as what types of factors go into a disclosure decision when the diagnosis affects the female reproductive system, which may have visible or invisible symptoms.

Another reproductive issue that women may experience is infertility. Infertility is one of the symptoms of PCOS, but on its own it affects about 15% of couples in the United States (Chandra et al., 2005). One study (Steuber & Solomon, 2011) set out to investigate factors that predict married partners disclosures about their infertility to their social network members. Specifically, they used the DD-MM (Greene, 2009; see above), to identify factors that contribute to partners’ decision to reveal their infertility. Fifty heterosexual, married couples were recruited who had been coping with infertility anywhere between eight months and five years. The couples were first asked to identify members of their social network. Then, the couples filled out measures to assess stigma, network characteristics, confrontation efficacy and communication variables. Results revealed that when personalized stigma was targeted at the husband, the couple was less likely to disclose their infertility to their social network. However, when women reported coping with personalized stigma, the individuals were more likely to disclose to their social networks. In addition, both communication efficacy and closeness were positively correlated with a tendency to share infertility-related information to social network members. In women with PCOS, only some may experience infertility; however, it is important to highlight that this study may provide insight into differential disclosure strategies to their social network based on the presence of infertility.

Disclosure is important to constructing and maintaining social relationships, but disclosing private information, such as infertility, may make one feel stigmatized, especially if unhelpful (e.g., giving unsolicited advice) social support is present (Martins et al., 2013). Martins et al. (2013) explored the interactive effects that social support and disclosure have on fertility-related stress. They examined the role that disclosure of fertility status has on moderating the relationship between social support and fertility related stress. Fertility related stress was broken down into three categories: personal, social, and marital stress. This study followed married couples for one year who were undergoing fertility treatments. They found that disclosure of infertility to their social network moderated the relationship between social support and personal and social stress, but not marital stress, such that the disclosure of infertility status strengthened the relationship between social support and stress. At highest levels of social support, the lowest social stress was seen in the groups that disclosed their infertility to all close relationships in their social network. The researchers proposed that because individuals that receive high support from others in their social network, in general, they may not fear social withdrawal because of their disclosures. Disclosure and social support are often related but have distinct constructs that can co-occur (Martins et al., 2013). Individuals may feel the obligation to disclose something to a close other, even if they perceive they may not be supportive. On the contrary, individuals may disclose something to a close other because of high perceived support. Due to the relationship between disclosure and social support, it is important to also further study the factors that will influence the quality of one's social support.

Social Support

Social support is a topic that encompasses many definitions, concepts, and ways of measurement. Barrera (1986) splits social support into three main categories; *social embeddedness, enacted support,* and *perceived social support*. Social embeddedness refers to the connections that individuals have to others in their social environments. Enacted support is defined as the actions other perform while they are aiding someone (Barrera, 1986). More specifically, enacted support consists of helping behaviours provided when one faces a life stressor (Barrera, 1986). An example of this specific type of support is exhibited when someone reaches out to a friend while going through a negative life event. Their friend may express helping behaviours in the form of a phone call or visit to check in. Perceived support is based on how confident someone is that support is there when needed (Barrera, 1986), which can be based upon recollections of enacted support (Lakey et al., 2002).

Researchers have presented mixed findings on the effects of various types of social support on health outcomes, such as well-being (Chen & Feeley, 2012). Chen and Feeley (2012) propose that enacted support which fulfills different life functions causes differential results in its effects on well-being, such as developing strengths to combat problems. Cohen and Willis (1985) proposed one of the first models for the positive association between social support and well-being. More specifically, their model encompasses two types of hypotheses for social support: the buffering model and the main effect model. The buffering model states that social support, generally, is related to well-being primarily in terms of a person under stress (Cohen & Willis, 1985). The person will be protected from their stressful event and the social support will prevent its negative influence on them (Cohen & Willis, 1985). The other model, the main effect model, has a more direct approach in stating that social support (including enacted support, perceived support and social embeddedness) will have a beneficial effect regardless of whether one is under stress or not (Cohen & Willis 1985). These various hypotheses may explain the discrepancies in the effect of social support on well-being as the specific reasoning for reaching out (a stressful situation versus not) may alter the outcome.

More recently, Feeny and Collins (2014) propose that social relationships not only buffer an individual from a life stressor but go above and beyond by supporting "thriving" in life (i.e., flourishing in life goals). Feeny and Collins (2014) believe that well-functioning, close relationships serve two functions. The first function is to teach individuals to cope with adversity. This includes highlighting an individual's strengths to combat their weaknesses. The other function is to teach someone to thrive in the absence of adversities. These two functions give a sense of empowerment that allows one to move on from a negative experience instead of dwelling upon it (Feeny & Collins, 2014). When general social support is present, an individual may cope better with the stressor and the negative emotions associated with it. As well, it may provide one with the skillset to cope which allows one to thrive in spite of the stressors present. Overall, the quality and effectiveness of social support seems to be the most important factor that will affect the outcome on well-being. Gable et al. (2012) propose that more effective support is the factor that causes less distress and anxiety whereas less effective support is associated with greater anxiety. Reaching out for support is not the only beneficial factor; the actual quality and effectiveness of the support can help predict the outcome on well-being.

Social Support in Chronic Illness

Although social support has been frequently studied as a broad topic, it also can be addressed in the context of those with chronic illnesses. Higher social support has been previously associated with better physical functioning, decreased illness related mortality and better self-management of symptoms (Feldman et al., 2020). However, the severity of one's illness may impact the amount of social support sought out, as more severe symptomology may require more support (Maguire et al, 2019). Specifically, illness status is a significant predictor of illness related functioning (Curtis et al., 2004). Social support in the context of chronic illness has been shown to increase one's medical treatment self-management (DiMatteo, 2004), which is important as developing mastery of one's disease regimen is related to positive adaptation to the disease (White et al., 1992). A supportive other may provide various types of support that aid in self-management of the disease. Social support may be presented as instrumental help with self-management tasks (e.g., reminders to take medication) or may be more emotional such as providing verbal encouragement and advice (Gallant, 2003).

The effect of social support on anticipated stigma and quality of life in those with chronic illness was studied by Earnshaw et al. (2011). The researchers anticipated that stress, social support, and patient satisfaction mediate the relationship between stigma and quality of life. They found that stress and social support mediated the relationship between anticipated stigma reactions from friends, family, and coworkers with quality of life. As well, patient satisfaction mediated the relationship between anticipated stigma from healthcare workers and quality of life. More specifically, those with chronic illnesses who anticipate greater stigma were also reporting lower quality of life. This relationship was explained by the presence of higher stress, lower social support, and lower patient satisfaction. These findings outline the importance of having high quality social support while living with a chronic illness. Variables such as anticipated stigma, stress and the quality of one's social support can have significant impacts on the overall well-being of people living with a chronic illness.

The recognition of psychosocial dimensions, such as social support, of chronic illness is important to investigate as physical functioning and psychosocial functioning are intertwined. Presley et al. (2021) assessed the impact of social support on diabetes distress (emotional burden, physician-related, regimen-related and interpersonal distress related to having diabetes) in a population of individuals with type 2 diabetes. Findings indicated that participants who were not satisfied with their social support were significantly more likely to have severe diabetes distress than those that were satisfied with their social support (Presely et al., 2021). Therefore, individuals that have strong social supports were better able to adjust to their chronic illness. Broadly, when the demands their chronic illness were appraised by the participants as being greater than the available resources, there was a disturbance in psychosocial adjustment. Overall, this study provides important insight about the overlap between illness severity, quality of social support, and psychosocial adjustment to a chronic illness.

Social support has been previously known to have both structural (e.g., amount of supportive people in one's life) and functional (e.g., receiving support from loved ones) elements (Feldman et al., 2020), in general. However, social support surrounding chronic illness is often studied in the context of one's specific illness. In a study completed by Feldman et al. (2020), researchers aimed to assess variables that were generalizable across different chronic illness groups, to see how they impact levels of social support. They predicted that the presence of pain symptomology would be associated with significantly lower levels of social support in general and illness related domains and the presence of an illness with an unestablished cause would be associated with lower levels of general and illness related social support. Overall, they found that reported social support levels were similar across those with chronic health conditions and healthy peers. Notably, those with pain as a symptom of their chronic illnessdisclosed their diagnosis to fewer friends than those without pain, thereby leading to less social support. This study highlighted the importance of assessing pain as a symptom when inquiring about social support, which is similar to White et al. (1992)'s discovery of illness severity and psychosocial functioning. Both pain and illness severity seem to impact social support levels and should be considered when conducting a study involving both social support and chronic illness.

Social Support and Women's Health Disorders

Social support and chronic illness are important to examine across a variety of illnesses. However, due to the uniqueness of many women's health disorders, it is also crucial to review social support in the context of these illnesses. Many women's health disorders (i.e., PCOS, endometriosis, infertility, etc.) have a variety of unique symptom presentations, and thus the experience of these disorders is different for each woman. As a result, many women may require different aspects of social support to help meet their needs.

Receiving high quality social support may be difficult, and an important aspect of social support is clearly communicating one's needs and desire for support. To integrate both disclosure strategies and type of social support received, Steuber and High (2015) investigated how disclosure strategies of women with infertility related to quality of social support outcomes. Results revealed that there are two optimal ways to receive high quality social support. The first is to disclose the diagnosis of infertility in a face to face and direct manner. Specifically, the effect of a direct disclosure on fertility related quality of life was fully mediated by perceived social support, indicating that if an individual already perceives positive social support, then a direct disclosure increased one's quality of life. Additionally, incremental disclosures (sharing small pieces of information at a time to gauge reaction) also positively impacted quality of life outcomes. Both direct disclosure and incremental disclosures involve the discloser to directly reveal information and thus both mechanisms appeared to have beneficial outcomes in receiving high quality social support. Steuber and High (2015) posit that when disclosures are happening in real-time, whether directly or incrementally, it gives the support seeker and the listener an opportunity to clarify and adjust aspects of the disclosure, and thus lead to more effective support.

There is only one study to date that examines social support in the context of self-management for women with PCOS (Barzarganipour et al., 2017). Bazarganipour et al. (2017) set out to explore PCOS patients' views about facilitating and inhibiting factors to self-management. They discovered five themes related to treatment self-management, including both facilitating and inhibiting factors. The first theme was related to *financial issues*, with patients reporting that they could not afford their various treatments. The second theme encompassed *patients themselves* as inhibiting factors, including inaccurate perceptions they had about PCOS as well as insufficient information about the disorder. The third theme was *healthcare provider systems* inhibiting treatment self-management, which included lack of information support (e.g., not informing patients about their treatment options) as well as an absence of holistic care (e.g., healthcare providers not respecting their needs for privacy, both emotionally and physically). *PCOS itself* was also an inhibiting factor, as many participants reported disease-related issues such as side effects and prolonged waits for treatment that were hindering their treatment adherence. Finally, *social factors* appeared to have both facilitating and inhibiting impacts on treatment adherence. Better understanding of PCOS and its impacts among family, friends and peers was something that improved self-management in most cases. However, some participants reported that peers directed them away from treatment, telling them PCOS treatment was painful or too expensive. Overall, the quality of the social support from healthcare providers, family and peers were a vital factor in treatment adherence.

Purpose of the Proposed Study

In this study, I focused on how women with PCOS disclose their diagnosis and experiences living with PCOS to others in their immediate social network, as well as how, why, and under what circumstances they decide to disclose. I also explored how disclosure impacts both social support and quality of life. I chose to study this topic for the following reasons: First, PCOS is the most common endocrine syndrome in women of reproductive age (affecting nearly 1 in 10 women worldwide), and many manage the syndrome without adequate social support from others. Second, its reproductive, metabolic/endocrine, and mental health aspects impact social/interpersonal relationships, although it is unclear how and to what extent (Farkas, 2014, Nasiri-Amiri et al., 2016). Third, one of the most pronounced barriers to diagnosis and treatment after provider difficulties are social support factors, suggesting the importance of disclosure in building social support as key to good treatment outcomes (e.g., self-management; Bazarganipour et al., 2017; William et al., 2015). Fourth, an emerging body of research illustrates that PCOS social support networks occur most often in virtual/online support communities, which suggests that perhaps disclosure and social support seeking within one’s social network may be difficult. Furthermore, these online support communities, while positive in some respects can be of questionable validity in others, and women often feel worse about themselves after visiting these sites (Chiu et al., 2018; Williams et al., 2016; Soucie et al., 2021).

Finally, it is important to acknowledge that most of the data collected on PCOS comes from large scale quantitative or biomedical investigations, and these studies lack a social science perspective. Of the limited qualitative data available, researchers have tended to explore women's' lived or diagnosis experiences with PCOS and only rarely capture the psychosocial/interpersonal impacts of the syndrome. No study of which I am aware has explicitly targeted the interconnections between disclosure, social support, and quality of life of women diagnosed with PCOS.

I posed the following research questions which guided my qualitative inquiry, which was explored through a semi-structured interview:

i) In what ways do women with PCOS choose to disclose their diagnosis to others, and what factors influence their decision to disclose?

ii) How do they broach and then explain their PCOS diagnosis to others?

iii) What are the most common reactions to disclosures from others, and how do women navigate and respond to others' reactions to their diagnosis?

iv) What aspects of social support are productive or unproductive in buffering women with PCOS from their illness-related concerns?

It was anticipated that this study would gain insight into the process of disclosure for women with PCOS, and what makes for a positive and productive disclosure experience. The results of this study highlight what PCOS-specific disclosures entails, how women navigated responses to their disclosure from others, as well as how social support unfolded overtime. As well, it offers tangible and practical strategies (derived from women with PCOS themselves), to those wishing to provide support for friends and family members with PCOS. It also works to combat the stigma that surrounds the disorder by providing effective communication techniques to properly relay a diagnosis, engage in conversations, and connect with others. Strong communication techniques are helpful in relaying information to healthcare providers when seeking treatment. Finally, this study may also impact long-term outcomes for women wishing to disclose the syndrome to others (e.g., fostering closure, building friendships, and enhancing relationship satisfaction).

