Understanding disorder, the female body and femininity: A qualitative exploration of the experiences of Polycystic Ovarian Syndrome treatment

by

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Abstract

Polycystic Ovarian Syndrome or PCOS is a condition characterized by different symptoms of menstrual abnormalities, overweight and obesity, acne, hair loss, and hirsutism (male hair growth pattern), based on the key feature of an increase in androgen synthesis by the ovaries. This is a condition that has been stated to be incurable and treatments are mostly directed at masking the symptoms and regulating hormonal functionality. PCOS is labelled as a condition based on the assumption that androgen excess is not part of embodied ‘femininity’. The diagnosis centers on clinical indicators of "increased" male hormones and the gender binary essentially shapes the medical diagnosis and treatment for this condition. This suggests a problem with PCOS patients' bodies since they depart from normal gender embodiment.

This research examined factors and symptoms related to androgen excess that are problematised by the participants in this study, and explores how this condition goes beyond its physiological problems and impacts women’s identities and sense of being. It explored women’s perspective of the disorder, their illness and treatment experience and its connection with their perceptions of ‘femininity’ and ‘womanhood’. It aimed to get a more nuanced knowledge of the experiences of how women identify their bodies in response to living with a gendered disease.

This qualitative study used a feminist narrative research approach with semi-structured interviews and one focus group, along with a body mapping exercise, to gather lived experiences of eighteen Indian and Indo-Canadian women living in Edmonton, Alberta (age category 18-30 years). It tried to understand how these women navigated PCOS symptomatology and treatment. It focused on their meaning-making of the condition and how it affected women’s lives.

The findings of this study reflected that PCOS is related to broader biomedical and socio-cultural ideals of femininity, so much so that for the participants, health and normative femininity get conflated. For women, struggles with PCOS were mainly struggles of ‘being a normal woman’ where they try to fix their bodily symptoms, menstrual cycles and their concerns about future motherhood. They experience incoherence with an ideal healthy female body (both in terms of appearance and abilities) and constantly try to reshape their bodies, signifying that they are in fact always trying to be a woman, authenticating their internal sense of gender. These navigating strategies were developed on the basis of symptom priorities and a constructed health hierarchy to get the desired female body, which were again based on social interactions with people and medical authorities.

Treatment narratives of the women in this study were largely based on whether and how the treatment helped them with symptoms associated with aspects or manifestations of femininity. There were two distinct narratives held by different women about treatment. The most prominent one was that they did not think the treatment method was useful for them, since they still felt ‘’unfeminine’’. The secondary narrative was that they felt and looked healthier and considered treatment to have improved their conditions, where being healthy was often synonymous with womanhood.

The lines between health, femininity and womanhood get blurred- for women their priorities are focused on making their bodies look more feminine and fertile. For medical doctors, the female body is healthy only when it has the capacity to procreate. In general, women in this study, equated ‘’healthy’’ and ‘’feminine’’. They were more apprehensive about how their appearance and internal functionality differs from what is expected of a ‘’normal’’ woman.

Preface

This thesis is an original work by Samadrita Chowdhuri. This research project received research ethics approval from the University of Alberta Research Ethics Board 1, Study Name "Understanding disorder, the female body and femininity: A qualitative exploration of the experiences of Polycystic Ovarian Syndrome treatment" Study ID Pro00132200, August 15, 2023.

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CHAPTER I

Introduction

‘’We do not just have bodies, we are bodies’’

-Snowber, (2012, p. 55)

Snowber’s quote reflects how our identities are intricately related with our bodies. It highlights that our bodies are not merely vessels for our experiences but are integral to our identity and being. For women, embodiment is often scrutinized through the lens of health and illness, where societal expectations and medical discourse intersect to shape their lived experiences. Throughout history, women's bodies have been viewed mainly in terms of their capacity for reproduction based on patriarchal terms, which eventually structured women's health and standards that defined what a female body should be (Ellerman, 2012). Women have struggled not just to take back control of their own bodies and knowledge, but also to participate in the production, interpretation, and sharing of that knowledge (Ehrenreich & English 2011).

However, when it comes to health and illness, the medical establishment gains authority and the fight for control gets restricted. Berger and Luckman emphasize, “an entire legitimating machinery is at work so that lay[persons] will remain lay[persons], and doctors, and (if at all possible) that both will do so happily” (1967, p. 88). Medical authority gets positioned to have specialized and unquestionable knowledge that supposedly focuses on well-being, but does this knowledge include women’s voices? Does it actually benefit women? For many years, there have been efforts to question the medical control of women’s health. For example, inspired by feminist movements, the pathologization of pregnancy and menstruation have been contested by women's health movement activists (Martin, 1987), but there are still certain problems that fall under the umbrella of women's health that have not yet received much attention. Polycystic ovarian syndrome (PCOS) , is one such example.

My story

Before moving on to the actual study, I would like to share my personal experience and how that has inspired my research. In 2019, I had severe facial acne after which my dermatologist recommended that I get tested for Polycystic Ovarian Syndrome (PCOS). After being diagnosed with PCOS, I was prescribed hormonal treatment by my gynaecologist and without asking any questions, I started it. I had read about PCOS online and was really scared. I came to know that this syndrome is not curable, it can cause infertility and if I do not become cautious about my lifestyle, it can lead to other diseases as well. After a few months on hormonal pills, I started having mood swings, had excessive menstrual pain, sometimes I even felt nauseous, but I kept taking the pills.

After a point I became exhausted; I was consuming these pills regularly which definitely helped my acne and periods but I did not feel like myself. Shortly after, during COVID-19, I reconnected with one of my childhood friends. In one of our online hangouts, I came to know that she also had PCOS and was diagnosed with it a long time ago. She shared how she had been taking hormonal pills since she was thirteen. She said:

> At that age, I did not even know if I wanted to be a mother when I grow up. My parents feared that if I did not get regular periods now, I would never be able to conceive. I mean I did not feel sick at all. I always questioned why I was on medicine for the majority of my life.

This statement made me question myself. Why was I going through hormonal treatment? Did I feel unhealthy? Why was I concerned about the acne so much? Why did the word infertility scare me so much? I wanted to understand why I could not question the doctor and why I started with the treatment in the first place. I needed to know how other women with PCOS are dealing with it. Do we actually know what we are going through and what we want?

What is PCOS?

Polycystic Ovarian Syndrome or PCOS is a condition characterized by different symptoms of menstrual abnormalities, overweight and obesity, acne, hair loss, and hirsutism (male hair growth pattern), based on the key feature of an increase in androgen synthesis by the ovaries. This is a condition that has been stated to be incurable and treatments are mostly directed at masking the symptoms and regulating hormonal functionality. It is the most frequent endocrinopathy among premenopausal women, the major cause of infertility and is the most widespread endocrine disorder affecting women today (Vrbikova, 2012;Wolf et al., 2018). Women with PCOS are reduced to having an abnormal body that needs to be addressed medically because they are unable to embody normative femininity (Fabricius, 2020).

The PCOS clinical guidelines on Medscape (a North American medical journal) direct doctors to do a visual exam for elevated testosterone, enabling the diseasing of PCOS-afflicted women's bodies in the healthcare system based on increase in male hormones. When visual indicators of high testosterone are used as a diagnostic tool, hirsutism, which is characterized by hair growth on the upper lip, chin, nipples, and linea alba of the lower belly, becomes a cause for medical concern (Lucidi, 2016). Doctors also consider indicators of male pattern baldness, enlarged clitoris, and increased muscular mass when diagnosing elevated testosterone. Some PCOS patients are provided alternatives for medical therapy for excess body and facial hair development, indicating that shaving and the use of chemical depilatories and/or bleaching lotion may be used in combination with weight loss (Lucidi, 2016). The diagnosis of androgen excess, which centers on clinical indicators of "increased" male hormones, suggests a problem with PCOS patients' bodies since they depart from normal gender embodiment.