CHAPTER 3

RESEARCH METHODOLOGY

Paradigms and worldviews

Ontology

A paradigm has been previously defined by Filstead (1979) as “a set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organized study of that world” (p.34). The paradigm selected is a vital part of guiding the researchers’ philosophical assumptions. Paradigms guide the research, including selection of participants, tools and methodologies used (Denzin & Lincoln, 2000). Ontology is centered around beliefs about the nature of reality and being (Guba & Lincoln, 1994; Ponterotto, 2005). There are two broad approaches to understanding our social reality: realism, and relativism (Denzin & Lincoln, 1994; Ponterotto, 2005). A *realist* ontology assumes that there is a singular reality that exists independent of human perceptions and influence. A *relativist* ontology posits that multiple realities or truth exist (all of which are equally valid) and are situated in a social, cultural, and historical milieu rather than one single truth. Reality is influenced by an individual’s perceptions, the social environment, and the interaction between the individual and the researcher at one particular moment in time. With this study, women’s disclosure and social support experiences frame their reality of PCOS; however, the participants’ recall accuracy of those events is not the focus of the study. Instead, this study concerned the meaning-making process that is dependent upon the individuals’ perceptions of their experiences and the interpretation of those experiences by the researcher. Thus, a relativist approach was suitable for addressing my research questions of the present study.

Epistemology

Epistemology is how knowledge is generated ranging from *positivism*, the view that there is a singular truth, which can be detected through systematic observation in a controlled experimental setting, to *constructivism/interpretivism*, the belief that knowledge is co-constructed through interpretation and deep engagement and reflection through research-participant dialogue. Constructionists argue that reality is held in the mind of an individual, rather than being an external and single entity (Hansen, 2004; Ponterotto, 2005). A social constructionist takes the position that our ways of understanding the world come from daily interactions between people, that our shared versions of knowledge are constructed through the course of our everyday lives (Burr, 2003). Thus, the view of a social constructionist stems from the goal of understanding lived experience, from the point of view of the individual living it.

By adopting a social-constructionist paradigm position in this study, I acknowledge that participants' experiences, and their meaning are constructed through conversation and dialogue, at a particular moment in time, and that their experiences are subjected to interpretation by the researcher. For the present study, additional factors may have influenced the participants' recollection of their experiences, such as the presence of the interviewer and their emotional state at the time of the interview. As well, I played an active role as a researcher and interviewed the participants, thus interacting with them, which introduces subjectivity. I interpreted participants experiences during the interview and asked further probing and follow-up questions for additional detail and clarification, based on their experiences, as well as my understanding of those experiences. Due to my research background with PCOS, as well as my own experience living with and managing the disorder, I acknowledge that my interpretations of the participant's stories may vary from other researchers with a different background (see *author's positioning statement* below)

Methods

Participants

My sampling strategy was purposeful, but also involved maximum variation sampling to ensure diversity of experiences. My maximum variation sampling techniques included recruiting participants using various modalities (social media platforms and online support groups) in which women from different Canadian provinces were reached. Following approval from the University of Windsor's research ethics board (REB) (#:40590), 28 women diagnosed with PCOS were recruited to participate (see Table 1 for demographic information of participants). Participants ranged in age from 19 to 43 (*M*=28.17, *SD*=6.03), with an average time to diagnosis of 3.03 years. To be eligible, participants must have been a Canadian or permanent resident of Canada, English speaking, over the age of 18, and previously received a PCOS diagnosis. Participants were also required to have disclosed their PCOS diagnosis to at least one person within their social network.

My sample consisted of 67% Caucasian women, followed by South Asian (7.14%), Latin American (7.14%), Black (3.6%), Arabic (3.6%) and Other (10.7%), which represents greater heterogeneity than previous PCOS research (e.g., Steuber & High, 2015, Moren et al., 2015, etc.). Most participants were married (46.4%), with others being Single (28.5%), Partnered/Non-married committed relationship (17.9%), or Casually Dating (7.14%). Most women had an undergraduate degree (39.3%), followed by completion of some college/university (17.9%), a graduate degree (14.3%), vocational degree/certificate (14.3%), a high school diploma (7.14%), a professional degree (3.6%) or a postgraduate degree (3.7%). In terms of targets of disclosure, most disclosed their PCOS to their parent(s) (92.8%), and friends (78.6%), followed by their partners (46.4%), siblings (32.1%), online communities (17.8%), extended family members (14.3%) and coworkers (14.3%). Participants primarily lived in Ontario (74%), followed by British Columbia (3.6%), New Brunswick (3.6%), Newfoundland and Labrador (3.6%), Saskatchewan (3.6%) and Quebec (3.6%).

Sample size considerations. While Braun and Clarke suggest that a minimum of six participants is typical for a valid thematic analysis (Braun & Clarke, 2013), my sample size of 28 interviews was chosen based on a variety of factors. Braun and Clarke (2019) suggest that saturation, the point at which no new information or themes are produced by the data, is not an adequate guideline when using a reflexive thematic analysis approach. This is because meaning requires interpretation and new meanings are always theoretically possible. Instead, they suggest following the *information power guidelines* described by Malterud et al. (2016), which states that the more relevant information a sample holds, the fewer participants will be needed.

Braun and Clarke (2021) also argue that ceasing data collection is an "*interpretive judgment"* (p. 210), which is based on the goals of the study. Due to the time restraints of this thesis and funding resources available, we justify that our 28 participants optimized results while still ensuring researchers were able to manage the complexity, richness, and reflection involved in staying true to a reflexive thematic analysis.

Table 1

Participant Demographic Information

ID #	Age	Ethnicity	Time to Diagnosis	Relationship Status	To Whom They Disclosed
1	23	Jewish	1 year	Single	Parents, siblings, and friends
2	26	White	2 years	Partnered/Non-married committed relationship	Partner, mother, friends, online
3	28	White	1 year	Married/Civil Union	Partner, friends, mother, extended family
5	33	South Asian/Irish	8 years	Casually dating	Parents, friends
6	26	White	3 months	Single	Coworkers, friends
7	22	White	3 months	Married/Civil Union	Parents, sibling, partner, friends
8	21	Arabic	A few months	Single	Parents, siblings, friends
9	41	White	2 weeks	Married/Civil Union	Mother, friends, partner
10	31	Black/East Indian	Unknown	Married/Civil Union	Partner, parents, siblings, extended family
11	28	White	1 year	Married/Civil Union	Friends, parents, siblings, husband
12	26	White	1 week	Casually Dating	Mother, siblings, friends
15	36	White	10 years	Partnered/Non-married committed relationship	Mother, extended family, partner
16	30	Black	6 years	Single	Mother, sister, friend
17	30	White	6 months	Single	Parents, online
18	26	White	8 months	Married/Civil Union	Mother, partner
19	29	White	10 years	Single	Parents, coworkers, friends
20	22	White	Discovered by accident	Partnered/Non-married committed relationship	Parents, siblings, friends

21	19	White	2 years	Single	Mother, friends
23	27	White	4 years	Married/Civil Union	Friends, partner
24	26	White	5 years	Partnered/Non-married committed relationship	Parents, siblings, coworkers
25	37	South Asian	Unsure	Married/Civil union	Parents, siblings, online
28	43	Latin American	1 year	Married/Civil Union	Friends
29	32	White	3 months	Married/Civil Union	Parents, siblings, partner
30	29	White	13 years	Married/Civil Union	Parents, siblings, coworkers, extended family
31	31	White	1 year	Married/Civil Union	Parents, siblings, partner
32	27	Latin American	10 years	Married/Civil Union	Parents, siblings, partner
33	21	White	Less than a year	Partnered/Non-married committed relationship	Parents, friends
34	19	South Asian	6 months	Single	Parents, friends, online

Note. N=28. Some IDs were removed (ID, 4,13,14,22, 26, 27) because participants did not participate in the interview.

Procedure

To recruit participants, a general advertisement was created for the study including information about study eligibility. This advertisement was posted and circulated virtually through social media platforms (e.g., Facebook, Instagram, and Twitter) as well as online PCOS support groups (PCOS awareness and support group-Canada, PCOS Challenge, and PCOS Awareness Association). Interested participants were asked to contact me through a research email. After participants reached out through one of these platforms, I confirmed eligibility and sent the informed consent form to participants via email (see Appendix A).

In addition, participants were offered a few dates and times to complete a semi-structured interview, which was conducted via the Microsoft Teams platform (see Appendix B). Participants read the informed consent document prior to being interviewed, which includes consent to participate in the study, consent to use anonymized quotations and consent to be audio and video recorded (or only audio recorded, if this was preferred). Participants were asked to confirm their interest in participating after reviewing the consent form.

On the date of the interview, participants logged into the Microsoft Teams Platform. I reviewed the consent form a second time with participants and asked them if they have any questions or concerns. I then outlined the study with participants and encouraged them to ask any questions that they had, while encouraging participants to ask questions, modify questions, or refuse to answer any questions they did not wish to discuss. Interview questions were structured around an interview guide that contained four domains: PCOS diagnosis (how did you come to be diagnosed with PCOS?), disclosure ("Have you told someone about your PCOS diagnosis?"), memorable and influential disclosure experiences ("Did anyone's reaction surprise you?") and social support ("Have you reached out for support regarding your PCOS diagnosis?"). I also asked participants follow up questions about their disclosure experiences, and the recipient's reactions to disclosure. I also asked participants questions about social support, and if the support was helpful or harmful, and if participants have consulted virtual communities for resources or support. I ended the interview by giving participants an opportunity to share anything they wish that was not covered in the interview process. I also explained the concept of member reflections, a credibility technique explained below, and told participant that if they wished to be contacted again for member reflections, they could do so at the end of the demographic survey. Then a link was sent to participants to complete a five-minute survey that consisted of a brief set of demographic questions to contextualize the sample, as well as a question asking participants if they wished to be contacted again for member reflections (see Appendix C).

All interviews were conducted by me (a Clinical Psychology Masters student) and a research assistant (another Clinical Psychology Master student). All study processes were overseen by my supervisor, Dr. Soucie (a psychology faculty with expertise in qualitative research methods and PCOS diagnosis and its impacts) and our research lab members. Before the interview started, participants were encouraged to find a quiet, distraction free place in their home to complete the interview. All interviews were conducted virtually via Microsoft Teams platform. Given the SARS-CoV-2 (COVID-19) pandemic, face-to-face interviews were not feasible. However, it is important to note that Deakin and Wakefield (2014) suggest that the use of online synchronous interviews through a video chat platform (such as Skype) are a useful replacement for face-to-face interviewing. They posit that the quality of responses gained through online research is as good as that of traditional face-to-face interview methods. As well, the use of online research allows for more flexibility for researcher and participant and is both time and cost effective (Deakin & Wakefield, 2014).

All interviews were conducted during a single session, with no preparatory work required of participants, and interview lengths were approximately 60-90 minutes (average 45 minutes), with additional time scheduled for technical issues or troubleshooting. When the interview was complete, participants were thanked and compensated for their time with a $20 e-gift card of their choice. Within 24-hours of each interview, the Microsoft Teams platforms provides a preliminary auto-generated verbatim transcript, which I downloaded and saved into a password protected folder. According to the Microsoft Teams' privacy and security mandate (https://docs.microsoft.com/en-us/microsoftteams/security-compliance-overview),Microsoft does not have access to the data, and all information stays with the tenant. Data remains encrypted at transition and at rest. Thus, the use of Microsoft Teams' video platform is a viable way to conduct our research. Once the interview transcript was available, five undergraduate research assistants (who signed a confidentiality agreement to confirm their accuracy and anonymity) aided in reviewing and editing the transcripts to ensure transcription accuracy, and de-identify the data. All potentially identifying information was be removed, and each interview was assigned a unique identifying code (e.g., ID#01). All de-identified transcripts were reviewed and verified for accuracy a second time by me. Following this confirmation of accuracy, the original video and audio files were then deleted from the Microsoft Team's server so all that remained were the anonymized transcripts.

Data Analysis Approach

My data analysis approach took that of Braun and Clarke's (2006, 2013, 2019, 2021) *reflexive thematic analysis* (RTA) procedures. I chose this analytical method as RTA as it is concerned with exploring participants experiences, perspectives, and behaviours about a particular topic of inquiry (Braun & Clarke, 2019, 2021). It is a recursive, iterative, and nonlinear approach that moves back and forth between each stage of analysis, recognizing that the research process is dynamic. RTA also requires researchers to engage in self-reflexivity and be upfront and transparent about their ontological and epistemological assumptions. It is a method of identifying, organizing and interpreting patterns of meaning across a corpus of data, guided by research questions and theoretical underpinnings.

Additionally, RTA is an optimal analysis for my study goals rather than interpretive phenomenological analysis (IPA) or grounded theory (GT) for multiple reasons. First, IPA focuses on the unique features of individual cases and personal experience (Braun & Clarke, 2020). The focus of my study was to construct themes across the data set, with the research having actionable outcomes, which requires organizing the data into themes, which does not occur when using IPA or GT (Braun & Clarke, 2020, 2021). I also aimed to analyze how meaning made from personal experiences fit into a socio-cultural and gendered context, which is an advantage that RTA gives us over IPA (Braun & Clarke, 2020).

Braun and Clarke's (2006, 2019, 2021) methodology requires a six-phase approach to data analysis which includes familiarization of the data, generating initial codes, searching for themes, reviewing themes, defining, and naming themes and constructing a report based on the themes. Each step is documented in Table 2. My analytical team was comprised of myself, a first-year master's student in child clinical psychology, one psychology faculty supervisor, also in child clinical psychology, and another master's student in clinical psychology serving as a secondary coder and data analyst who has experience assisting in similar studies. This person's role was to augment the validity and trustworthiness of the qualitative analysis.

Stage 1. First, in stage 1, the transcribed interviews were moved into Microsoft Word documents, labelled by each participant's identifier code. I then read through all of the interview transcripts in one batch, and wrote down my initial thoughts, and impressions of emerging and reoccurring ideas in a research journal. These early thoughts and impressions across all of the transcripts collectively were both my own thoughts and views, as well as the early theoretical connections I saw from the first review of the data. I asked myself questions as I read through the data. These questions were focused on how the participants are making sense of their experience, the perspective and overall worldview they are taking toward their experience, and the different ways they are make sense of the topics covered in the interview. I also noted how I was making sense of their sense-making. I then re-read each of the transcripts individually and noted my impressions in my research journal. I met with my research assistant and discussed these impressions weekly. Then, when my research assistant and I needed additional assistance making sense of some of the ideas, we met biweekly with my research supervisor.

Stage 2. Then, in stage 2, I began line-by-line coding with my research questions in mind, but being open and flexible to the ideas, wishes, needs, motives, etc., that participants discuss. Each code was a short, active, and specific segment of the data, which represents a single meaning instance. I kept detailed notes how codes were being generated, how similar codes were clustered together to form categories, and how they relate back to the research questions, and my social-constructivist epistemology. This process was iterative, until I arrived on a set of categories, which was then built into themes. I met with my research assistant weekly throughout this process, to reflect further on the codes being used. My research assistant performed secondary coding on a subset of 11 of the 28 transcripts. My research assistant and I then met to compare our codes for each of the transcripts in this subset, ensuring that we integrated our ideas together into a coherent set of themes. We also discussed our potential themes, and how these themes relate to one another and fit into the overall dataset with our supervisor.

Stage 3. In stage 3, the focus was on primary theme development based on larger patterns that were emerging in the data set. A theme is an element of data that represents a patterned meaning in the dataset. To identify themes, I examined the codes and categories generated in step 2. I used these codes to consider combining them into one organizing concept, which formed a theme. Throughout theme development, I considered the themes on their own and as a whole, to ensure they related back to the overall analysis. To aid in theme development, I employed a thematic map, to give a visual representation of themes. The thematic map allowed me to explore and revise the connections among themes. I presented this thematic map to my research assistant and supervisor and had them reflect and give feedback on the themes I had thus far (see *Figure 2* for a representation of how repeating ideas where organized into subthemes, and then larger themes).

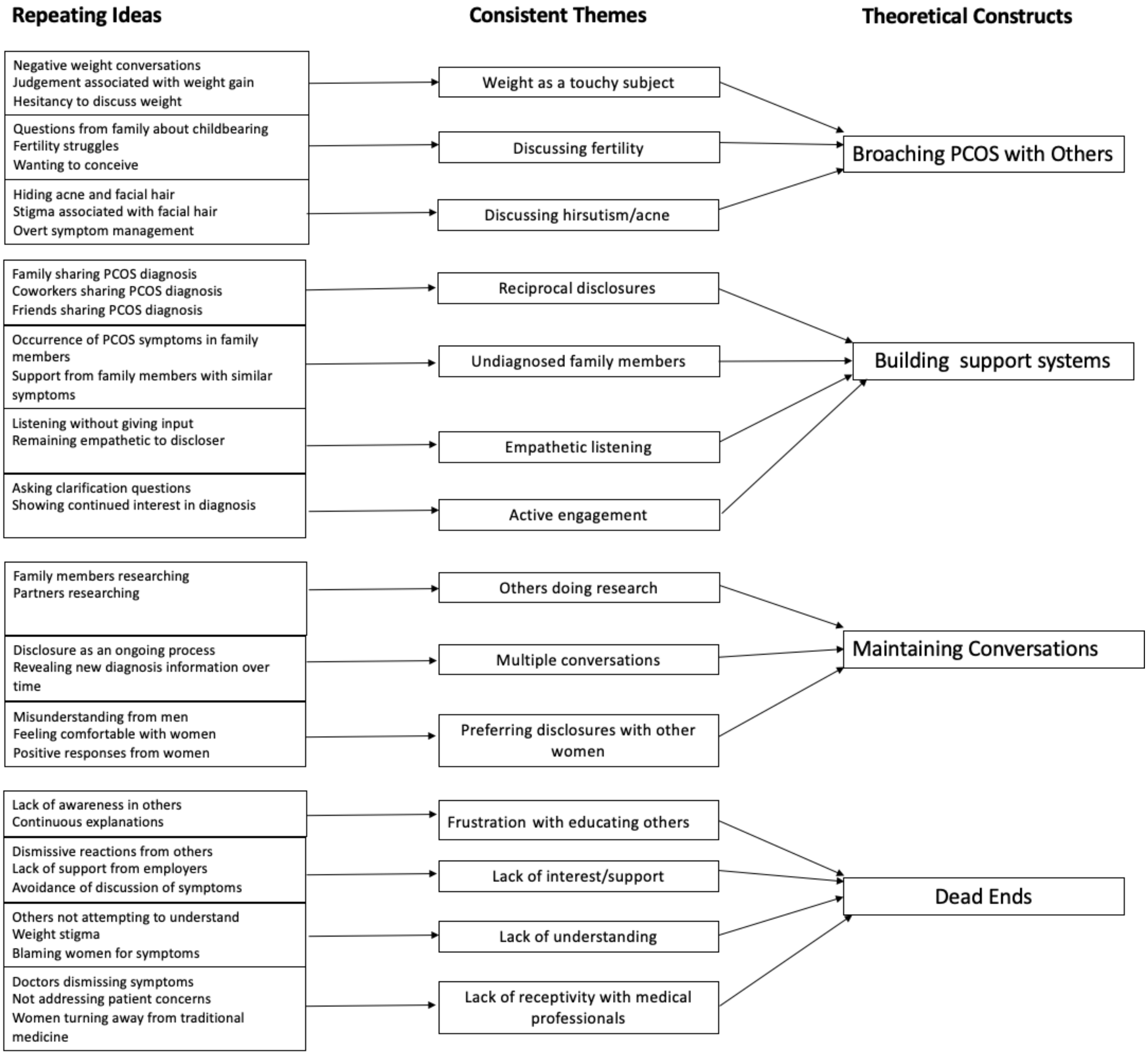
Stage 4. In stage 4, the goal was to refine the themes and analyze whether my analysis fit well with the data. I ensured I was not misrepresenting any of the themes and that my description captures their essence. To check the themes, I reviewed the codes, themes and reread the data to confirm that each theme were correctly captured the meaning of the data. If a theme did not appear to fit the data well, or its central organizing concept was unclear, I then took a different approach to that theme. I either reoriented the theme, assessed if the coded data fits into a different theme, collapsed themes together, or discarded the theme and developed a new one. I also had my research assistant review the thematic map in parallel to the subset of transcripts that we discussed. We reflected on how well our themes fit into the data, and which themes should be collapsed or reorganized to better represent the data set.

Stage 5. The fifth stage was aimed at naming the themes. This is where I made sense of the patterns in the data, to interpret their meaning and form a coherent story about the data. I first wrote theme definitions in a journal to define the focus of each theme. I examined the thematic map, again, and the assumptions underlying each theme, their implications, and their meaning. As well, I interpreted each theme's relationship to the overall story of the data. This step helped me determine whether each theme was correctly outlined and if any themes were open to an alternate interpretation. Finally, I named the themes, aiming to capture their core meaning. Once the themes were named, I met with my research team to gain novel opinions on how clear the themes were named and represented.

Stage 6. The final phase involved generating a report, which involved organizing the final analysis to write up this thesis. This phase focused on the data's story, aiming to tell a coherent and compelling interpretation. A set of exemplar quotes were chosen to use to construct this report and provide samples of each theme. In selecting quotes from the data, I looked for those that represented the breadth and depth of each theme. I also considered the ideas that underlie the pattern of meaning making in the data set and the implications for the participants, for those with PCOS, and more broadly for the academic field.

Figure 2

Clustering of theoretical concepts into themes



Establishing Trustworthiness and Credibility

Lincoln and Guba (1985) outline the importance of trustworthiness and validity in qualitative research. To foster transparency and trustworthiness in our analysis, I employed multiple criteria of validity in qualitative research put forth by Tracey (2010), which are specific to thematic analysis, which include rich rigour, sincerity, credibility, and member checking. My supervisor, myself and all researchers involved were transparent, up front, and honest about our training backgrounds, strengths, and limitations, as we engaged in the analysis through self-reflexivity.

Rich Rigour. According to Tracey (2010), rich rigour encompasses the use of theoretical constructs, data and time in the field, research context, sample, care and practice of data collection and procedures. When interviewing, I demonstrated rigour based on the number and length of interviews, the breadth of the interview and the types of questions asked. For the present study, richness of the study was enhanced by spending time interacting with the participants to establish rapport at the beginning of the interview, and then maintaining that rapport throughout the interviews. My interviews were about sixty to ninety minutes long so that I was able to gain in-depth information about the impacts of disclosure, social support, and quality of life. As well, the interview guide was designed to ensure that I could delve deeper into participants thoughts, perceptions, beliefs, and decisions related to disclosure, as well as their experiences disclosing PCOS, and seeking out support.

Sincerity. Sincerity relates to authenticity and genuineness (Tracey, 2010). It means that the researcher is honest and transparent about biases, assumptions, goals, and backgrounds (Tracey, 2010). To achieve sincerity, I engaged in self-reflexivity throughout the early and later stages of the analytical process. This meant that I documented my thoughts, and reactions to each interviewer in a Microsoft word document that served as a living document of my reflexive journal. I critically engaged with how my academic background, biases and motivation shaped my research process and analytical decisions. I dated and saved these entries, and frequently returned to them during the analytical process. Then, every week, I peer-debriefed with my research supervisor and a secondary coder to discuss emergent and reoccurring ideas, as well as a list of prepared comments and questions that emerge throughout my coding and data analysis process. I wrote summaries of concepts, and reactions that were discussed with my supervisor. This audit trail of analytical decisions including any conflicts or ethnical issues that may arise during the research process were fully documented.

Credibility. Credibility includes the trustworthiness, verisimilitude, and plausibility of the research findings (Tracey, 2010). In qualitative research, an important method for achieving credibility is using thick description (Tracey, 2010). To demonstrate thick description, researchers are advised to show the data's complexity by providing enough detail that readers can come to their own conclusions about the data (Tracey, 2010). In the present study, I achieved thick description by including exemplar quotes from the participants interviews in the interpretation of the data, along with thorough explanations of my interpretations of these quotes. I was also upfront about limitations in these interpretations throughout the discussion. Additionally, I enhanced the credibility of the study by holding a peer debriefing meeting with my research team to discuss the themes that were constructed. The research team heard my own experiences, reflections and ideas about the results of the study, and aided in discussing, modifying or collapsing themes to better fit the data.

Member Reflections. Member reflection is another credibility approach that was taken in this project to ensure that my RTA reflects the participant experience in an authentic way (Braun & Clarke, 2021). Member reflection is a practice aimed at demonstrating a correspondence between the findings of the research and the participants being studied (Lindlof & Taylor, 2002; Tracey, 2010). Member reflection also allows participants to express if they find the research comprehendible and accurate (Tracey, 2010). It gives participants the opportunity to express their opinion of the findings, and thus point out any problems with the research that they do not agree with. In the present study, member reflection occurred via email. Participants who consented to being contacted to review the results (*n*=11) were forwarded a copy of the tentative themes, consisting of the diagram shown in Figure 3, as well as a brief written description of each theme in non-technical language. They were then given a link to an online survey in which they were able to express their opinions about the themes. Participants were asked if they believed the themes represented their disclosure and social support experiences with PCOS, and if they had any feedback or thoughts about the analysis.

Broadly, most participants included in their written responses that my themes provided an accurate representation of their experienced. One participant gave feedback on the name for the first theme. Thus, I modified the name using her feedback to better represent the participants experiences. Based on the results of response validation, themes were then altered or removed. For example, one of our participants expressed that they did not like the original name of our theme “defending hirsutism and acne”, as they felt it made women with PCOS seem like they were using their symptoms as an excuse. As a result of this feedback, I altered the theme to instead say “Describing and defending hirsutism and acne.” Participants that completed member reflections were compensated for their time with a $5 e-gift card.

Authors’ and Team members’ positioning

Give the use of social constructionist epistemology, and RTA, it is recognized that the findings represent one way to interpret the data, and there are multiple plausible data interpretations. It is important to note that RTA views researcher subjectivity as playing a major role in the co-construction of knowledge. Both the participant and the researcher actively co-construct meaning, and so it is important to establish our role as the research team in the process of data engagement, and interpretation.

I am a graduate student diagnosed recently in Ontario, Canada with PCOS. My journey to receiving a diagnosis was a long and difficult one but resulted in relief upon receiving answers to many unanswered questions. My interest in studying women's health began when I discovered a lab on campus that researched many complex topics related to women's health. I decided to pursue my graduate studies researching PCOS and women's health. Specifically, how women with PCOS disclose their stories to their social circles and how this impacts their quality of life. My research emerges from unanswered questions I come across in my own journey with the disorder and choose to pursue my curiosity through my research.

My supervisor is an Assistant Professor of Psychology in the Child Clinical track and studies women's healthcare, with a focus on diagnosis and misdiagnosis experiences with healthcare providers in Canada. She identifies as a PCOS-diagnosed woman. Like many women, she experienced a lengthy diagnosis process in Ontario, Canada, and was routinely dismissed by many medical providers. She sought private care in the United States while she was a graduate student (her health coverage that was tied to her graduate teaching position). She was officially diagnosed with PCOS after being referred to the University of Michigan's Endocrinology division at the age of 27 and is currently managing her condition with the assistance of a nurse practitioner at a Women's Health clinic in the Windsor-Essex region. She immersed herself in the PCOS literature and learned that diagnosis delays were strikingly common among women with PCOS, worldwide. Her goal was to understand the mechanisms underlying these diagnosis lags, which she suspected was the result of practitioner communications, and institutional gender-based discrimination. These experiences led her to focus her program of research on the institutional determinants of women's health, particularly as it relates to PCOS, and other chronic women's health conditions.

My research assistant is currently pursuing a Master of Arts degree in Clinical Psychology in Ontario, Canada. She mainly studies stigma and help-seeking related to mental health treatment but is eager to learn more about women's health and PCOS. She joined the Health Experiences and Longevity (HEAL) Lab, which focuses on qualitative research, with the goal of incorporating individuals' lived experiences into her research. She is interested in the current study because she believes that self-disclosure and social support are fundamental to an individual's quality of life and everyday experience with chronic illness.

Table 2

Phases of Data Analysis

Phase of Thematic Analysis	Means of Implementing Phase
Phase 1: Data Familiarization	Read entire data set at least once, and became familiar with it Asked myself questions while reading through data. Documented theoretical and reflective thoughts while reading, and documenting in research journal
Phase 2: Generating Initial Codes	Identified features within the dataset that are related to my research questions (codes). Continued reflexive journaling, noting down codes that are emerging in research journal. Documented all team meetings and peer debriefings
Phase 3: Searching for Themes	Examined the codes, and aimed to cluster them and identify higher-level pattern, a pattern of meaning within the data set (a theme).