Oral contraceptive pills, insulin stimulation medicine, and antiandrogens are the most often used treatment approaches (Witchel et al., 2019). It is believed that hormonal contraceptives help to reduce androgenic effects of PCOS. The first-line treatment options for the clinical signs of PCOS, notably irregular menstruation, hirsutism, and acne, are combined hormonal contraceptives (CHCs). CHCs are believed to help regulate the clinical symptoms of hyperandrogenism and menstrual cycles because they include both an oestrogen and a progestogen component (de Melo et al, 2017). The side effects of such routine intake of birth control constitute mental health problems, high blood pressure and even hypertension (Lucidi, 2016). Metformin and other insulin stimulation drugs increase insulin sensitivity, which improves glycaemic management and lowers testosterone levels (Witchel et al., 2019). These medicines and line of treatments are mainly focused on inducing artificial hormones and regulating menstrual cycles to mask symptoms that manifest the dominance of male hormones which makes this syndrome even more complex. Its gendered aspect brings up questions of whether the pathologization and construction of this syndrome is another example of attempts to control women’s bodies.

Situating the study

This research examines factors and symptoms related to androgen excess that are problematised by the participants, and explores how this condition goes beyond its physiological problems and impacts women’s identities and sense of being.

The perspectives of women with PCOS have not been thoroughly studied, and I believe that these perspectives have a special ability to contribute to the conversation on PCOS. The institutional inability to use women's testimonies of lived experience to guide therapeutic procedures has kept women with PCOS marginalized and controlled in the medical system (Crete & Adamshick, 2011). The relevance of this research is based on the fact that it explores and understands women’s perspectives of the disorder, their illness and treatment experiences and their connections with their perceptions of ‘femininity’ and ‘womanhood’. PCOS is labelled as a condition based on the assumption that androgen excess is not part of embodied ‘femininity’; the gender binary essentially shapes the medical diagnosis and treatment for this condition.

It is important to understand how women with this condition are dealing with it and to explore the treatment options they prefer. This work will not only bring up the diverse problems women are facing, but also why they prefer particular treatments. People with health issues are neglected in medical settings, both at the clinical and research levels, such that the focus is on malfunctioning individual parts rather than the total person. By examining the influence of social, cultural and medical discourses that are intertwined with this syndrome, we can better understand how disorders are constructed and treated (Amiri et al., 2014).

In recent years, PCOS has become a very common ‘disease’ in India, where every one in five women has it (Pruthi,2019), but it is still a condition most people are not aware of and has been less explored in research initiatives. The high incidence of PCOS among Indian women was one of the primary reasons why this exploratory research focused on their experiences. Global literature on PCOS is heavily dominated by quantitative studies. In contrast, this qualitative research aims to get a more nuanced knowledge of the experiences of Indian and Indo-Canadian women with PCOS living in Edmonton by examining how women identify their bodies in response to living with a gendered disease. Previous qualitative studies on PCOS have mostly focused on symptom manifestations and examined how they have impacted the illness experience.

In this study, I explore illness experience with regards to symptoms but also illuminate treatment approaches and perspectives to understand the reasons why women go through treatments, whether and why they prefer certain forms of treatments or if they are challenging conventional forms of the same. Building on previous research done on PCOS that has focused on experiences of women, it will try to explore how ‘health’ is connected with the construction of a 'normative female body'. The driving question for my study is to understand how this condition is constructed as a femininity problem under the label of a health concern.

The research questions are as follows-

- What are the treatments Indo- Canadian women prefer with regards to PCOS?
- How do these preferences arise from their lived experience of PCOS?
- Do these preferences and experiences connect to the broader biomedical and socio-cultural ideals of femininity? If so, how?

To answer these research questions, I used *stigma* (Goffman, 1959) as the primary theoretical lens in this study. I wanted to understand how stigma is intertwined in my participants’ lives and how it influences women’s approach to this condition and treatment pathways. To explore the stigma management practices and treatment preferences of my participants, I have used *intelligibility* (Butler, 1999, 2004) as a guiding conceptual framework that explains how women with PCOS try to 'fit in' through their attempts to have the normative female body and become culturally intelligible. I wanted to understand how these attempts are connected to biomedical and socio-cultural ideals of femininity. Furthermore, I connected these concepts with *medicalization* (Foucault, 1973, 1980) which again explains the diseasing and correction of PCOS bodies and also captures women's experiences in medical settings where these ideals are reified. I expand and discuss these concepts in chapter three, where I introduce my theoretical lens.

The theoretical and conceptual framework that I applied in this research builds on previous literature on PCOS. I mainly reviewed qualitative studies that focus on women's lived experiences. However, unlike past literature that has mostly engaged with PCOS symptoms, this study relates symptom experiences with treatment preferences to understand how the ideals of femininity are intricately connected with this health condition.

I conducted qualitative in-depth interviews, one focus group, and a body mapping exercise to collect data based on feminist narrative research (Clandinin & Connelly, 2000; Cresswell, 2013). I focused on the body as the central component of our involvement with and understanding of the world, with an emphasis on the body as lived and experienced. I have engaged with the narratives and experiences of eighteen Indo-Canadian women with PCOS (age category 18-30 years) living in Edmonton as reflecting both their own subjective experience and the larger social experiences of living with this condition. I see these experiences as representative not only of gendered experiences but also of broader patterns in approaches to treatment and management. I further elaborate about my methodology in the second part of chapter three.

By elevating the voices of these women, the research aims to portray the complex realities of women living with PCOS, emphasising the junction of medical, social, and emotional aspects of their life. In the end, I hope that this work will help create a more inclusive and supportive atmosphere for people who are impacted by PCOS by raising awareness and understanding of the condition. This thesis seeks to both inform and motivate changes in the way that PCOS is understood and treated in the medical community as well as in the society at large.

Overview of Chapters

This thesis consists of six chapters. Chapter 2 outlines literature on qualitative studies on PCOS and presents rationale for the focus of this study.

In Chapter 3, I review my theoretical framework, discuss my guiding conceptual lens, and outline my methodological approach and my methods of inquiry. This study calls on three forms of qualitative data—in-depth interviews, a focus group discussion and body maps which have been thematically analyzed. The findings of this research are structured into three chapters.

The fourth chapter presents and discusses the body mapping exercise and how the participants categorized and expressed their embodied experience of PCOS. The main observations from the body maps serve as references for the other findings chapters.

In Chapters 5 and 6, I analyze dominant findings related to the concepts of theoretical interest. In particular, Chapter 5 addresses the concept of stigma and intelligibility and shows how for women, struggles with PCOS are mainly struggles to be a woman. It focuses on how ‘’being a woman’’ is an integral element of these women’s lived experience of this condition. It expands on how women associate an ideal female body as a healthy body when it comes to PCOS and elaborates on their intimate embodied insecurities.

Chapter 6 deals with the other important element of their PCOS journey, the treatment aspect of the PCOS experience and explores the other themes and two specific narratives that were prominent in the process of data collection and analysis. In juxtaposition to Chapter 5, Chapter 6 highlights narratives of symptom and health preferences with regards to PCOS, drawing on narratives of stigma management, medical encounters and patient blaming. It also explores treatment narratives that build on themes from the findings.

And finally, in Chapter 7, I summarize findings and discuss how the study addresses the objectives and discuss the study's practical contributions. These findings from this study explicitly includes women's voices and provides insight into the aspects of culture, health and femininity.

CHAPTER II

Literature Review

Initially, studies on PCOS were conducted from a medical framework starting in 1990, with one of the first multidisciplinary attempts by the National Institutes of Health (NIH) in the United States to establish an official medical framework for PCOS. The agency's main objective was to establish diagnostic criteria to facilitate diagnosis and treatment (NIH, 2012). Most studies since then focused more on the incidence of symptoms, risk factors and other health concerns. Medical research on PCOS has focused on identifying the condition (Azziz et al., 2006), understanding its aetiology and pathophysiology (Chen et al., 2011; Sirmans & Pate, 2016), and developing symptom alleviation interventions (Badawy & Elnashar, 2011; Goodman, et al., 2015). Medical literature's perspective on PCOS, and indeed any ailment, has always been limited to the body's biological components. This covers bodily organs, systems, and activities, including the ovaries, hormones, skin, hair, menstrual cycles, and pregnancy, but it mostly ignores the existence of health and disease outside of the body (Harari, 2001).