	Keep detailed notes in research journal about the development of concepts and themes
Phase 4: Reviewing Themes	Refined the themes, checking that my analysis fits with the data and no themes were misrepresented. Themes and subthemes were reviewed with research team members
Phase 5: Defining and Naming Themes	Made sense of the patterns identified in the data set, to develop a story about the data set. Named the themes, aiming to capture their breadth and depth, while highlighting my understanding of them. Peer debriefing and meetings with the research team to come to a consensus on themes Documented theme meetings in research journal.
Phase 6: Producing the Report	Organized the data analysis to tell a coherent account of the data's story. Used member checking, to confirm validity of themes with participants. Reported on reasoning behind theoretical, analytical, and methodological choices made throughout the entire study Used exemplar quotes to show the breadth and depth of data

CHAPTER 4

RESULTS

Four themes were constructed through active engagement in the data in relation to women's PCOS disclosures and their social support experiences: Conversations about PCOS opened with *Theme 1: Broaching PCOS with Others.* While broaching PCOS was an entryway for discussing symptoms and sharing their impact with others to open the conversation, women reported frustration with continuously needing to educate others. Through these conversations, however; *Theme 2: The Building Blocks of Social Support* was constructed, which fostered heightened intimacy and connection, which led to *Theme 3: Maintaining Meaningful Conversations* over time which moved the PCOS conversation forward, and into many new domains and avenues. The final theme, *Theme 4*: *Dead Ends*, encapsulated a lack of interest, and receptivity in engaging in PCOS conversation either by close others, or by medical professionals, and resulted in no further engagement, and consequently a lack of support (see Figure 3 for a diagram of the four major themes, as well as their interconnectivity).

Theme 1: Broaching PCOS with Others

("it's almost like an explanation for these…things that weren't deemed as okay")

Many women found that broaching the topic of a PCOS diagnosis began as a means for explaining or sharing the symptoms they were experiencing with others. Specifically, many women found themselves explaining changes in their weight, fertility struggles, hirsutism, and acne, as these symptoms were deemed to be "embarrassing or unfeminine."

Changes in weight as a sensitive topic

Discussing fluctuations in weight, a symptom due to variable levels of insulin resistance, was a sensitive subject for many, as women were unsure of how to interpret the nature of weight comments as either a concern or criticism. One participant reported that she preferred it if people "not react to my weight, whether it goes up or down…that would be really helpful, and not commenting on my eating choices" (Participant 15). In addition to not being judgmental, participants appreciated support over any weight fluctuations. Participant 6 received a supportive reaction after gaining weight:

> My mom has been a huge support and like, making just those, even those little lifestyle changes like going for that 30 minute walk a day no matter what or making sure like- it's been a couple months now and not that eating a salad every day is gonna make me lose weight, but it's gonna actually make me eat my vegetables. So, making those little changes like she's been so supportive that way.

There were further instances where weight was discussed in a supportive and positive manner. Participant 19 had a productive conversation about weight with a co-worker who shares a PCOS diagnosis, "she's kind of done the legwork… on the exercise regime she does, and she's shared about the naturopath that she's seen and what's really worked for her. So, I found that was really helpful and a good source of support."

Conversations that stem from a non-judgmental place and were based around answering questions and providing helpful suggestions seemed to be a safe discussion point when it came to broaching and talking about weight. Additionally, when women specifically asked for others' assistance with weight related issues, it seemed to open the conversation and give others permission to discuss weight. Participant 19 added that she found it beneficial to have her mom's support when trying to make better diet choices:

> I'm sharing that it's something that I'm struggling with or maybe I'm looking for…my parent's help with accountability. My mom… she's really done a lot of work herself on … choosing healthier food… She's had a lot of success with that, so I appreciate what she's learned and… any tips in keeping me accountable, and same with my coworkers and friends.

Women found it beneficial when someone else could relate to the lifestyle changes, they wanted to implement to assist their PCOS. The support from close others, such as parents and coworkers, helped keep women accountable, without being harmful. However, this was only in the instances where women asked specifically for the assistance, with women with PCOS actively directing the conversation.

Another beneficial aspect of support around the topic of weight was when close others defended women’s weight. Participant 29 recalled that her grandparents were not as understanding as her mother:

> My grandparents are an older generation, they'll sometimes make comments about weight or something along those lines, and my mom constantly has to go back to them and go “You need to remember she has something that's causing [weight gain]”

Even when some individuals didn’t understand PCOS, having others defend and support the symptoms was beneficial. It provided women with a tangible aspect of support, knowing that some people in their lives were trying to be understanding of the disorder.

Despite these positive experiences, it should be cautioned that the topic of weight can become sensitive in some circumstances. Some women found themselves being “blamed” or “shamed” for their weight gain and struggled to approach the topic with others for fear of being judged. After multiple failed attempts at explaining PCOS as a cause for her weight gain, one participant decided to stop discussing it with others: “it’s a negative conversation when I bring it up, so I choose not to go to [my mother] for support anymore” (Participant 16). Some people found comments about their weight to be bothersome, despite good intentions from their family and friends. One participant described her experience discussing her weight with her fiancé:

> When I would complain about my weight and stuff, he'd be like, well, have you tried like cutting out like bread or doing this? And I know he’s trying to be helpful when he makes those suggestions, but it's so hard for me because I know how hard I'm working. (Participant 2)

Another participant had to make her weight an off-limits topic with her mother and “we came to the conclusion that we’re not gonna discuss weight anymore” since “it comes across as degrading to me for her to say… you could stand to lose 15 or 20 pounds” (Participant 2). Whether comments are poorly intended or not, individuals should consider whether the conversations they are having are productive or harmful and should be warned to “just be aware that your words can be really hurtful to someone who’s been trying their best for so long’ (Participant 2).

Additionally, these experiences spanned across various cultural backgrounds. Participant 8 described that she had trouble discussing weight loss with her family since they do not follow a typical western diet.

> I think, a frustrating part of like all of this as well, like just how I guess White [PCOS diets] are like even a lot of the diet stuff…I'm not gonna eat that… that's not what I eat like at home. (Participant 8)

Due to this participant following a traditional Arabic diet, she found it difficult to ask her family to adjust their cultural views to help her dietary changes.

Sharing fertility struggles

Participants often shared their fertility struggles with others by disclosing that PCOS is associated with the potential for fertility and pregnancy-related complications. Specifically, disclosures to romantic partners were common as a means of explaining potential difficulties in conceiving children. One participant outlined that “I had to have the discussion with my husband because we’ve been trying for 10 years to have a child and… it’s definitely on my end” (Participant 1). Another participant chose to disclose her PCOS to let her partner know of potential fertility struggles, “the reaction from my boyfriend was some fear about difficulties conceiving later on down the road” (Participant 20).

Others decided to use their fertility struggles as an explanation for choosing to remain childfree:

> People won't just accept that you don't wanna have kids, that's not okay. You can't just be like "I don't want kids." But if you say, "I can't have kids," then they feel bad about pressuring you to have kids. (Participant 3)

In fact, many women faced familial pressure to conceive children despite their continual fertility struggles. As a result, women often disclosed their PCOS to justify their lack of children and silence their families, "We have told family members solely because they were like 'so, babies, when are we having babies' and it's just 'no'" (Participant 30).

Some loved ones expressed fears about the PCOS diagnosis impacting one's ability to have children. In fact, disclosing a PCOS diagnosis caused one participant's family to express "concern as to my future and my ability to have children in the future… people are obviously concerned about that element" (Participant 1). However, despite these fears, participants seemed to care more about the supportive reactions of others:

> I don't have kids; I probably won't ever have kids and… the reaction that I got from [boyfriend] was like "that's OK… that's how life is, you can just have my nieces and nephews and my family, and you'll just be the best aunt that there is" and to this day that is still stuck out to me as the best reaction. (Participant 15)

Even though fertility struggles are not outwardly obvious, participants appreciated others remaining supportive and normalizing their situation. Participant 23 appreciated simple having others that she could relate to and talk to about her fertility struggles:

> When I started to have fertility issues, I met a lot of other mom friends and once we all kind of were talking about our experiences and some of them had kids a little bit later we realized that so many of us had PCOS and it was a way for us to really like bond and connect and talk about it.

Even though it was beneficial to have close others relate to fertility struggles, it was not a requirement to be able to support these women. Instead, providing them with a space to discuss their fertility struggles and tangible means of support was beneficial enough. One participant's husband got creative in his ways of supporting his wife's fertility struggles:

> I looked at the cost of our fertility bills and stuff. My husband bought me a sewing machine to try and help me through this and, um, I started making scrunchies and I started making headbands and I was like, you know, there's just not enough awareness. So, I use social media to introduce myself, my business, and I said, "This is what I suffer from, this is what a lot of women suffer from," and then I kind of laid it out there for people. (Participant 30)

Overall, participants used their PCOS diagnosis to share their fertility issues to partners and family members and were most supported when faced with reassuring reactions and support from others. These types of reactions made one participant feel as though "I still was looked at as a person in that moment, not someone with a problem" (Participant 15).

Describing and Defending Hirsutism and Acne

Two symptoms of PCOS, hirsutism and acne, served as a unique means of broaching the topic of PCOS with others. Some participants felt the need to defend these outwardly visible and feminine-identity challenging symptoms to others by explaining that PCOS is the root cause of them: "I'd tell people almost as an excuse for having really hairy legs or like having really bad chest acne" (Participant 33). In fact, these features were described by participants as "embarrassing" and "unfeminine," and many women felt the need to overly justify their presence. One participant spent hours each day ensuring she was able to hide these symptoms from those around her, so she didn't have to disclose her PCOS diagnosis:

> I shine a light on me just in case like in sunlight it looks like a five o'clock shadow or something and I have like my phone camera and then I have like a mirror ring kind of thing. And I'm like so crazy about it. So, it takes forever. And I was doing it every single day and I was just like, I can't like, it takes so much time. (Participant 2)

Some women found their hirsutism to be a more challenging symptom to explain than acne; however, and preferred to discuss their hirsutism only with other woman who would understand or could relate:

> I feel like acne is something that’s relatable to people my age like they can understand like oh yeah, I have acne too, whereas the hair growth on my face is more like I can only talk to PCOS friends about that. (Participant 2)

For some, these outward symptoms, which caused discomfort, opened a productive conversation around PCOS. Some participants found that discussing these outwardly visible symptoms provided them with a safe and secure space to share their concerns. Listening to participants’ struggles with these symptoms was supportive in its own way. Participant 3 recalled discussing her symptoms with her fiancé continuously:

> I tell him everything I'm like...“This chin hair, this situation,” and… now that he knows I can lean into, like, telling him like… this is like a PCOS thing… and then I'm, like, able to… talk openly about it, I think. (Participant 3)

Having others listen was beneficial enough to many participants that wanted to discuss the bothersome aspects of PCOS. Additionally, participants were able to discuss their symptoms with others that related to these visible aspects of PCOS. Another participant recounted discussing her hirsutism with a friend that was experiencing hormonal imbalances, “I was being open about my problems, and they felt like they could confide in somebody who understood, like, the lack of periods, the hair and all that stuff” (Participant 34). Having positive, honest conversations about the stigmatizing aspects of PCOS normalized them. Additionally, participants had conversations with others that highlighted the intersectionality between cultural backgrounds and varying presentations of PCOS. Participant 8 recounted a time she reached out for support from a friend for her hirsutism:

> Keeping in mind these, like artificially constructed standards about body hair, even the testosterone thing like uh, one of my other friends with PCOS, she is black and so I've

> been talking about like this association with like having more testosterone and men and like whatever. And like I have some stuff around men and like, feeling more like a guy or like, I don't know. And she was like, you know, like a lot of black women naturally have higher levels of testosterone and, like, that doesn't make them men. And I was like, Oh well, that's a good point. (Participant 8)

When participants were able to discuss these symptoms openly and freely, it lifted some of the negative connotation surrounding these conversations. It gave women a space to relate to others on both a gendered and cultural level.

Theme 2: The Building Blocks of Support

(“Navigating [chronic disorders] is very difficult, and so… how to empathize with that, how to show up for people in your life that are experiencing that is important”)

When participants had a positive first interaction with others about their PCOS diagnosis, they were able to work toward building a sustainable support system with those specific individuals. Many of these initial conversations around weight, fertility, and visible symptoms of PCOS (hirsutisms) resulted in experiences that made participants feel supported and set up a healthy space for them to both process and discuss the realities of their diagnosis. First, many participants experienced reciprocal disclosures from others. Conversations with others also started a new and unexpected avenue of engagement with undiagnosed family members. Additionally, these conversations were beneficial if the listener did not judge the participant, actively listened, and expressed empathy.

Reciprocal Disclosures

For many women, discussing their PCOS with others who also have PCOS opened an important conversation around the diagnosis. When a disclosure happened, it allowed others to begin to feel comfortable enough to open up about their own health diagnoses. For one participant, discussing her PCOS with others going through the same thing made her feel less alone, as she recounted, “That’s the first time I ever sat down with women that actually had PCOS too and had conversations with them and felt like I’m not the only person” (Participant 2).

In fact, reciprocal disclosures weren’t limited to other women with PCOS. Instead, women with other reproductive disorders also shared their experiences, giving women an outlet to discuss their struggles with these disorders. One participant remembered how it made her feel when others would open up to her as well, “I've told people and then they're like, ‘I have it too,’ or, ‘I have endometriosis’ and it's, like, it just opens up, like, the conversation and makes you feel so much less alone.” (Participant 3).

Some women were surprised to discover that others close to them had a PCOS diagnosis but were not willing to share until the topic was discussed together. One woman recalled that her cousin did not share her diagnosis until she disclosed her own PCOS diagnosis to her:

> My cousin had never mentioned it to me until I said that I had it. And then it was like, “Oh, well, I have that too” And I was like, “Wait, when did you get diagnosed?” And then she was like, “At this age.” And I was like, “That's how old I am.” And then it was a shared… experience. (Participant 3)

These mutual experiences provided women with the knowledge that there are others out there that understand their experience with PCOS. Another participant reached out for support from a friend and was surprised to learn her friend also had a PCOS diagnosis:

> I was really struggling at that moment, and I was just trying my best to get through it, but then the minute I reached out about it, she was just so supportive and all over it and was like I have it too. And I don’t think that she also realizes how common it was, but it was just for in that moment for me, I was like, “Oh okay, like it, it's not just me” and she was just so open about it, and she's just, she's an open person, period. But she just related to me on the level that that made me feel a lot better. (Participant 21)

Others may not realize the profound impact it can have to share their own PCOS diagnosis with close others going through the same thing. It forms a connection and provides a space for mutual understanding of PCOS. It also caused many participants to realize that they are not alone in the diagnosis and that many other women struggle with the same symptoms.

Overall, it was the willingness of others to be honest that made these conversations positive experiences.

Undiagnosed Family Members

Some participants had family members that had experienced PCOS symptoms in their lifetime but had never tied them to PCOS specifically or received a formal diagnosis. However, these symptoms that others experienced were often not discussed until participants began to disclose their own diagnosis to their family members. The family members that had experienced similar symptoms often remained engaged and supportive of the participant, and the conversation, while also connecting with their experiences. One woman explained that the most supportive person for her was “my auntie because my auntie has very similar traits to me, but she has never heard of [PCOS]” (Participant 15). Another participants family tried to normalize PCOS for her by sharing:

> “Oh, you know, your aunt has that.” And I was like, “Oh, I, I didn't really realize.” I knew that she'd had fertility issues. And she has type 2 diabetes. And I guess looking back kind of has a lot of the, the visible signs and symptoms of PCOS. So, it probably should have been a given to me. (Participant 21)

By sharing that other family members had PCOS, or symptoms of PCOS, it showed participants a sense of understanding and acceptance. Other participants were met with support from undiagnosed family members over specific symptoms they were experiencing. Another participant went to her mom for support about her hirsutism and recalls her mom trying to offer a solution:

> I told my mom and my mom kind of has, like, she's never been diagnosed with PCOS, but she also has…hair on her face but she's had it lasered, which, like for me like, it's hormonal so it'll just come back if I get it lasered. So, I haven't done that, but it worked for her. (Participant 2)

Family members being able to empathize with symptoms of the disorder provided participants with the necessary support they were seeking. For one woman, it was many extended family members that resonated with what she was experiencing. It was after those disclosure experiences that the participant realized there may be multiple undiagnosed family members:

> I also assume that there's a hereditary element to this because there has been like quite a bit of… issues with fertility in my family, so I feel like there's…probably been quite a few people in my family that have gone undiagnosed and so like there was an understanding there of like, “Oh okay like we can put a name to this.” (Participant 1)

Overall, participants who had family members with similar symptoms were able to have conversations about their disorder openly and honestly. It supplied women with support systems that were able to provide guidance on the symptoms they were experiencing.

Active, Non-Judgmental and Empathic Listening

Listening and being present in the moment without judgement or giving unsolicited advice was the most impactful reaction that women recounted when disclosing a PCOS diagnosis to another person. For some listeners, giving advice may seem well intentioned, but participants reported frustration over unwanted advice(also known as miscarried helping), “no matter who I tell, it’s like everyone wants to give me their opinion on how to fix it” (Participant 2). Instead, one participant reported that the disclosure experience that stood as most memorable to her was one in which the audience just actively listened, in a non-judgmental way “It’s like they’ve been impactful to me because they just listen. They don’t offer advice. They don’t, you know, make assumptions, they just listen and validate” (Participant 32).

It appears the most effective way to navigate the initial conversations about a PCOS disclosure stem from close others providing empathy and active listening responses . Another participant stressed the importance of listening instead of offering advice:

> I think listening does a very long way. Um, there’s definitely times for input and for advice but sometimes just being able to talk and get what’s on your chest out there is more important than anything that they can say back to you. (Participant 11)

A positive first conversation about PCOS may also impact a woman’s willingness to discuss her diagnosis with that person in the future. A constructive initial interaction between a discloser and listener is imperative to ensure the conversation can remain open. One woman stressed the importance of an initial disclosure experience by outlining:

> You can’t listen to react, you have to just listen and let the person talk and get things off their chest, and then maybe they’ll feel more comfortable coming to you again and talking to you about things that are a little bit more personal the next time. (Participant 16)

Predominantly, the most effective approach to building a supportive relationship during a PCOS disclosure includes active listening, not offering unwanted advice and engaging in a conversation free of judgement. When listening to a loved one disclose a diagnosis, people should strive to “listen and hear what I’m saying…then just believe me” (Participant 3)

Another important feature of active listening is expressing empathy. It is imperative for listeners to try to gain insight into what women with PCOS are going through and remain compassionate toward their struggles. One woman described the importance of empathy, “Navigating [chronic disorders] is very difficult, and so just like how to empathize with that, how to show up for people in your life that are experiencing that is important” (Participant 32). Understanding what a woman with PCOS is going through on a day-to-day basis is beneficial in knowing how to best support them. In fact, many women did not expect others to be able to offer solutions to their problems, but instead appreciated perspective-taking and empathy toward their situation. Another participant described her expectations from others:

> I know a lot of people think that when you come to them with an issue, they want you to fix it, but a lot of times they just want someone to listen, and they want someone who will kind of empathize with them. (Participant 2)

Validating women's experiences and emotions toward their diagnosis is beneficial in building a supportive relationship. When someone discloses a diagnosis, it should not be taken lightly as "if you tell somebody…you let them in and they become a part of your support system" (Participant 6). Thus, people should strive to understand the magnitude of being chosen as a listener, and the impact their reaction may have on the discloser.

In fact, being a reliable listener starts to build trust and intimacy in these discloser-listener relationships. When disclosers know that they can rely on a positive interaction with people, they know that connection is there to return to when needed. Participant 19 outlined how important these connections are overtime, "I was just checking back in and delivering new information and, and getting the same support that I, uh, knew I could expect from these people." As more support is needed, women with PCOS returned to these effective listeners for additional support, which then further deepen those connections.

Theme 3: Maintaining Meaningful Conversations

("all of the research in the world …doesn't have a human face to it, it doesn't have actual experience)

When done correctly, the initial conversations around PCOS start to build up supportive connections. In fact, these initial conversations are the basis of beginning to form supportive relationships and deepen connections. Over time, as the building blocks of support start to foster intimacy in relationships, it leads to women returning to those same relationships to fulfill both their disclosure and support needs. These relationships are built up in a few ways; when others show their understanding by doing research on PCOS themselves, when there is a space to continue conversations over time, most often when participants felt a sense of connection with other women.

Research by Others

One of the starting points for maintaining meaningful conversations about PCOS with others is others showing interest in the topic by doing their own research on the condition, and learning themselves about what PCOS is, and how it impacts a person's life, broadly. Some participants reported that they "wish [others] would seek out some information themselves" (Participant 29) as a way of learning about PCOS and showing their support. When other's showed interest, it reassured participants that they cared about their well-being. Researching by others consisted of individuals seeking resources and information to explain how PCOS may affect a person. These resources included consulting internet, reading forums in PCOS or women's health support groups, consulting medical professionals, and asking participants questions directly.

Participants outlined their most memorable disclosure experience as being one in which individuals chose to research PCOS. Participant 7 recounted her partner showing support "He… kind of took matters into his own hands and tried to do, like, an extent of his own research for how he could maybe help me." These disclosure experiences were further confirmed by Participant 33 when she described that her most memorable disclosure experience was with, "my boyfriend… I know he like researched PCOS after [the disclosure] because, he was like, well, I wanna know what this is."

In fact, women appreciated when others tried to understand PCOS on their own, by taking initiative, and interest in the condition. Some listeners used their research as a means of being empathetic and understanding. For example, understanding the origin of PCOS symptoms (such as weight gain) allowed listeners to comprehend why typical treatment methods may not work for a woman with PCOS (e.g., working out on its own may not help a PCOS woman lose weight, if their concerns involve weight loss). One participant expressed her deep appreciation a toward her friends for researching the topic, “everyone was really understanding and if they didn't know what [PCOS] was, they researched it and- so that was really nice” (Participant 23). Another participant expressed her gratitude for her brother, as he tried to understand her PCOS:

> My brother found a video of a doctor on YouTube who does kind of out there medical cases, and he actually found a PCOS one and he showed it to me. And I'm like, yeah, that's what I have. He goes, “Oh, okay, that makes sense now I understand.” (Participant 29)

The degree of engagement and effort they put in to try to understand PCOS was meaningful to participants. The opposite also held true; when listeners didn’t understand the disorder and didn’t try to further research, it was damaging to participants’ disclosure experiences. Another participant recounted a time she discussed going to a weight loss clinic and tried to relay her experiences to her parents:

> I brought up something about how they specialize in people with PCOS, and [my father] said, well, what does that have anything to do with it? So I would say it would be fair to say he never went out and researched it. I don't think my mom has either. (Participant 5)

The lack of understanding from this participant’s parents about how PCOS functions damaged rapport when it came to conversations around PCOS. Thus, if a disclosure experience occurs and the listener continues to have questions about PCOS, it would be beneficial for listeners to do their own research to better grasp how PCOS may be affecting their loved one.

Evolving Conversations Over Time

An important part of maintaining conversations with others is recognizing that conversations around PCOS are often maintained over time. Due to the chronic nature of the disorder, symptoms may change from day to day and thus having only one conversation about the disorder is not sufficient. Some women only feel the need to disclose aspects of their illness as they come up, but particularly in the context of intimate, early conversations with others. One participant confirmed that, “I don’t feel like I very often disclose everything at once, I feel like it’s sort of in phases” (Participant 1).

Since disclosure conversations happen more than once, it is important for both the discloser and listener to know how to maintain strong communication about the disorder. If conversations about PCOS remain advantageous, the discloser may feel comfortable continuing to reveal more information to listeners. After continuous positive conversations with a friend, Participant 16 expressed that “if I ever feel like I’m a little sad or I’m feeling extra bloated, or anything that kind of makes me feel negative about what’s going on with my body, I feel like I can talk to [my friend].” Keeping communication practices open is important for not only disclosure reasons, but also for reaching out for future support. If women feel as though they can continuously discuss their PCOS, they keep these connections to also reach out for support.

These ongoing conversations are not just happening in a personal context; they are also happening if the symptoms of PCOS interfere with a woman’s job. Participant 30 recalled how she has, “had to have the conversation with a few bosses because I've had to go home because I bled through my pants or…I didn't have a diaper.” Regardless of the audience, conversations around PCOS are not a one-time occurrence, “conversations of disclosure are sort of over time” (Participant 1). Thus, effectively relaying a diagnosis, as well as a positive reaction from the listener, is a concern that can occur in both one’s personal and professional lives.

Sense of Community and Connection with Other Women

A common target audience that many women felt comfortable disclosing their PCOS to was other women. Many participants expressed that they felt as though other women would understand their disorder, given that they understand how a woman’s reproductive system functions. Participant 2 confirmed that, “especially with women, I felt really comfortable… I felt safe telling them and I also felt like it helped me explain a lot to them." The comfort in telling women was not limited to loved ones- participants also expressed a willingness to disclose to other women with PCOS. Participant 8 described that she found disclosing to other women with PCOS helpful, "there was a lot of relief associated with [disclosing], like it was this one sigh of relief and being like, 'Oh I'm not alone.'" Women were finding consolation in the fact that other women had experience similar struggles with the same disorder.

Some participants found turning to online communities of women with PCOS to be a more accessible way to connect with others. Participant 20 recounted that she, "felt a little bit alone in my diagnosis so just being able to connect with other women virtually I thought was a really good platform." Not all women knew other women with PCOS that they could have face-to-face conversations with, so virtual communities proved to be a beneficial resource. Another participant expressed, "I just love the online support and I think it's important to just talk to people who have PCOS" (Participant 25). Connecting with other women through these virtual platforms was a strong source of support for participants that wished to find others experiencing similar stressors. PCOS was continuously described as a "lonely diagnosis" and thus forming connections and a sense of community and connection with other women is an important part of navigating this chronic illness.

Theme 4: Dead Ends

("I don't really wanna play educator anymore")

Sometimes, conversations in which women disclosed a PCOS diagnosis did not prove to be fruitful or engaging. These disclosure experiences are labelled as "dead ends" since women often refused to return to the same person that they had a negative experience with. The audience for this type of dead-end conversations was not limited to close others; it also largely included medical professionals, although the pathways between close others and medical providers were slightly different. However, these dead-end conversations often occurred when the listener had a lack of education or awareness of the diagnosis, a lack of interest in understanding the diagnosis, a lack of receptivity, and failed to try to support the discloser or in the case of a medical professional, failed to acknowledge a patient's concerns.

Lack of awareness and understanding of PCOS

Many women expressed frustration over having to continuously explain what PCOS entails to the people they were disclosing to. Given the high prevalence of the disorder, participants felt as though they should not have to keep explaining it, but "some people need an explanation because it's still something that is not quite known" (Participant 30). Others compared it to other common disorders that have more awareness around them, "when someone tells you they have diabetes, you're like that must be difficult, that must change certain aspects of your life, but I don't think when people hear you have PCOS that they think your life is any different" (Participant 3). Women expected others to have general knowledge about the effects PCOS can have on one's life, or at least express a willingness to try to understand the disorder. In fact, participants at least expected other women to have an awareness of the disorder, given that it is reproductive in origin, "I think that speaks volumes… PCOS is so common, and I feel like it's sad that women don't really know it exists" (Participant 20).

What was more prevalent than women not knowing about PCOS was men expressing a lack of willingness to understand. Many close others (e.g., fathers, brothers, partners, etc.) refused to even try to understand the disorder, given that it is a disorder that only affects individuals with a female reproductive system. Participant 7 justified her husband's lack of knowledge of PCOS by expressing that, "he tries to and, you know, tries to be supportive the best he can, but I just don't think he really understands purely because he's a man." For another participant, her husband not wanting to understand or support the disorder drove them apart, "I think it was ultimately kind of what pushed us apart, because he didn't want to learn, and didn't want to help support me" (Participant 15). PCOS affects so many areas of one's life so understanding the disorder is a vital part of being involved in a diagnosed woman's life. Women were willing to explain the disorder to men in their lives, but when the men remained uninterested, this resulted in a dead-end conversation.

When others were not receptive to trying to understand PCOS, many participants gave up on further disclosures. Participant 2 explained her PCOS to her mother and was still met with confusion, "I've talked to [my mother] about it before, and she's still like what's PCOS? And people don't really know what it is. It's weird, and it affects so many women." When women are met with continual confusion over the disorder, they become more hesitant to even try to explain it to others. Participant 25 reflected that, "I guess it comes back down to like trying to make my family and friends understand because they just don't understand, and I think I've wasted too many hours or too many years trying for people to understand." For this participant, these experiences got bad enough that they gave up on explaining the disorder to others altogether.