My study is qualitative and builds on previous research that concentrates more on women's voices in understanding what living with PCOS looks like. This literature review focuses on qualitative studies since the aim is to situate this study amongst research that tries to explore PCOS not only as a disorder but as a condition that impacts women's lives in and beyond their bodies.

In this chapter, I discuss some of those qualitative studies and the aspects of lived experiences the authors address in them. Most of these studies focus on symptoms that challenge notions of femaleness and expand on how women feel isolated. Some studies focused on women's issues with body image, elaborating on symptoms that affected women's physical appearance and talking about how hirsutism, body weight and acne have made women question themselves. The other issue that came up in studies was problems with fertility; women shared their insecurities about not having reproductive capacities due to this condition.

I also address literature that deals with women's experience with medical doctors and physicians to relate how perceptions about PCOS and treatment in the medical world fails to include women's experiences and reproduces hegemonic ideas of women's bodies. In general, all the studies found that based on interactions and bodily experiences, symptoms of PCOS affect women's sense of gender identity.

Research on physical symptoms

Studies that focus on physical symptoms of PCOS mostly observed that participants were always concerned about their appearance as a woman. Research on experiences associated with hirsutism all brought up that body and facial hair led to social isolation and rejection by intimate partners and people around the participants. Warfield and Sherer's (1965) in their study on hirsutism in PCOS-affected women observed that some aspects of women's bodies and behaviours were seen as masculine. Interviewees shared that they frequently had to shave every day, that their pubic hair and tiny breasts "was of masculine distribution," (p. 96). Similarly, Money and Clopper (1974) also stated that women who had hirsutism (symptom of PCOS) were preoccupied with restoring a feminine (hair-free) appearance (Money and Clopper, 1974). Pfister and Rømer (2017) also noted that women in their study expressed that they feel more feminine when they remove their body hair and adhere to femininity norms, as they perceive the hairless body as a symbol of "proper" femininity. (p.180). According to research conducted by Keegan et al. (2003), women who had excessive hair growth experienced substantial distress and humiliation, which resulted in social withdrawal and a negative self-image. Feelings of inferiority and diminished femininity were made worse by the stigma attached to hirsutism-something that was considered unwomanly.

Another important feminist study on hirsutism was done by Kitzinger and Willmott (2002) who conducted and examined interviews with women with PCOS in the UK and how they negotiated their identities. They concluded that women with PCOS were "challenged in their perceptions of themselves as feminine and as women" because of issues with hirsutism, irregular menstruation, and infertility (p. 358). In order to acquire a hairless and thin figure, these women engaged in hair removal and training regimens. "Constructing the accomplishment of the culturally mandated body as a choice, supports the assumption that appearance can be controlled" (Kitzinger & Willmott, 2002, p. 358). These women tried to conform to the socially prescribed standards of femininity by resorting to strategies by hiding the manifestations of this condition, in this case, hirsutism. This study specifically demonstrated the power of a single PCOS symptom as well as the complexity of the body's experience with a visible symptom.

Acne was another major physical symptom that led to stigmatization and became a source of distress for women with PCOS. A study undertaken by Scaruffi et al. (2014) revealed that acne was not only a cosmetic problem but also a source of emotional distress for women with PCOS. Women often felt stigmatized and reported to be less confident due to persistent acne, leading to a negative impact on their quality of life. They felt that they were not attractive anymore and were actively resorting to strategies to conceal their acne. Acne-prone women with PCOS frequently experience feelings of self-consciousness and anxiety around their appearance. Their social life and relationships are profoundly impacted by it which causes humiliation and a desire to retreat from being rejected and stigmatized in social situations (Dewani et al., 2023).

Weiss and Bulmer (2011) in their study, noted how women often experience the feeling of loss of feminine qualities and attraction as a result of manifestation of this condition- such as hirsutism, acne, and other symptoms, lowering their self-esteem and physical comfort, as well as significantly impacting their mental health. The association between PCOS symptoms, low self-esteem, and compromised mental health was also explored in a research study by Karacan et al. (2014). Zaikova (2021) argued that women with PCOS frequently have problems with body image, stigma associated with obesity, embarrassment related to overt symptoms and characteristics of body dysmorphia. The latter is crucial as it can be extremely difficult for many PCOS-affected women to reduce weight and acquire a more "normal" body shape (Louwers & Laven, 2020). Researchers overall have hypothesized that the degree of body satisfaction experienced by those with PCOS could be negatively impacted by symptoms such hirsutism, acne-prone skin, and higher deposits of abdominal fat.

Samardzic et al. (2021) identified three themes that pertain to how young women with PCOS place themselves in respect to Western notions of femininity which corresponded to "being thin, hairless and able to reproduce". The themes were- "justifying abnormality" which focused on women's experiences managing and explaining their physical changes. The second theme was "pathologizing the abnormal", which examined how participants pathologize physical characteristics of PCOS that, in their opinion, deviate from the norms of femininity and normality. The last theme was a dread of miscarriage, which included worries about future relationships as well as women's anxieties of PCOS-related infertility.

Research on menstruation and fertility

Menstruation and fertility are very significant aspects of PCOS that came up in different qualitative studies. As previously mentioned, many studies discussed physical symptoms that affected women’s appearance and how women question their identity with regards to their “unfeminine” features. However, women were also extremely concerned if there were menstrual problems. They either felt different from other women or were worried that their present issues with menstruation may affect their fertility in the future, since regular menstruation is one of the essential definitive elements of a female body (Hennegan et al.,2019). Snyder (2006) investigated the life experiences of American women who had been diagnosed with PCOS. She also discovered that her interviewees believed their PCOS symptoms made them different from other females. The participants said that they had always yearned to be "normal," which they defined as having a regular menstrual cycle and seeming more feminine (Snyder, 2006). Meyer and Zerssen (1960), from their study, claimed that women with polycystic ovaries had a deep-seated uneasiness about a feminine sex role.

Menstruation was an important part of the lived experiences of women with PCOS in terms of their role and identity. Menstrual periods that are irregular, or non-existent have a substantial influence on the physical, emotional, and social life of women with PCOS. In Kitzinger and Willmott’s study, the majority of women discussed not feeling normal, about a sense of separation brought on by irregular or non-existent periods. On the other hand, women in the study by Morris et al. (2016) shared that the unpredictable nature of their menstrual cycles caused anxiety and concerns over long-term fertility. Sharma and Mishra (2018) also discussed the profound alienation of women with PCOS in India. The syndrome's close relationship to highly taboo subjects in the nation's prevailing cultural narrative—that is, the idea that talking about one's period is unclean—contributes to the topic's lack of presence in Indian society, making women who have this condition experience stigma at different levels. Kitzinger and Willmott's (2002) research also pointed out that irregular or absent periods contributed to feelings of inadequacy and a diminished sense of womanhood for their participants. The study highlighted that menstrual irregularities make women feel less feminine and more anxious about their future fertility.

Fertility was a major theme in Mishra and Sharma's study on Indian women where they concluded that women who were married but unable to have children frequently felt incomplete. Except for those who had previously given birth, all the married women felt inadequate since they had never experienced parenthood. The women who were getting married immediately expressed that they did not want to experience infertility in the near future, which is why they were seeking PCOS treatment (Mishra & Sharma, 2022). Infertility was also a primary aspect in women's illness experience in Pathak's (2015) study. She pointed out that women's relationships and mental health were severely impacted by present and future infertility. These women also went through medical treatments to cure it which added yet another layer of stress and emotional upheaval. Soucie et al. (2021) stated that the narratives of Canadian women in Ontario brought out the physicians' reluctance to take women's concerns seriously unless fertility was at stake again stems from a worldview in which women's value is limited to motherhood. A similar observation was made by Samardzic et al. (2021). They discovered that women in their study emphasized obtaining an intimate partner as a crucial objective for marriage or long-term commitment. Having PCOS presents a barrier since it may prevent someone from getting married if they are unable to become pregnant. In all these research initiatives, women were more concerned about their identity as a woman.