Participant 25 further recounted that, "I realized the hard way that there's really no point in talking to people who don't struggle with the same issue as you because they just don't get it. They just don't understand." It is important for people to recognize the severity of the effect their reactions may have on individuals trying to disclose a PCOS diagnosis. If a negative reaction is bad enough, women will shut down any further disclosures and then stop reaching out for support altogether. Thus, participants continued to urge others to, "just listen to people, and take it seriously" (Participant 3).

Lack of receptivity from medical professionals

Avenues for disclosure also included discussing a PCOS diagnosis with various medical professionals. Many women experiences that not all medical professionals were receptive to listening to their concerns about their PCOS diagnosis. It was a general expectation across participants that, "they're supposed to be the medical professionals, they're supposed to be helping you with something that you're not really educated on" (Participant 7). Many participants did not find their physicians to be able to offer beneficial advice. Participant 16 recounted her experience with physicians, "I kind of got shut down a lot, a lot of doctors for some reason have no idea what they're talking about when it comes to PCOS, unfortunately, and it's really sad." Despite the medical knowledge that providers have about PCOS, they seldom explained the diagnosis to women adequately. Women expected to have their questions answered but were instead met with an overload of clinical information. Participant 3 recalled her experience:

> I went in for my, like, follow up appointment about the birth control and then she just was like, "Okay, so you have PCOS," and then just kept talking. And I remember kind of just thinking, like, "Wait a minute. What is that?" Like, I had no idea….and then, um, so she told me and I remember kind of being like... "Oh," and then she went on to talk about how, like, "You know, you're on birth control now, but if you want to get pregnant, um, you know, you'll go off it and then if you can't get pregnant for- the first six months then we'll talk again." And I was kind of like, "Woah, woah, woah, wait, what? Like, why, why does that matter?" Cause again, I had no idea what PCOS was. And, like, it wasn't, I wasn't given like pamphlets. I wasn't told anything.

The need for effective patient-provider interactions was continuously stressed by participants. Improving these interactions would have consisted of patient-centered care on the part of the provider, "I wish that people would just be open to hearing what I have to say and be more open to receiving information from patients" (Participant 20). There are dangers to not receiving effective medical care for PCOS, and having unsupportive patient-provider communications can lead to a woman to not want any medical care at all:

> My doctor was incredibly problematic, like the doctor who diagnosed me retired and someone took over his practice and the person who took over his practice was not good, really not good and you know, really, really pushed me about my weight. And, Uhm- Yeah, only once he was no longer under supervision…. I was so uncomfortable with him that I opted to be without a doctor rather than with him, so it was pretty bad. (Participant 5)

Participants did not doubt that medical professionals understood the diagnosis medically, but rather were hopeful that they would be open to having discussions around symptom management, “I felt like he had basically no insight on it. If I complained about symptoms, he would just tell me to lose weight” (Participant 5). Given that PCOS is a multifaceted chronic disorder, it is important for women to find a medical provider that can support their diagnosis comprehensively.

Lack of Support

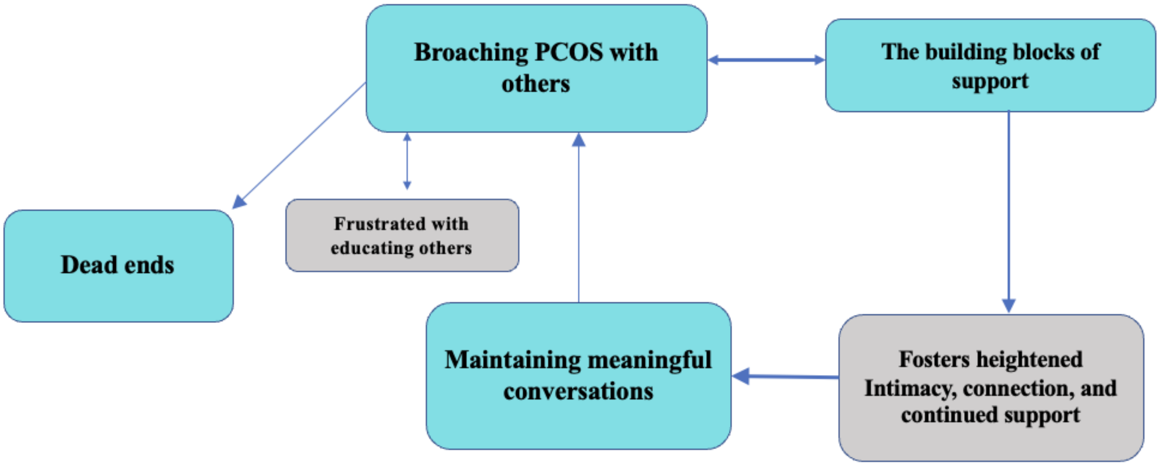
Another cause of a disclosure dead end conversation was when the audience was not supportive of the PCOS diagnosis, regardless of whether that audience was a close other or a medical professional. The negative experiences women described with healthcare providers caused many to begin to turn to alternative medicine for support, which proved to be beneficial. Participant 33 described her naturopath as being the most supportive person she has seen, “I had dealt with like medical, Western medical doctors and none of them had helped me, and so I thought, you know, maybe this will help as an option. So, I kind of did some research into it and then was able to find her and it's been very helpful.” Another participant had a similar experience with her physicians, “going in and making appointments and sitting there and just wanting to have a conversation about, “Hey maybe can we try something different?” They [medical professionals] just absolutely shut it down…You’re, you’re in there for two minutes and you feel like an idiot. So, definitely the doctors have been the least helpful, minus the naturopath" (Participant 7). When participants found that their medical providers were not receptive to their concerns, it caused participants to no longer trust their opinions, and instead seek support from alternative medicine resources to help treat their diagnosis. Many women reported that alternative medicine options (e.g., naturopaths) provided them with the support they needed. For example, medical doctors often would try to suggest that birth control pills were the only solution for patients, which many patients did not like. However, naturopaths were instead willing to listen to exactly what their patients' concerns were and provide alternative options. Most women expected to receive that level of patient-centered care; one that included listening to concerns, answering questions and educating patients on all potential symptom management options.

The lack of support felt by the women with PCOS was not limited to medical professionals; it also included close others in women's lives. Some participants remained hopeless about receiving support for their diagnosis, expressing that, "I don't think I really have anyone; I don't think there's a lot of support for PCOS" (Participant 9), or "I don't really have a support system in place for [PCOS]" (Participant 30). Often this lack of perceived support stemmed from other's negative reactions to the initial disclosure. When participants reached out for support but were instead met with a lack of understanding, or being blamed for the diagnosis, it shut down that specific avenue for support. Participant 16 described how the lack of support has started to affect her by reflecting, "you wanna talk about [PCOS] and you wanna get some sort of support, and when you don't get that support back, it just makes you not wanna talk about it at all."

When a dead-end conversation occurred, often it led participants to have to look elsewhere to try to receive support. One participant started reaching out to friends she wasn't very close with due to her mom's lack of understanding and support, "when I first got the diagnosis, my mom was not super supportive about it, and I think I was just looking for any kind of emotional support and validation that I could get (Participant 8)." If met with negative initial reactions from a listener, women cautioned that they would no longer speak about their diagnosis with that person. Participant 25 had a negative experience disclosing her PCOS to her mother and was accused of using her PCOS as an "excuse" As a result of this bad encounter, Participant 25 refused to discuss her diagnosis with her mother any longer, "I think that was the first and the last time I spoked to her about PCOS." Overall, these participants highlighted the damaging effects that negative reactions to initial disclosure can have on women trying to seek emotional validation and support for their PCOS diagnosis over time.

Figure 3

The interconnection of themes surrounding the disclosure and social support of PCOS



Note. The boxes outlined in grey are not themes but rather show the bridge between one theme to another. Arrows with one head represent a directional relationship. Arrows with two heads represent a bidirectional relationship between themes.

CHAPTER 5

DISCUSSION

Overall, this research provides unique insights into an under researched topic: the avenues to disclosure and social support for women with PCOS. I set out to explore the ways in which women with PCOS choose to disclose their diagnosis to others as well as how they go about broaching their PCOS diagnosis with others. We also examined the various reactions others had to a PCOS disclosure, as well as what aspects of social support were productive or unproductive buffering women against the stressors associated with their PCOS related concerns. As represented in Figure 2, these findings suggest that there are multiple, bidirectional avenues through which disclosure and social support evolve in women with PCOS. Four major themes characterized the approach that women take when discussing their PCOS diagnosis with others, which represented a temporal pattern that begin with: *(a) broaching PCOS with others, (b) the building blocks of support, (c) maintaining meaningful conversations and (d) dead ends.*

Broadly, most disclosure experiences began with participants broaching the topic of PCOS with another person, which served two main functions: describing or explaining symptoms to others or sharing struggles/connecting with others who have had similar experiences such as family members or friends. These early conversations included discussions of weight fluctuations, sharing infertility struggles and describing hirsutism and acne as impacting their appearance. These visible and invisible symptoms have been reported by women with PCOS in other studies as the most distressing aspects of the syndrome to live with and navigate socially because they challenge and impact a women’s sense of identity and femininity (Chrisler, 2011; Kitzinger & Willmott, 2002; Kogure et al., 2019; Samardzic et al., 2021). Symptoms of infertility and hirsutism have also been specifically connected to perceptions of family tension and reduced quality of life (Acmaz et al., 2013; Nasiri-Amiri et al., 2016; Pfister & Romer, 2016), as well as to disruptions to life goals and plans (e.g., family planning) (Ee et al., 2020; Thorpe, et al., 2019; Williams et al., 2015). It is not surprising that these symptoms were salient throughout women's conversation with others in our study.

However, despite the stigma and isolation from these symptoms, participants were motivated to open the conversation and discuss these sensitive topics with others, which is consistent with both *autonomous* and *agentic* disclosures that are common in people living with illnesses that are stigmatized by society (Sharratt et al., 2020). While participants did feel discomfort, they initiated most conversations because of circumstance or necessity (e.g., as an explanation for symptoms) but they also held control of the narrative, illustrating the intentional nature of ongoing PCOS disclosures. Participants explained, shared, and in some cases defended the occurrence of symptoms as a way to open the conversation about PCOS, while also striving to educate others and disrupt myths and misconceptions about the syndrome. Participants were also direct in the types of social support that they needed (e.g., asking family members to go on walks with them to support weight loss) with the ultimate goal of starting an informed conversation about PCOS with others, which created a space for a reciprocal discussion. They also deliberately chose to end these conversations when they were no longer serving those goals.

Additionally, it is important to highlight the targets of PCOS disclosures. Often, women in our sample disclosed to family, friends and/or their romantic partners. These "audiences" for disclosure are common in the chronic illness disclosure literature (Greene, 2009; Kaushansky et al., 2017) because people have already established an emotional connection with those individuals, and so that established connection is crucial in broaching a PCOS diagnosis because of the expectation of social support. These connections may also provide an explanation for why women seldom disclosed to others not as close to them, such as a coworker, unless there was a professional need. If targets of disclosure are outside of a woman's close social network, it may decrease the likelihood of them disclosing and receiving support from these distant members, unless symptom flare-ups prompt explanation.

However, two contradicting outcomes were possible when women provided an explanation for their PCOS symptoms; either they were believed and supported by others, or "shame and blame" was projected back onto them. In the case of shame and blame, participants were most often shamed for gaining weight. Obesity on its own has been known to be accompanied by stigma about weight. Stereotypes about individuals with obesity often characterize them as lazy and lacking in self-discipline (Puhl & Heuer, 2009). Thus, weight conversations are already difficult to broach and maintain, not only with close others but also with medical practitioners for fear of blame and judgement (Khan et al., 2018). However, when others were supportive and open to listening actively about PCOS, women were able to discuss their symptoms without fear of judgment and felt supported when doing so. The building blocks of support came in the form of *reciprocal disclosures, family members discussing their own PCOS symptoms (or suspected symptoms),* and listeners exhibiting *active, non-judgmental, and empathetic listening*. These supportive interactions fostered heightened intimacy and connection and served as a bridge for maintaining ongoing and purposeful conversations about PCOS with others.

Interestingly, family members discussing their own PCOS-related symptoms was common given the partial yet unclear genetic origin of PCOS (Franks et al., 2006). Others shared their own struggles with being diagnosed with PCOS. In both instances of reciprocal disclosures, women were able to find connection and common ground while also forming a shared experience. Many expressed that they felt understood and that they saw themselves in others' experiences and struggles. This shared and reciprocal experience deepened the interpersonal connection. When others were able to simply provide a listening ear (i.e., "*just listen* and validate", Participant 32) and express their empathy, it gave women a safe space to freely discuss their PCOS without the fear of marginalization that often can accompany discussing stigmatizing conditions. These positive interactions also help to mitigate the risk and vulnerability that often comes with disclosing sensitive health diagnoses and led to increased trust and future reciprocity (Barned et al. 2016; Steuber & Solomon, 2011).

Maintaining these conversations over time involved a few components; others completing their own research on PCOS to better understand it, the audience allowing conversations to be ongoing as new information about a PCOS diagnosis becomes available, and being able to have a sense of community and connection with other women. These three circumstances exhibit forms of *enacted* social support (Barrera, 1986), which aids in fulfilling different functions and thus having differential results on well-being. Specifically, these types of social supports aid in buffering an individual from life's stressors (Feeny & Collins, 2014). In our case, when women disclosed their PCOS to others, and others provided them with these forms of instrumental support (such as researching the topic to see what they can do to help their loved one), it has protective effects on a woman's quality of life and well-being. The social support in the form of providing a space to maintain conversations as well as forming a sense of community with PCOS women, may indirectly aid in better self-management of women's PCOS symptoms (Feldman et al., 2020), which then had direct impacts on one's quality of life (Earnshaw et al., 2011). Therefore, our data suggest that the effect of social support extends beyond fulfilling one's emotional needs by also impacting self-management practices and quality of life.

However, when broaching a PCOS diagnosis did not go as expected, that audience becomes a *dead end* which curtailed the discussion of PCOS. This was the case if the audience exhibited a lack of *awareness or understanding of PCOS*, or a *lack of receptivity to their concerns* (in the case of medical practitioners), both of which resulted in a *lack of support*.

In instances where the audience was close other (family members, friends), women reported their frustration over others not trying to understand PCOS and a lack of perspective-taking in how it may affect their lives. For example, frustration often stemmed from family members expressing that a woman with PCOS should try to lose weight through diet and exercise, without attempting to understand the underlying drivers that make weight loss difficult (e.g., varying levels of insulin-resistance). Many women believed that if these individuals tried to understand them, they would not place the blame so much on the woman themselves, but rather on PCOS as an underlying cause. The occurrence of these unhelpful attempts at support is known as miscarried helping, which describes interactions in which others try to be helpful, but the help is perceived as negative by the discloser (Tanaka et al., 2017). These types of interactions can cause arguments, tension, patient resistance to help and poor self-care (Tanaka et al., 2017).Due to the negative outcomes surrounding miscarried helping, it is important to equip close others with techniques that can aid them in avoiding miscarried helping altogether.

Additionally, when the demands of a chronic illness (like PCOS) outweigh the available support, women may experience a disturbance in their psychosocial adjustment to PCOS (Presely et al., 2021). When their social support needs are not fulfilled by the people around them, and they felt defeated, the women in our sample turned to alternative support methods, such as online support groups to combat isolation. Virtual support communities have been the main source of social and educational support in past research and has been primarily the result of women not being supported or heard by others in their lives (Holbrey & Coulson, 2013; William et al., 2016; Soucie et al., 2021). However, while these virtual spaces provide an avenue for connecting the others, and accessing information and resources, previous literature has questioned the validity of the information on many of these sites and reported that women feel worse off about themselves after visiting these websites regularly (Chiu et al., 2018; Williams, et al., 2015; Soucie et al., 2021). These previous findings contradict the experiences of women in my study, who generally reported positive online experiences. Thus, future studies should aim to address the mechanisms behind the contradictory experiences of women with PCOS turning to online communities.

Thus, a few things would be beneficial to improve initial disclosures between the woman with PCOS and the audience. First, when the audience is exhibiting a lack of awareness of the disorder, without making attempts to understand the disorder, it may make a woman feel as though effort is not being made to support her. It would be beneficial if instead, close others make attempts to ask questions, while remaining empathetic, to try to better understand PCOS, as the current study illustrates. These approaches seemed most beneficial in women who reported positive discloser-audience interactions, which is line with past research on chronic illness social support strategies (Gallant, 2003; Earnshaw et al., 2011). It would also be beneficial for the audience to provide support in the form of finding out what a woman needs to support lifestyle and self-management for her PCOS, or what types of emotional support will aid in psychosocial adjustment to a PCOS diagnosis.

Dead end conversations also occurred in the context of medical practitioners. Many women felt as though their medical practitioners were not willing to listen to their PCOS related concerns, and their continuous need for PCOS symptom support. Poor patient-practitioner communications have been previously discussed (Crete & Adamshick, 2011; Hillman et al., 2020; Soucie et al., 2021a, 2021b; Tomlinson et al., 2017) as an obstacle to receiving a timely diagnosis; however, in our case, they also appear to be an obstacle to receiving follow-up support for the management of PCOS as well. Given the number of women that stressed the need for useful conversations about PCOS, these poor patient-practitioner communications may be irrevocably damaging to the patient-provider relationship (Soucie et al., 2021). Many women avoided their medical practitioners after a negative interaction with them, and instead found new providers, discontinued seeing any provider at all, or ventured into alternative medicine (e.g., naturopaths). Although interactions with alternative medical professional proved to be beneficial for management of the disorder, these professionals were not able to fulfil all support needs or answer all questions related to PCOS. For example, many women still expressed concerns over comorbidities as well as questions about progression of the disorder. These concerns are best directed at medical doctors, and thus it is important that these medical practitioners practice patient-centered care by being receptive to women's individual questions and concerns about PCOS. Patient-centered care acknowledges an individual's specific heal needs and desired health outcomes as a driving force behind all medical decisions that are made (NEJM Catalyst, 2017). Thus, practicing patient-centered care would likely mitigate the healthcare concerns being expressed by women with PCOS.

It is important to note that my themes also spanned across various cultures, religious identities, and demographic origins. Some women discussed their PCOS in the context of their cultural backgrounds or religious expectations and reported similar experiences, regardless of where they are, who they are with and where they originate from. I interviewed women from different provinces across Canada, and from many varying cultural backgrounds. Based on the demographic variability of my participants, it highlights the intersectionality of cultural identities and disclosure experiences, outlining that culture adds an additional layer of feminine expectations in addition to the already present Western expectations. Thus, these findings appear to be transferrable to a variety of different populations, and contexts.

PCOS extensions to the DD-MM

Overall, these findings can be related back to the Disclosure Decision-Making Model (DD-MM) of health disclosure decision making (Greene, 2009). Step one of the model, *assessment of information,* includes the discloser examining all information they have about the diagnosis. It also involves examining the stigma surrounding the illness to navigate the vulnerability and risk of disclosure. PCOS has been previously known to be a highly stigmatized disorder, due to its symptoms (e.g., weight gain, hirsutism, acne, etc.) contradicting a societally desired feminine appearance (Kitzinger & Willmott, 2002; Pfister & Romer, 2016; Samardzic et al., 2021; Thorpe et al., 2019). This previous literature is in line with the women's disclosure experiences in our study. They who often felt the need to explain or defend PCOS to avoid stigmatization and marginalization. Greene (2009) proposed that targets of disclosure are those with whom one may have a good relationship with, and whom they may anticipate a positive and supportive response from. Many women in our sample continued to reopen the disclosure process and moved on to seeking social support again from that same person, if they had a positive response from the listener. Additionally, Greene (2009) posits that noticeable symptoms of a chronic disorder may have impacts on the timing of a disclosure. Women with PCOS often felt the need to disclose to explain their visible symptoms (such as acne and hirsutism), regardless of if they were fully ready to disclose their PCOS to others. However, women that had more invisible symptoms of the disorder (such as infertility) only felt the need to disclose when they were asked questions about childbearing by others. Thus, the routes to disclosures of PCOS are similar to that of other chronic illnesses; varying presentations of PCOS may affect the timing and audience of a disclosure.

The next step in the DD-MM model is *assessing the receiver*. Two features of an audience are considered in this model: relational quality and anticipated response. Women with PCOS placed importance in this step of the model; if a negative experience happened with a listener, they often refused to return to that listener for support or future disclosures. Negative disclosure experiences also hindered relational quality, as PCOS-centered conversations or support could no longer occur in the context of that relationship. Greene (2009) states that a discloser will have to anticipate a positive, empathetic response toward the disclosers situation before willing to disclose a diagnosis. One of the steps in our model, *the building blocks of support,* outlined the importance that many women put on active listening, empathetic responding, and being present in the moment. If they were not receiving these anticipated responses, they seldom would return to that same avenue to receive support.

Finally, *disclosure efficacy* is the third step in the model, which includes one's confidence in being able to relay a health diagnosis to others. Many women expressed concern over having to do their own research on PCOS. As a result, they were seldom able to answer all questions that listeners had. However, this underscores the importance of medical practitioners being receptive to patients concerns, as women consider how much they understand their diagnosis before relaying it to others.

Interruptions to disclosures are also an important consideration in Greene's (2009) model, which also parallels portions of our model. Two interruptions to disclosures may occur, which include questions being asked and reciprocity (Greene, 2009). Both disclosure features were seen in our data. Reciprocity was common when other women shared a similar diagnosis, which is common in other chronic illness disclosures as well (Dindia, 2000). It is also common for empathetic responding to be increased in those that share a health diagnosis (Dindia, 2000), which is in line with women's PCOS disclosures. Additionally, questions being asked by a receiver are often an opportunity for one to spontaneously disclose their diagnosis (Petronio et al., 1996), which we often saw when women answered questions about their visible PCOS symptoms by disclosing.

Strengths and Limitations

This study has several strengths. First, to my knowledge, no previous studies in the literature on PCOS have explored disclosure experiences and their role in building and fostering social support. Much of the literature on PCOS examines it from a biomedical perspective that views PCOS from a negative perspective. Seldom has PCOS been studied from a biopsychosocial standpoint, and within the context of how it may impact health outcomes (mental and physical). My study takes a novel look at link between the disclosure and social support aspects of PCOS, as well as the impact of symptom stigma on these experiences. The study notes various forms of support that are helpful, and contribute to the maintenance of productive conversations, and relationship-building approaches.

Methodological coherence was another strength of the study. To answer my research questions, I situated the study within a social-constructivist paradigm, which states that social reality is constructed on an individual level and involves reflecting on one's experiences and the world around them. My paradigmatic position was upheld by completing multiple in-depth interviews. This approach allowed for the participants to construct their own stories about their disclosure and support experiences without constraints. While I guided them through the interview process, I was able to gain insight into how they made meaning of this process. Given that PCOS is a multifaceted, complex, and sensitive topic, qualitative methods are crucial to capture the lived experiences and stories of participants. Additionally, given the virtual nature of the interviews, I was able to recruit participants from multiple provinces and territories across Canada, allowing me to capture the widespread experiences of women outside of Ontario. Finally, through member-checking procedures, I was able to receive feedback from participants about my results. This feedback allowed me to continue my reflexive process with the data and themes, and to further refine my results to ensure they were representative of participants' experiences. I encouraged participants to email any members of the research team as needed and stayed in contact with them throughout this process to ensure accurate representation of their experiences.

A further strength of the present study is related to the similarity of my background and experiences to the participants, as a PCOS diagnosed woman. Before beginning each interview, I disclosed my own diagnosis to participants in attempts to make them more comfortable and to reassure them that I resonated with their experiences with the diagnosis. A few participants expressed their gratitude for this revelation, and explained they felt less stigmatized knowing that I shared the same diagnosis. Participants' knowledge about me as a person who has been diagnosed with PCOS did foster a connection; however, it was likely to influence the experiences shared with me during the interviews. Additionally, due to my own experiences with PCOS, I had pre-existing assumptions about participants experiences disclosing and getting social support for their PCOS. However, as mentioned above, I engaged in personal and co-reflexivity practices through journaling, as I critically acknowledged my role as a researcher, which is crucial to the RTA analytical process. Sending the participants copies of the themes constructed from the data and getting feedback was a way to ensure trustworthiness.

However, the lack demographic variability of participants, in relation to their socioeconomic status and education level, is a limitation of the study. Ninety-two percent of the participants had completed some level of post-secondary education, and eighty-nine percent of our participants had a combined household income of above $50,000. The homogeneity of these aspects of the sample prevented me from fully attending to how participants' experiences were shaped by their varying social identities and education levels. The results of this study highlighted the importance of one's confidence in being able to relay their PCOS diagnosis to others, so it is possible that individuals with higher education may better be able to understand the complexity of PCOS, and therefore better able to relay their diagnosis to others. Intersectional perspectives were missing from this research study, and future research should prioritize and amplify how participants' identities (age, gender, race/ethnicity, class) and their lived experiences impact their relationships, and disclosures (Soucie et al., 2022). This is crucial in understanding PCOS from a truly biopsychosocial perspective and ensures that researchers are inclusive of voices historically left out of PCOS literatures.

Future research should aim to recruit participants who are of varying backgrounds and socioeconomic statuses to understand the impact of access to PCOS supports. Specifically, in our sample, many women turned to alternative medicine for social and informational support when their practitioners were not receptive to their concerns about their PCOS. However, in the Canadian healthcare system, alternative forms of medicine are seldom covered by personal insurance or by Canada's universal healthcare coverage. Thus, individuals who are of low socioeconomic status, for example, may not have the financial means or resources to access these services (e.g., a naturopath). Future research should aim to capture the ways in which individuals of low SES overcome barriers to receiving supports for their PCOS diagnoses. To engage these marginalized groups, researchers should aim to consider how recruitment approaches may privilege some people over others from participation. Given the COVID-19 pandemic, our recruitment had to occur primarily online. As such, this may have excluded groups that do not have the technology to access the internet and social media. Thus, alternative recruitment procedures in future studies may be beneficial.

Additionally, many of our participants discussed the limitations their debilitating PCOS symptoms placed on their jobs. Women recounted the need to disclose their PCOS diagnosis to various employers to explain absences or modified working abilities. Future research should aim to capture the experiences of working-class women with PCOS, to better understand the disclosure experiences these women have with their employers, as well as the modifications that may need to be made to one's workplace to provide equal opportunities for these women to work. Exploring these avenues in this population of working-class women may aid PCOS-diagnosed women in learning effective disclosure strategies for the workplace. Additionally, it may equip them with strategies to overcome PCOS related obstacles and receive the appropriate supports in the workplace.

Finally, as mentioned above, the interviews were also conducted virtually during the middle waves of the COVID-19 pandemic. Participants were instructed to find a quiet distraction free place to complete the interview, but not all participants were able to remain distraction free. During a few interviews, given the COVID-19 pandemic requiring everyone to stay home, some women had family members or children interrupting the interviews. This may have served as a distraction from thoughts and ideas that these women were elaborating upon.

Implications for Close Others and Practitioners. Findings from this study have relevance for close other wanting to support a woman with PCOS and for healthcare practitioners. Overall, participants expressed satisfaction with alternative medicine (such as naturopathic doctors and psychologists) and their ability to answer their questions and address their PCOS-related concerns. However, many participants had concerns over their medical doctors not being receptive to their concerns. It is clear that women have higher expectations for their health care providers. They want providers who are understanding, respectful, provide honest communication, and answer their questions. The present study is not the first time that women with PCOS have expressed these concerns (see Soucie et al., 2021), but rather adds to the growing need for practitioners to follow guidelines put forth by Teede et al. (2018) surrounding the diagnosis and management of PCOS. These specific guidelines are an international, evidence-based set of guidelines on the diagnosis, management, education/health literacy, multidisciplinary care, self-empowerment, mental health, and quality of life impacts of PCOS (Teede et al., 2018; Soucie et al., 2021). Thus, practitioners would be able to provide more patient-centered care to their PCOS patients by practicing under these guidelines. Additionally, these findings stress the need for multidisciplinary teams in the ongoing treatment of PCOS. Women would benefit from multiple approaches to their care, such as using traditional Western medicine approaches (e.g., endocrinologists) in combination with alternative medicine (e.g., naturopathic doctors) and complementary services (e.g., psychologists). Our findings reinforce past literature highlighting the need for this enhanced approach to PCOS management (Teede et al., 2018; Soucie et al., 2021).