Research on medical encounters and treatment

The literature I have engaged with until now were more focused on women's interactions and behaviour in their daily lives and relationships. However, other research concentrates on the power dynamics that exist between women with PCOS and their doctors and how these dynamics in turn influence the illness experience. There is substantial evidence indicating that physicians often dismiss women's symptoms in gendered ways, leading many women to struggle to be taken seriously (c.f.,Young et al., 2019). With regards to PCOS, literature shows that as a condition which is essentially gendered and medicalized, women’s experiences, concerns and credibility become discounted because they are not important to the already determined factors in health discourses.

In their study on young Canadian women, Samardzic et al. (2021) found out that young women’s perspectives about their PCOS experience were not given much importance by their physicians. Women were asked to not worry about the condition and the symptoms and brushed off their concerns by indicating that they were young. The difference between PCOS in medical practice and PCOS in life and experience is highlighted in Ellerman's (2012) thesis, ‘’Don't Blame it on My Ovaries: Exploring the Lived Experience of Women with Polycystic Ovarian Syndrome.’’ She ascribes this gap to patriarchal systems' suppression of women's personal accounts of their experiences and proposes a more holistic approach to women’s health disorders, where focus should be on the person and not only on the body.

Other studies exposed how a sense of blame and responsibility was projected on women by physicians, especially in the area of body size. According to Soucie. et al (2022), women with PCOS are frequently advised to modify their lifestyles to control their symptoms, such as weight gain, but they are also shamed for their weight (e.g., “you're going to be a whale”; Soucie et al., 2021a, p. 5) or held accountable for their weight gain without taking into account the genetic, social, political, and economic factors that limit a woman's ability to control her weight. Hiselein and Thatcher (2006) reported that many women who were advised to lose weight received no assistance or minimal guidance from their physician – something that becomes even more crucial when one's insulin resistance can make weight loss challenging to achieve. Humphreys and Costarelli (2008) found that doctors frequently provided inadequate support in helping their PCOS patients lose weight. Nevertheless, recommendations for weight management in people with PCOS were frequently worded to convey the idea that reducing weight is a simple, straightforward procedure and a responsibility that they should fulfil to ensure they remain healthy and fertile.

Soucie et al. (2023) in their research noted that practitioners dismissed how patients felt about treatment and always prescribed “certain forms of treatment as a one-size-fits-all approach (e.g., birth control, metformin)’’ irrespective of how these impacted women and their body (p. 95).

Another study that elaborated on how the control of medical authority and biomedicine ignored patient’s perspectives was Smith-Tran’s research. Her article on PCOS was filled with firsthand knowledge based on autoethnography. She highlighted the distress of learning that one had a chronic illness and the subsequent feeling of losing power and control over one's body. In her research, she critiques conventional biomedicine and medical therapies and advocates for discussing personalised management techniques and redefining exercise as medicine (Smith-Tran, 2018).

Comparing Discourses about PCOS

On one hand, research on PCOS in Indian women shows how PCOS is primarily associated with fertility and reproductive concerns. On the other hand, Western studies focus more on symptoms like hirsutism and obesity, which are more appearance based.

In her article, ‘’Bearding, Balding and Infertile: Polycystic Ovary Syndrome (PCOS) and Nationalist Discourse in India’’, Buddhavarapu (2020) also shows how leading newspapers in India have associated infertility as the main problem, when it comes to PCOS. While Indiatimes described PCOS as "the leading cause of infertility" in women, the Indian Express described PCOS as a hormonal disorder that causes "difficulties in conceiving" (Moghul 2015; The Indian Express 2015). According to The Times of India (Unnithan, 2015), PCOS is "a very prevalent reproductive disorder" (Buddhavarapu, 2020, p.419). Buddhavarapu (2020) in her study argued that infertility is a significant effect of PCOS, which presents a significant obstacle for patients attempting to conceive. However, the public focus on infertility in India as the primary cause of the condition is not only a result of hypercritical, hysterical fixation with the female body, but also reproduces it. Pathak and Nichter in their study expand on the how approach towards PCOS is based on the fact that ‘’irregular menstrual cycles and subfertility have long been of considerable concern in India.’’ (2015, p.22).

When it comes to Western studies on PCOS, there has been concentration on physical symptoms like hirsutism, acne and overweight, which expose Western discourses highlighting what the ideal female appearance should be like. In the West, it is often accepted that notions of beauty and attractiveness influence desire, and that overweight women are inherently unwanted (Gailey, 2012). For instance, Harris (1990) discovered that people perceived overweight women as nonsexual and worthy of a more ugly and fatter sexual partner. They also believed that fat women were less beautiful, less likely to date, and had worse self-esteem. According to previous research, women in Western cultures are under a lot of societal pressure to get rid of "unwanted" body hair and typically aspire for a hairless body (Toerien et al., 2005, p. 399). Thus, it appears that in modern Western societies, having no hair is the standard and a sign of femininity (Toerien

& Wilkinson, 2003, 2004). Similarly, women in Morotti et al.'s study PCOS found it difficult to conform to the ideals of bodily attractiveness set by society and the media. It is common for the patients' perceived ‘’unattractiveness’’ to result in sadness, a loss of feminine identity, and restrictions on their emotional health, life satisfaction, and quality of life. Participants expanded that the PCOS diagnosis negatively affected their sense of self-worth (Morotti et al., 2013).

My study focuses on Indian women and Indo-Canadian women living in Canada to understand the similarities and differences in the discourse on PCOS and whether different cultural backgrounds affect the ways women perceive and experience the condition. As seen in the literature, the question of femaleness, femininity and womanhood came up through the symptomatic experiences of PCOS. Inspired by the literature review, I wanted to explore the common themes that came up, especially feminine appearance, fertility and treatment. For my research, I examine how these themes were viewed by my participants in relation to their gender identity (see Appendix A). My study also brings out the various reasons behind treatment decisions of women and explores how medical discourses and socio-cultural ideas associated with this condition influence women and particular notions of femininity.

CHAPTER III

Theoretical Framework and Methodology

In this chapter, I outline my theoretical framework and methodology that is based on my research questions. In the first part of this chapter, I describe the theoretical foundation of my research and how I have incorporated guiding concepts to help frame my interview questions and my findings. In the second part, I discuss my methodology and expand on my methods of recruitment, data collection and analysis. After a critical review of past studies on lived experiences of PCOS, I shift focus to one of the primary goals of this project, which is to gain a more nuanced understanding of the experiences of Indo-Canadian women with PCOS by investigating how women characterise their bodies in response to living with a gendered illness.

Theoretical Framework

The theoretical structure in this study was influenced by a social constructionist understanding. It was based on a feminist framework focused on gender and bodies. My conceptual framework consists of three theories- theories of stigma are the central framework for my study, which I connect with theories on intelligibility and medicalization.

Primary lens: Stigma

Social constructionism posits that social interactions and social processes shape how we see the world. In this perspective, ideas, classifications, and standards are produced and preserved by society (Berger & Luckmann, 1966). This approach places a strong emphasis on how language, society, and institutions shape our perceptions and understanding of the world. For this study, I adopt a social constructionist understanding of stigma as developed by Erving Goffman. Theories of social construction in general assert that some medical conditions are culturally rooted and socially built at the experiential level, and medical knowledge is likewise socially constructed in a way that reflects gender, class, race, and ethnic disparities (Khan & MacEachen, 2021). Goffman’s concepts of stigma represent the idea of expectations and standards of conduct and appearance that are attached to bodies. He explains how these indicate identity in a static manner; how they are heavily stereotyped and stigmatized in accordance with societal categories such as gender, ethnicity, class, ability, etc. (Goffman, 1959). Stigma and social construction with regards to illness, has three constructs- the cultural meaning of disorders, illness experience as socially built, and medical knowledge as socially produced (Conrad & Barker, 2010). The cultural meanings of illness are again based on two premises: illness has both a physiological and an experience element, and these elements function independently of one another, and some conditions have social or cultural meanings, which influence the illness experience and treatment as well.