There are also practical implications for those wanting to support women with PCOS. The present study provides insights into what women with PCOS find beneficial in their disclosure and support experiences. Specifically, the findings of this study highlight the importance of close others to remain a supportive disclosure avenue for women with PCOS in order to not become a dead-end conversation. It also highlights the need for effective social support in populations of women with PCOS, and the beneficial impacts that high-quality support has on quality of life in women with PCOS.

Conclusion

This study examined the disclosure and social support experiences of women with PCOS. Utilizing a reflexive thematic analysis, themes centering on broaching PCOS, building supportive relationships, maintaining meaningful conversations and avenues to dead ends were identified from the data. Findings of this study address a gap in the current body of literature by highlighting the complexity of disclosure and social support experiences and their impact on women with PCOS, and ways in which social supports may be beneficial in improving illness-related quality of life. This study has direct implications for future research within the field of chronic illnesses and has the potential to inform the development of services aimed at supporting women with PCOS.

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APPENDICES

Appendix A: Informed Consent

University of Windsor

CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: The Role of Disclosure and Social Support on Quality of Life in Women with Polycystic Ovary Syndrome

You are asked to participate in a research study conducted by **Noelle Citron** supervised by Dr. **Kendall Soucie** from the **Psychology Department** at the University of Windsor. This research is being conducted as Noelle Citron's master's thesis.

If you have any questions or concerns about the research, please feel to contact our general email inbox (pcos@uwindsor.ca) or **Noelle Citron** at citronn@uwindsor.ca**, or Kendall Soucie** directly at ksoucie@uwindsor.ca (519-253-3000 ext. 2222).

PURPOSE OF THE STUDY

The purpose of this study is to explore how women with Polycystic Ovary Syndrome (PCOS) disclose and/or talk about their diagnosis to family, friends, and others in their lives.

PROCEDURES

To capture your experiences disclosing your PCOS to others in your life, we will interview you about your personal experiences broaching and talking about PCOS with your friends, family members, and others in your life, and then ask you to fill out a brief 5-minute survey. Interviews will take approximately 60-90 minutes and will be conducted by Noelle Citron, a graduate student in Psychology at the University of Windsor. We ask that you complete the interview in a quiet, distraction free location. All interviews will be audio recorded, or audio and video recorded. We will be asking you some questions about your PCOS diagnosis, such as how you came to be diagnosed with the disorder, and what it's been like living with and managing PCOS, since you have been diagnosed with the syndrome. We will then ask you questions about disclosure, like how you typically broach, and then explain PCOS to others, as well as how other's reactions to your disclosure impacted you, and your willingness to talk to others about the syndrome. We will ask you to also reflect on who you typically turn to for support for your PCOS-related concerns, and why you turn to those people or sources for advice and guidance. Once the interview is complete, you will be asked to complete a short 5-minute survey packet to collect some brief demographic information (e.g., age, length of time to diagnosis).

POTENTIAL RISKS AND DISCOMFORTS

The questions in the interview contain questions about both positive and negative experiences with members of your social circles. You may find that the challenges and barriers that you may have experienced when reaching out for social support are difficult to think about and disclose. This may result in some minimal discomfort. If you feel any discomfort at any time, you are free to end the interview with no negative consequences. You are also free to refuse to answer any questions that make you feel uncomfortable. We will also provide the contact numbers of several local counselling services, some PCOS information resources and on-campus services. You may also contact the principal investigator for the study, Noelle Citron, if you have any questions, concerns, or require assistance.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

While no direct benefits for participants are expected as a result of participating in this research study, we do anticipate indirect benefits. It is likely that you may learn new insights about yourself, and your relationships, as you reflect on your past experiences within the context of PCOS. Insight into chronic health disclosures will help to shape how, why, and under what circumstances you choose to disclose your PCOS to others, how you manage risk and vulnerability, as well as how others' reactions shape your future disclosures. You will likely also benefit from knowing your experiences will help to shape scholarly and advocacy work, in this area. Finally, you will also learn about many features of psychological research including surveys and interviews.

COMPENSATION FOR PARTICIPATION

You will receive a $20.00 E- gift card to a place of your choice for your participation in this study. Participants who are willing to be contacted again, in 4-6 months to review the themes generated from the interviews, will receive an additional $5 compensation for providing feedback pertaining to study results.

CONFIDENTIALITY

Your package of completed questionnaires and audio recorded interviews will each be given an identifier code. This code can in no way be traced back you. Signed consent forms which do not contain an identifier code will be stored separately from questionnaires and typed interviews in a password protected file located on the University of Windsor's One Drive online storage, available only to the primary researcher (Citron) and supervisor (Soucie). The interview sessions will be video and/or audio recorded and subsequently transcribed by the primary researcher who will ensure that any identifying information does not appear on any of the printed transcripts. The only individual with access to the audio recordings will be the principal investigator and research supervisor. Once the audio recordings have been transcribed, they will be deleted from the MS Teams server. Transcribed data will be de-identified and only the principal investigator and supervisor will have access to the transcribed data. As the interview data is intended to capture participant responses at specific moment in time, participants will not have the opportunity to review and/or edit their responses post interview. Raw data will be stored and identified only by the ID number. Furthermore, study participants will not be individually identified in any publications or presentations that may stem from this research; only aggregated data will be presented.

PARTICIPATION AND WITHDRAWAL

You will receive full compensation if you chose to withdraw from the study at any point without penalty. If you wish to withdraw your data, please email pcos@uwindsor.ca on or before three weeks following your interview. You may also refuse to answer any question that you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

If you would like to be informed about the findings of this study, you may go:
Website address: to http://scholar.uwindsor.ca/research-result-summaries or https://www.healuwindsor.com/

SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations, but only aggregated data will be presented.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Office of Research Ethics, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

Please indicate your answer with an "X":

I am willing to participate in an interview about my experiences disclosing and receiving social support for my PCOS diangosis:
☐ No ☐ Yes

I consent to the video-taping or audio-taping of interviews. I understand these are voluntary procedures and that I am free to withdraw at any time by requesting that the viewing be discontinued. I also understand that my name will not be revealed to anyone and that viewing will be kept confidential. I understand that confidentiality will be respected and the viewing of materials will be for professional use only.
☐ No ☐ Yes

I consent to the use of direct and anonymized quotations from my interview responses to be included in any reports, publications and/or presentations that arise from this study.
☐ No ☐ Yes

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I understand the information provided for the study titled **The Role of Disclosure and Social Support on Quality of Life in Women with Polycystic Ovary Syndrome** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

____

Name of Participant

______________________________________ ____________________

Signature of Participant Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

______________________________________ ____________________

Signature of Investigator Date

Appendix B: Interview Guide

Semi-Structured Interview Guide:

Hi **_____**, thank you for your interest in our study, and for agreeing to participate. My name is _______ and I'm currently a master's student at the University of Windsor.

Would you like to tell me a little bit about yourself, so I am able to get to know you a bit better? Feel free to only share what you feel comfortable sharing.

Today I would like to talk with you about your experience living with PCOS and disclosing PCOS to at least one other person in your life. Since I am going to be asking you questions about your own diagnosis, I'd also like to share a little bit about mine. I also am a PCOS diagnosed woman and have been living with PCOS for about 5 years now. A lot of my research interests have come from my own experiences with the disorder, and it's where the idea for the interview we're doing today came from.

We'll start by re-confirming your consent. As you know, the purpose of this study is to learn more about your experience with PCOS, specifically to learn about times you have told others about it and reached out for support. Your identity will not be revealed at any point and your responses will not be tied back to you. As we do the interview, please feel free to modify or decline to answer any questions; you also may suggest any questions you think I should be asking. If you need to take a break at any point, please let me know. This study has received ethics clearance from the University of Windsor REB.

We will start with our camera's on but if the internet connection gets poor, we may need to switch off our cameras (if participant only consented to audio recording, omit this line) Can you please confirm that you are willing to participate, and you consent to being video-taped (or audio recorded)? Please remember that you may withdraw from this study at any point during the interview and for any reason. Following the interview, you'll have three weeks to withdraw your data for any reason.

Thank you! Do you have any questions for me before we begin? (also ask if they have any requirements, like needing extra breaks, etc)

I am going to start the recording now.

START RECORDING******

(General questions about PCOS).

1. Can you tell me how you came to be diagnosed with PCOS? How old were you?

2. What has it been like for you to live with PCOS currently/(alt prompt: In what ways has PCOS affected your daily life? (particularly right now--- during COVID-19)
3. Have you told anyone that you have PCOS? Who did you disclose your PCOS to?

(Specific questions about disclosure):

Now, I'd like to ask you a few questions about disclosure, so who you've told and why you decided to tell those people in your life**.**

4. Why did you decide to tell these people/this person (ask them to discuss each of the people they told and why they chose to tell them)?
5. How did this person/people react when you told them?
6. Did any of their reactions impact or influence you in any way?
7. Did anyone's reactions surprise you? (Were their reactions as expected?)
8. How do you typically explain your PCOS to others?

(Most memorable disclosure)

Thank you for sharing these experiences with me. It helps me to understand who you told, why you told them, and how their reactions to your talking about your PCOS with them impacted you as well.

- a. Of these experiences that you shared with me, what was your most memorable or impactful disclosure experience?
- b. Why was this experience memorable?
- c. Has this experience impacted how likely you are to reach out to this person again in the future?
- d. Has this experience impacted the chances of you reaching out to others in the future?
- e. *Additional prompts:* When did this happen/how old were you, what led up to it, what exactly happened (if unclear), what were you thinking/feeling during this experience, and how you react/respond? Finally, what was the impact of this experience on your life story/sense of self?

(Social Support: Informal vs. Formal help-seeking avenues).

I want to now turn to social support, and I want to ask you who you reach out to talk about PCOS.

10. Who did you typically reach out to for PCOS help and support? (alt: prompt: Have you reached out for support in any of the following ways:
    - In person (friend, family, partner, close other)?
    - Online/virtual communities?
    - Community resource?

    - Healthcare/mental health resource?
    - Others?

11. Why did you choose to reach out for support from these resources or people?
12. Would you consider these resources or people trustworthy? Why?
13. Which/whom was the most helpful and why? Least helpful and why?
14. What would you like others (family members, friends, communities, etc.) to know about how to best support you?

(Ending interview: long term concerns, and reflections).

Thank you for describing who you reach out to for support and providing some great thoughts on what others should know to better support women with PCOS. The last section of this interview asks about any long-term concerns that you have about the future.

15. What impact do you expect PCOS to have on your future? What long-term concerns do you have?
16. If you could give someone who thinks they have PCOS advice, what would it be?

(Final comments)

Thank you for speaking with me today and for sharing your experiences telling others about your PCOS diagnosis, and what it’s been like for you to live with PCOS and manage it every day. I am grateful for your time today.

17. Is there anything that we have not covered in this interview that you feel is important for us to know? Do you have any questions for me?
    a. Encourage participants to follow up via email if they have any additional questions, or if they forgot to mention something. (Keep an open dialogue)
    b. I will send a list of resources to support you with an e-gift card for 25.00 of your choice, too.

Member reflection:

Before we sign off, I’d like to ask you if you would be willing to be contacted again in about 4-6 months for the purpose of member reflection. Member reflection is a way for us researchers to know if the results we got from the data are accurate. We would send you a copy of some of the themes we are finding in the data, then you would fill out a brief survey to give us your opinion on our results. You don’t have to agree or disagree now, but instead during the demographic survey, you will have the opportunity to select whether or not you wish to be contacted again.

Appendix C: Demographic and Diagnosis Questions

Background Questionnaire

Please respond to the following questions

1. How old are you (in years) __________?
2. What province are you currently residing in?
3. What is your gender? (open ended)
4. How long did it take for you to receive a PCOS diagnosis? (open-ended)
5. What is your ethnic background?
    1 = White
    2 = Chinese
    3 = South Asian (Ex: East Indian, Sri Lankan)
    4 = Black
    5 = Filipino
    6 = Latin American
    7 = Southeast Asian (Ex: Vietnamese, Cambodian)
    8 = Arab
    9 = West Asian (Ex: Iranian, Afghan)
    10 = Japanese
    11 = Korean
    12 = Aboriginal (North American Indian, Métis or Inuit)
    13 = Other (Please specify_____________________________
6. Were you born in Canada (Y/N)
    a. If no, in what country were you born?
7. What is your current relationship status?
    a. Single; Casually dating; Partnered/ Non-married committed relationship; Married/ Civil union; Separated; Divorced; Widowed; Other ______________(please specify)
8. Do you have children? (Y/N)
    a. If yes, how many children do you have? ______
9. What is your total combined annual household income?
    a. $0 – $9,999
    b. $10,000 – $19,999
    c. $20,000 – $29,999
    d. $30,000 – $39,999
    e. $40,000 – $49,999
    f. $50,000 – $59,999
    g. $60,000 – $69,999
    h. $70,000 – $79,999
    i. $80,000 – $89,999

    j. $90,000 – $99,999
    k. $100,000 or more
    l. Choose not to disclose _____

10. What is the highest level of school you have completed or the highest degree you have received?
    a. Some high school
    b. High school diploma or equivalent (e.g., GED)
    c. Some college/ university
    d. Vocational degree/ certificate
    e. Undergraduate degree (Bachelor's)
    f. Graduate degree (Master's)
    g. Professional degree (e.g., MD, JD)
    h. Postgraduate degree (Doctorate)
    i. Prefer not to say
11. Which of the following categories best describes your employment status?
    a. Employed, working 1-39 hours per week
    b. Employed, working 40 or more hours per week
    c. Not employed, looking for work
    d. Not employed, NOT looking for work
    e. Retired, other
    f. choose not to disclose.
12. How would you describe your current living situation? (select all that apply)
    a. Alone
    b. Spouse/Partner(s)
    c. Child(ren)
    d. Sibling
    e. Parent(s)/Guardian(s)
    f. Group setting
    g. Personal care attendant
    h. Other (please specify)
    i. choose not to disclose.
13. Which of these spaces best describes where you live?
    a. Urban
    b. Suburban
    c. Rural
    d. Prefer not to answer
14. Are you a student? (Y/N)
    a. Full time, part time, other?

VITA AUCTORIS

NAME: Noelle Citron

PLACE OF BIRTH: Windsor, ON

YEAR OF BIRTH: 1997

EDUCATION: Holy Names High School, Windsor, ON, 2015

University of Windsor, B.Sc., Windsor, ON, 2019