The concepts of stigma and social construction are related, the former is a characteristic of the construction and idealization of the idea of a ‘normal’. The social constructionist lens views gender to be ‘’created through interpersonal interpretation of action’’ (Elson, 2004, p. 8). Currie and Raoul (1992) assert, “Women’s most private and personal experience—their relationship to their bodies—is mediated by cultural and political processes” (p. 25). Indian culture see menstruation and fertility as taboo subjects, and when a woman's body deviates from the accepted norms of form, look, and function, such as during pregnancy and fertility, there is a fear of stigmatization, especially for those who are non-normatively embodied (Pathak, 2015). Prior research on reproductive disorders have indicated that stigmas may have detrimental effects, such as stigmatised social identities, biases, stereotypes, and other sorts of discrimination (Miller & Kaiser, 2001). Saucier and Caron's (2008) study related Goffman's concept on stigma to highlight how women with PCOS navigate a stigmatized identity in their daily lives, facing negative judgments in their social interactions.

Sharma and Mishra (2017) in their study on women with PCOS, also used Goffman’s concept of stigma and contended that women are stigmatised because of socially manufactured meanings that force them to conceal diseases and conditions unique to women, as the public disclosure of biological processes that are special to women undermines societal morality. People with PCOS struggle with the diagnosis based on the idea of going back to a normal, healthy female body or seeking help owing to stigma surrounding appearance, menstruation, infertility, and chronic health concerns. Pathak (2015) in her study on Indian women with PCOS argued that her participants talked about the condition in more emotive terms and stated that the health aspect of the condition was not as much difficult and upsetting as the stigmatization they had to face. She stated that women expressed their efforts to conceal the fact that they had PCOS and worked on managing it.

In line with Goffman's theory that explains how stigma may result in a spoilt identity and negatively affect social connections, Kudesia et al. (2013), also observed that internal and external stigma experienced by women with PCOS impacted their self-identification and social interactions.

Liora Moriel, a queer theorist, developed Goffman’s ideas on stigma and stated that "passing" is the deliberate process of moving from the "margin to mainstream," involving complex survival strategies or attempts to become culturally intelligible, that may benefit both the individual and the community (Moriel, 2005, p.170). Through her work, Moriel aims to deepen our understanding of how identities are created and interpreted, as well as how people manage and negotiate them within intricate social contexts. Keegan et al. (2003) found that their interviewees who had PCOS, used "passing" strategies to minimise and conceal the obvious symptoms of PCOS and function well in social settings. They also avoided social situations that would expose their bodies or interfere with their depilatory routines.

For PCOS, gender identity becomes integral because the condition impacts external and internal characteristics of the female body. Stigma is a widely recognised barrier to social acceptability, health-seeking behaviour, and treatment decisions and adherence for a variety of health disorders (Corrigan, 2004). I use stigma as a conceptual lens to understand all of these, to connect the intricate realities of my participant's lived realities to larger discourses about health and gender.

Guiding framework: Intelligibility and Medicalization

Connecting Goffman's concepts on ''stigma'' I use Judith Butler's' ''cultural intelligibility'' as a guiding conceptual framework to reflect how women negotiate their gender identities as a part of the stigma management process and how they are using treatments to conform to femininity norms.

Butler claims that gender or sex differences are the foundations on which the body is understood connected with societal definitions and interpretations of its function and representation (Butler, 2004). She talks about how interactions lead to body structures, organs and their purpose to get predetermined through construction and reproduction of norms and meanings. According to Butler (1990), the term ''heterosexual matrix'' refers to the cultural and social structure that creates a consistent and normative framework between sex (biological traits), gender (social roles), and desire (sexual orientation). This matrix assumes that there is a binary difference between the sexes, which correlates to binary gender roles. Only by gendering themselves in accordance with recognized criteria of this matrix are individuals capable of becoming intelligible (Butler, 1999). “It is through the body that gender and sexuality become exposed to others, implicated in social processes, inscribed by cultural norms, and apprehended in their social meanings.” (Butler,2004, p. 20).

In Perram's (2017) study, she examined how women with PCOS perpetuate conventional conceptions of femininity through their life narratives in online health forums. She refers to Butler’s theory on gender regulation and argues that the physiological and performative shapes that gender adopts are directly exemplified by treatments for PCOS in women that try to suppress "male" hormones. The gender binary is produced and normalised by social and medical demands to seem more "feminine" and to avoid symptoms that are perceived as "masculine." She writes, ‘’women are held to a standard of femininity that they are clearly not meeting, and in response the only offered solution from the medical community is to chemically and procedurally alter their bodies until the feminine standard is reached.’’ (Perram, 2017, p.9). Similarly, Pfister and Romer (2016) use Butler’s concept on ‘’performativity’’ to understand how women with PCOS struggle to negotiate their gender identity through regulatory practices. They also point out that women with PCOS ‘’might also challenge the heterosexual matrix by doing gender in a different way than the norm.’’ (p. 172).

The body is exposed to processes of doing and undoing, in both inner and outer dimensions which shows how bodies are not completely our own and also belong to the social sphere (Connell,1985). PCOS bodies are treated to deal with two specific kinds of symptoms - ones that are visible to everyone and ones that are internal and relational. Hormonal treatments are directed to treat internal symptoms that ensure the body’s hormonal functionality. Other techniques focus on women’s external appearance. Butler states that she does not “mean to suggest that purely cultural signs produce a material body, but only that the body does not become sexually readable without those signs, and that those signs are irreducibly cultural and material at once” (Butler, 2004, p. 87).

Butler poses a question, or more specifically calls it ‘’a question for ethics’’, when one considers not only what makes their own life bearable but also what makes the lives of others bearable - which illustrates how she conceptualizes that bodies are not entirely our own and also belong to the social sphere (Butler, 2004, p 17). The body becomes a social reality which is not only a medium that is used to adapt to the current socio-political and economic conditions but also is used to maintain medicalized and essentialist ideas of female bodies based on the concept of ‘futuristic motherhood’ and fertility (Irni, 2017).

Even if the intelligibility of the female body is coherent on the outside (congruent with social norms and expectations), the ‘essence’ of femininity still needs to be protected internally- women have to maintain their reproductive and hormonal functionality even if their outward appearance is coherent with the ideal imagery. In this study, Butler’s concepts were utilized to understand the behaviours, experiences and decisions of women with PCOS based on stigma management. Butler’s ideas on ‘’cultural intelligibility’’ was utilized as a lens to understand if and how the women are navigating through culturally specific ideals of femininity. The existing discourse on middle-class Indian femininity or respectable femininity shows how the ‘liberal’ Indian woman still conforms to traditional ideas of purity and domesticity (Radhakrishnan, 2009). The very hormonal treatment that seeks to empower these women by giving them control over their bodies, is used to make them feminine, fertile and intelligible. Ussher et al. (2017) talks about how migrant and refugee women’s sexual embodiment can be shaped through the conflict between norms and discourses in their country of origin and the country they moved to. Similarly, my study will also include Indian women who have migrated to Canada to analyze how discourses of these distinct countries affect their navigation through embodiment and treatment decisions, reflecting how these women try to be socially and culturally intelligible.

Michel Foucault’s concept of medicalization was also used to understand the construction of disease and how medical discourses control women’s bodies, and are related to stigma management, as a guiding framework to my central theoretical lens of stigma. The female’s dehumanization as an object of investigation, to be detached, inspected, investigated, scrutinized, and labelled, is the foundation on which medical knowledge powers over women’s bodies through the medicalization of the same (Foucault, 1973). The "modality of docility," as described by Foucault (1995), implies "an unbroken, persistent compulsion, overseeing the processes of the action rather than its product," (p. 137).

By instruments of femininity and medical management, women with PCOS are therefore persistently forced into surveillance and management of their bodies. Their bodies have been ‘objects’ that need to fit the society’s construction of how women’s bodies should be- carriers of children only functional for procreation. Foucault extensively argued on how knowledge emanating from social relationships and interaction implicitly promote behaviours, relationships and beliefs that lead to creation of discourses in society. These discourses are enhanced by various forms of regulatory processes that ensure that the people conform to them (Frank, 2020).

The authority to determine what is ‘’healthy/unhealthy’’ and, more significantly, what is "normal" is exercised by institutional powers like the medical establishment. In the past, social deviation has been linked to sickness and illness (Turner & Samson, 1995). Because of this, women find themselves in what Sherwin refers to as "many double binds" in terms of the standards pertaining to health hand disease- their identities and bodies get attached with constructs of being unfeminine, unhealthy or diseased, unattractive and infertile (Sherwin,1992,

p. 179). Ellerman (2012) in her study refers to medicalization to relate how women with PCOS feel the pressure and compulsion to have children in the future and are prepared to go through all sorts of medication and intervention for the same in the present.

According to Foucault’s theory on medicalization, power moves via "the whole social body down to its smallest particles," (Foucault, 1980, 156). He states that the body, which is the site where smallest social practices converge, interconnect, and relate to more significant organizations of power. Power is often regulatory and order-maintaining in terms of norms, codes, and rules through which the social organization is created and perpetuated. The "normalizing gaze" is always at work in an ongoing assessment of one's conformity, whether it comes from other people or from one's own self-normalization. Women with PCOS are often exposed to this normalizing gaze- on one hand they get stigmatized because of visible symptoms or the diagnosis and on the other hand they self-regulate their bodies through different cosmetic or medical solutions.

Hancock (2018) expanded on his theory and states that medicalized power functions as a kind of social control over the body. According to Lupton (1997), criticisms of medicalization have historically highlighted the following points: medicine now plays a role in social regulation; it can actually worsen patients' health rather than improve it; an increasing number of social problems are being medicalized; and a dependency cycle is created. She points out. ‘’ Feminist critics have viewed the medical profession as a largely patriarchal institution that used definitions of illness and disease to maintain the relative inequality of woman by drawing attention to their weakness and susceptibility to illness and by taking control over areas of women’s lives.’’ (p. 96). For instance, PCOS bodies are exposed to regulation wherein the conventional treatment consists of inducing artificial hormones into the body. There are significant side effects to these medicines, however women still consume them to control any form of masculine manifestations.

According to Samardzic et al. (2021), women who have PCOS actively do "body work" (p. 572) as a means of aligning to social norms. They contend that having a chronic illness such as PCOS, whose symptoms are not curable permanently and go against social norms, makes life more challenging for women. To attain and maintain the boundaries of conventional femininity, women conform to strict norms and gendered and medicalized discourses about their bodies (Chrisler, 2013). Keegan et al. (2003) in their study state, “Through self-surveillance and correction to such norms, and the regulation of bodies through body practices such as depilatory regimes, women are rendered less socially oriented and more focused on self-modification” (p. 338). McKellar (2015) claims that because of the blurring of the boundaries between what is considered ‘’normal’’ and ‘’disorders,’’ the rise in the medicalization is problematic. This shows that individuals are not just becoming consumers of a market culture that is centred on health and self-medicalizing in daily life, but also that the spectrum of what is regarded acceptable is being narrowed. Conrad (2007) says, “the great danger here is that transforming all difference into pathology diminishes our tolerance for and appreciation of the diversity of human life” (p. 148).

The likelihood of being othered and likely characterised as disordered and/or in need of modification and control increases (e.g., Bartky, 1997; Shildrick, 1997). However, although women take charge of how they want to alter their PCOS symptoms, they still comply with these standards, which is how the neoliberal subject is controlled in the present world.

Butler-Wall (2012) discusses Foucault's idea of individual autonomy, where he suggests that a person's freedom is connected with self-care and self-management efforts. She further discusses that while the individual is considered a free subject, they are continuously influenced by ‘’government rationality’’ (Foucault, 1991, p. 9) and ideology, leading them to act in socially conditioned ways. The state leverages the notion of freedom to establish conditions that shape subjectivity and govern control. Rose (1996) synthesizes Foucault's conceptions of biopower, addressing both the discipline of people and the administration of populations, in his article included in the edited collection Foucault and Political Reason: Liberalism, Neoliberalism and Rationalities of Government- ‘’The two, apparently, poles of ‘power over life’ that Foucault identifies- the disciplines of the body and the bio-politics of the population- thus find their place within liberal mentalities of rule, as rule becomes dependent upon ways of rendering intelligible and practicable these vital conditions for the production and government of a polity of free citizens.’’ (p. 44).

Women with PCOS supposedly have agency to alter their bodies with medicines and other technologies but this agency is an illusion, since they are unconsciously perpetuating existing social standards about the female body which is essentially medicalized and gendered. Bartky (1990) states that according to Foucault, the mechanisms of power have changed, they are not limited to institutional structures and mechanisms of surveillance. Power and its consequences now permeate more subtle channels and affect people directly—their bodies, their gestures, and everyday behaviour. Within a neoliberal context, Crawford talks about the idea of responsibilization that highlights the individual's duty for controlling their health and well-being (Crawford, 2006). This shows up as the assumption that women with PCOS will have to be able to control their illness on their own by altering their body or their lifestyle (Pathak, 2015). Women with PCOS internalize gendered and medicalized ideals and expectations, which lead them to control their symptoms through personal effort and are also often victims of blaming if they struggle to manage their condition. This mirrors the neoliberal emphasis on personal responsibility (Griffiths & Bentley, 2018).

The idea that the female body is not viewed as solely a biological truth, but as a social condition which is dominated by medical definitions of what it is to be a woman, was used as a reference point to explore the treatment seeking behaviours of the women in this study, to bring out how they have internalized them.

Methodology

This qualitative study was informed by a narrative research approach combined with aspects of feminist methodology. By giving voice to women's bodily experience, it served as a platform for feminist research techniques and, in the process, produced experiential knowledge that might broaden this particular area of study. Echoing Scott, this study believes that "Experience is at once always already an interpretation and something that needs to be interpreted" (1991, p. 797). In this approach, narratives were about lived experiences of PCOS to understand how the condition is intertwined with their lives, through their stories. I used this methodology to organize my participant's stories into a coherent framework, often integrating elements like cultural contexts, health and gender discourses (Creswell, 2013).

Narrative studies in general shed light on interpersonal relationships, societal morals, perceived role obligation, and other perspectives on identity. Narratives describe individual experiences, and may reveal people's identities and perspectives about themselves, where the narratives become the raw data (Cresswell, 2013). I focused in particular on the ways that personal narratives might be utilized to comprehend the experience of a health condition. Smith (1999) points out that "storytelling is a useful and culturally appropriate way of representing the diversities of truth within which the story teller rather than the research retains control" (p. 145).

Similarly, I studied how identity conflicts, stigma, and treatment choices are created as distinctive parts of the PCOS experience with a focus on the personal narratives and perceptions obtained through interviews and focus group discussions (Jarvis, 2021). In its most basic form, narrative inquiry starts ‘’with experience as expressed in lived and told stories’’ and employs narrative as a research methodological tool (Clandinin & Connelly, 2000, p. 40). Narratives of the participants helped me understand “socially situated interactions that are embedded in interpersonal, cultural, institutional, and historical contexts” (Chase, 2018, p. 547). Jones (2016) argued that despite not being exclusively a feminist technique, narrative inquiry may be utilised as a tool to critically engage feminist viewpoints and give researchers rich data that can challenge preconceived notions, voices and silence, and current knowledge. I specifically used narratives as a path to capture broader cultural and medical (western) discourses on PCOS and normative femininity and to critically examine how these discourses impact women. I used narratives to represent participant agency, voice, and perspective to encourage the value of participant experiences (Jones, 2016).

Feminist methodology varies from conventional research in terms of methodology in a specific way, it is politically motivated and it aims to alter social inequalities and actively works to eliminate the power gap between research and topic and the researcher and the subject (Cook & Fonow,1986). It led to more participatory interviews and discussions in this research, wherein knowledge of the participants was considered to be substantial, and the focus was on a non-hierarchical relationship between the researcher and participants (Eichler,1997).

Positionality

In feminist narrative approaches, reflexivity is one of the most important aspects of research. Reflexivity is the purposeful and conscious application of feminist knowledge to one's own life and scholarship (Allen, 2000). In researching gender and its interconnections, feminist reflexive practice continuously acknowledges the conflict between homogeneity and diversity, which ensures transparency.

I am a PCOS patient, myself and also an Indian woman, in the similar age category of my participants, currently living in Edmonton, Alberta. My experience with this syndrome has been one of learning and understanding, occasionally accompanied by frustration and fear, but overall, something that has helped to raise my consciousness about what women actually go through in relation to their own bodies and how they live with this disorder and navigate themselves in social interactions and healthcare systems.

To ensure transparency, I maintained my own research journal after focus group discussions and interviews to record my emotional engagements, to ensure my coding and analysis are not guided by my bias. There is a chance that researchers will occasionally explore and develop their own voices in an effort to reflect the voices of others (de Vault, 1999,). This can be addressed through emotionally charged research by challenging how researchers present their subjects, the issue of study, and themselves. Using this approach, my study was co-informed by both the intellect and the emotions.

Throughout the actual study process, researchers can be sensitive to their own emotional needs and experiences as well as those of the participants (Blakely, 2007). In this way, emotions are reconceived as a research instrument and a source of information that may be employed in the investigation and investigated. Narrative inquiry also aims to draw attention to presumptive beliefs by putting an emphasis on intentionality, and the meaningful connections individuals create in their interactions and experience (Sools, 2012). This approach also helped me better understand and address the taken-for-granted assumptions I have about this condition.

In response to the concern of being too close to this research topic, I would like to state that although scientific investigation has historically emphasized objectivity, personal experience is significant and has the potential to offer knowledge that simply cannot be obtained from unbiased study. This exploratory research sought to learn more about the participants' viewpoints, experiences, and ideas for the future, from their perspectives. There is no room for "conclusions" in the present study, but it does call for some afterthoughts (Merton, 1973, p. 559).

Methods

As part of my data collection instruments, I conducted in-depth face-to face semi-structured individual interviews (both in person and virtual) with participants, followed by a virtual focus group session (comprising six participants) with people who were not part of the interviews. ‘’In depth interviewing is an effective qualitative method for getting people to talk about their personal feelings, opinions, and experiences. It is also an opportunity to gain insight into how people interpret and order the world.’’ (Milena et al., 2008, p.1279). When conducting in-depth interviews, researchers often look for "deep" information -that is, knowledge that goes beyond what is typically found in focus groups, surveys, and informal interviews. Typically, this information relates to personal topics including a person's identity, life experiences, beliefs, and choices, as well as cultural knowledge or perspectives (Johnson & Rowlands, 2012). My method of conducting interviews was based on the idea that people's viewpoints and experiences are relevant and knowable, and that by building rapport and having well-structured talks, one may elucidate their "lived everyday world" (Patton, 2002; Kvale, 2007). The individual interviews were conducted based on an interview guide (Appendix B) that were guided by my research questions, in a semi-structured format. (Kvale, 2007)

A focus group interview can be defined as “a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment” (Krueger & Casey, 2009, p. 2). Focus groups are “especially useful as a complement to other methods of data collection for providing in-depth information in a relatively short period of time ‘’ (Gundumogula, 2020, p 299). The focus group in my research study focused on women’s experiences regarding the symptoms, treatments, and diagnosis and had follow-up questions based on the discussions, which were again based on the topics that were structured by me to be covered in those discussions. The focus group questions were also based on certain new topics or aspects that were not anticipated by me during my interviews. (Appendix E). The narratives of interview participants brought up interesting conversations on culture, menstruation and motherhood.

Seidman (2013) argues that “at the root of in-depth interviewing is an interest in understanding the lived experience of other people and the meaning they make of that experience.” (p. 9). I facilitated the focus group discussion, wherein questions or prompts were provided by me to help participants engage in discussions. The discussions were recorded and transcribed by me. Being a patient of PCOS myself, the findings from the semi-structured interview conversations helped me see new perspectives that I was not aware of, it brought out similarities and differences between the experiences of the participants and further helped me re-construct my focus group questions.

I also used a supplementary method of data collection through a short body mapping exercise. As a means of gathering data, the body mapping technique seeks to understand participants' experiences of their bodies, lives, and surrounding environment, as well as the significance they attach to these experiences (Coetzee et al., 2019; Dew et al., 2018; Lys et al., 2018). Since body mapping employs the medium of art production to extract and evaluate participant data, it is also sometimes referred to as an "art-based" research approach (Coetzee et al., 2019).

At the end of the interviews and the focus group, a body outline was given to the participants and they were asked to associate their PCOS experiences with their different body parts. They were informed that they had complete freedom to add onto the outline or even draw on it. They were asked to associate any kind of feelings, thoughts or memories they have with their bodies in terms of their PCOS journeys. This process provided the participants with the chance to understand the extent to which their bodily experience and their settings are connected. For some of the participants this activity helped them provide a more detailed account of their experiences than they could have with more conventional qualitative methodologies (Hartmann, 2022). For virtual interviews and the focus group, the outline was shared through a whiteboard on Zoom. Among the eighteen participants, only one participant did not do the body mapping exercise.

These methods of data collection (in-depth interviews, focus group and body maps) involved reflective discussions that helped both the participants and me to understand the meanings of the experiences they shared. Together these methods highlighted contextual factors, integrated physical experiences with emotions and social contexts, and connected visual and symbolic factors to verbal narratives. These techniques were used to increase the participants' engagement and to make the process of data collection more meaningful. By capturing the intricacy of dealing with a chronic disease through these methods, narratives in this study provided a deeper, more comprehensive knowledge of the experiences of the participants.

Sample

The sample included a total of 18 participants. As stated earlier, the study focused on Indian and Indo-Canadian women living in Canada within the age category of 20-30 years. I recruited Indian women in Edmonton, Alberta, to explore how discourses on PCOS and femininity in both the countries influence diagnosis, women's idea of the disorder, and how they make decisions regarding their treatment.

The age category helped bring out how different aspects of constructed ideas of femininity influence the experiences of women with PCOS who are in different phases of their lives. It included married or single women, working women from different professions, and students. I assumed that the diverse backgrounds might expose how this condition is viewed differently or similarly by these women and what aspects influence decision-making with regards to treatment. However, the sample focused on women who have been diagnosed with PCOS within the last ten years, to control for the diagnosis time period. Recruitment was done with the approval of the University of Alberta health clinic to reach out to women who have been diagnosed with PCOS. Apart from that, social media platforms like Facebook and Instagram were used for recruitment. Both purposive and snowball sampling strategies were used.

I interviewed twelve women for this study and conducted one focus group discussion consisting of six participants in the age range of 18-30 years. Most participants were recruited through posters on university campus buildings in Edmonton. Only two participants reached out to me through social media platforms (Instagram and Facebook). The educational backgrounds ranged from high-school diplomas to master's degrees. Ten participants were pursuing their undergraduate degrees, four women had completed their bachelors, two women were Master's students and the other two participants were pursuing their doctoral degrees. Although I did not specifically gather information on their academic endeavours, some of the fields of study that were mentioned during data collection included engineering, computing science, history, anthropology, psychology, education and philosophy.

Most women identified as immigrant Indians from various parts of the world (India, USA, UAE and Kenya) however, five of them identified themselves as Indo-Canadians, who were either born in Canada or have been living in Canada for most of their life and identified as Canadian citizens.

Analysis

Thematic analysis is a useful tool in narrative research since it allows researchers to methodically examine narrative content in order to identify underlying themes that arise from people's stories (Creswell & Poth, 2018). My analysis process started with "familiarisation". According to Braun & Clarke (2019), this process is vital to the process of analysis as it involves engaging deeply with the data. This is significant because it encourages the transition from inactive to active participation. All recorded interviews and the focus group discussion were transcribed. Data from the interviews were analyzed first to shape the focus group discussion. The familiarisation part of my study approach started with transcribing. I transcribed the interview recordings myself, making sure to review the transcripts afterward to make sure all the errors were fixed. I was able to fully immerse myself in it as I wrote the transcriptions of the data. I noted down any observations that struck me in my journal while I listened to my session recordings in order to become even more acquainted with the material. This included, but wasn't restricted to recurrent, typical events and topics that I wished to explore. Using the pictures of the body maps as a reference, I then re-examined the transcripts again. I tried to relate the labels used in the body maps with the interview and discussion data and noted down any similarities or connections my participants made.

Based on the transcripts and the body maps, I used thematic analysis to extract themes from the data, which included both open and axial coding. I first read and open-coded each interview transcript. Axial coding included drawing connections between the codes I had generated through open coding. This eventually helped me form a code book after which I formed categories based on emerging patterns in the data. This helped me group conceptually similar categories that I formed, into higher-level themes to structure my findings (Creswell, 2013).

The themes from both the interview conversations and the focus group discussions have been incorporated in my analysis. My research questions and my reflexivity in this research were the primary guides in the process of coding and analysis. The aim was to identify thematic patterns and similarities while also taking into consideration individual variations in experiences and background and personal narratives of being diagnosed and treated with this condition (Samardzic et al. 2021). The themes also helped me bring out the major narratives that came up in the process of data collection (McKellar, 2015). These narratives not only aided in connecting the experiences of the women but also in differentiating the ways in how they view themselves or the condition. I also followed the same process for coding when I analyzed the body mapping outlines. The outlines on the other hand gave the participants an opportunity to actually word out their bodily experiences and express their perspectives about their body. For me, this exercise was extremely significant since it helped with more in-depth discussion about the participants' bodies, their relationships and views on femininity.

Timeline

After gaining formal ethics approval for my research, I started recruiting participants in the month of August, 2023. I simultaneously conducted interviews and started my analysis. After finishing up with my interviews and analysis of data in the next few months, I conducted my focus group session in December, 2023 and finished my analysis of the discussion.

Ethical Considerations

Owing to the ethical considerations, the information and consent form (Appendix D and F) outlining the participants' rights to withdraw from the focus groups and the interviews was provided, which also specified their right to not respond to certain questions. Certain inquiries, about health problems, intimate relationships, treatment effects may cause the participants to relive unpleasant feelings. I had always focused on the participants' choice of which questions they chose to ignore in order to get around this possible problem. I also explained to them that if any of them felt uncomfortable during the process, they would be asked to take a break and discussion or the interviews would continue only if they wanted to. Informed consent was obtained from all the participants after being given a thorough explanation of the study, what will be studied, and about the interview goal (Chapter 3, TCPS2).

For the focus group, participants had to sign a confidentiality agreement to keep everything in the focus group confidential. The participants were given the opportunity to review the interview transcripts for clarification and to ensure fair representation of their interviews. Confidentiality and anonymity of participants has been strictly maintained, to protect all participants' privacy and identities (Chapter 5, TCPS2). Women participating in the process were also informed that the findings will be used for the researcher's educational advancement and then were given the choice to participate in the interviews and focus group discussion. The study was carried out based on a non-judgmental ground, wherein women were free to express their perspectives. All the participants were also informed about the positionality of the researcher, and their connection to the research topic.

CHAPTER IV

Mapping the PCOS body

''This is mostly just a chart of my insecurities''.

-Hrithika

In this chapter, I describe the body mapping exercise I conducted and present a few examples of body maps. The maps not only help understand how the women view their bodies in association to PCOS but will also serve as a frame of reference to the following chapters wherein I expand on the participants' narratives and statements. The following chapters build on this basic understanding of their intimate embodied insecurities and give us further understanding of the social and bio-medical discourses and relations in which these are experiences and understood. (See Appendix A for conceptual framework)

The purpose of the body maps was to depict the embodied subjectivity or lived experience of these women. I connected the body maps with two of my specific research questions:

1. How do these (treatment) preferences arise from their lived experience of PCOS?
2. Do these preferences and experiences connect to the broader biomedical and socio-cultural ideals of femininity? If so, how?

The subjectivity expressed in these body maps gave me a sense of how my participants characterise their bodies when it comes to PCOS. It helped me understand which parts of their embodied experience are most significant and which are related to their treatment preferences. The narratives associated with these maps exposed how these women compare their bodies with the existing ideals of the female body.

Through the creation of body maps, participants are able to visually represent stories about their experiences with the condition, their lives, and their bodies while also expressing and symbolizing their emotions. I deliberately chose to employ body maps in my research because they are a useful tool for delving into intricate concepts and experiences which were challenging for the participants to express in the interviews and discussion.

Body mapping

This exercise was simple but gave participants the freedom to openly discuss and think back on their experiences. At the end of the interviews and the focus group discussion, I presented a body outline for my participants and asked them to try to write their thoughts, feelings, memories and experiences with regards to PCOS and relate them with their body parts. Most people just filled in their symptom experience on the body maps and labelled the symptoms with the respective body parts. Others also associated specific memories and emotions with the body parts and elaborated why they felt a certain way while analyzing their experiences of living with PCOS. Almost all participants reflected on how they viewed their bodies but also narrated incidents which included other people and interactions that had become significant in their bodily experience of their PCOS and treatment journey.

In these body mapping sessions, I encouraged creativity and reflection from the participants by asking follow-up questions that allowed them to go into more detail about their answers. The reason for this was that several of the women who had given less detail to their map went into greater detail when I asked them to explain what they had added. This is because for certain women in this study, the process's creative component alone would not provide sufficient introspection and communication.

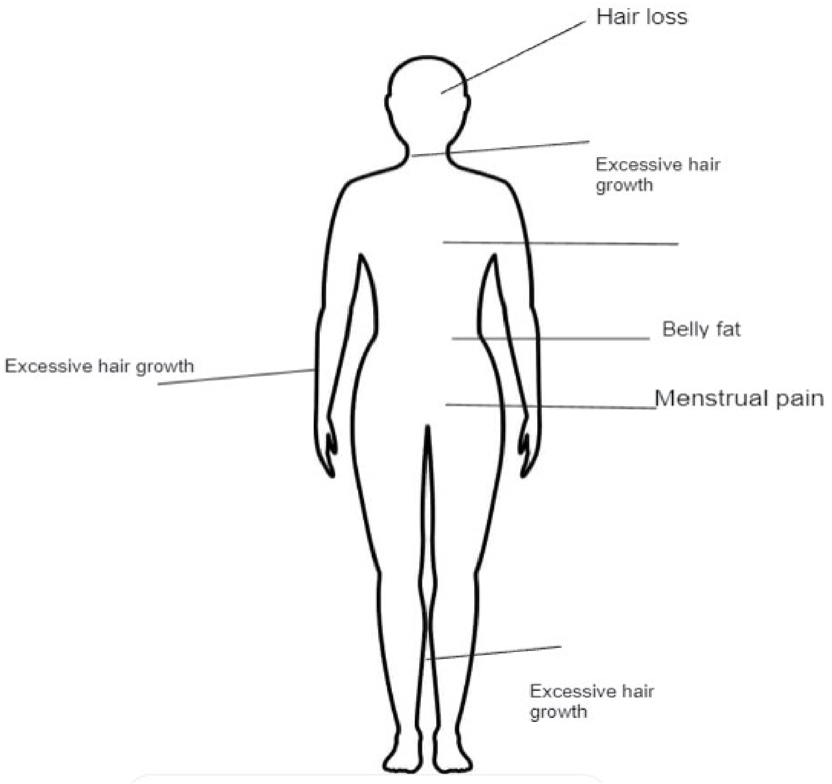
Another limitation that I faced with body maps was that for the focus group and virtual interviews, participants faced a few technical difficulties and the medium in general restricted their creativity. It became difficult to incorporate or draw anything, so most of the body maps ended up having only symptom labels. However, even these labels became meaningful and significant. When these women explained their body maps it helped me connect their affective capacities to the socio-cultural meanings and helped them ‘’locate their bodies in a social order’’ (Plage & Olson, 2021, p. 2730).

Following the session, the majority of women said they had realized how much their experiences had affected them and how those had led to insecurities and self-loathing. This was similar to Hartmann’s (2022) study where she concluded that self-esteem and self-image are both aspects that get significantly affected in women with PCOS. The commonality amongst all the body maps was that women mostly focused on negative emotions and experiences.

Visualizing living with PCOS

The following section represents some of the body maps of the participants from both the interviews and the focus group discussion. I have also included some statements from the conversations where participants expand on why they had labelled specific body parts with certain memories or emotions. These will not only help us understand how PCOS and its symptoms affect women differently but also give us a sense of how there are similarities in how women view their bodies and identities.

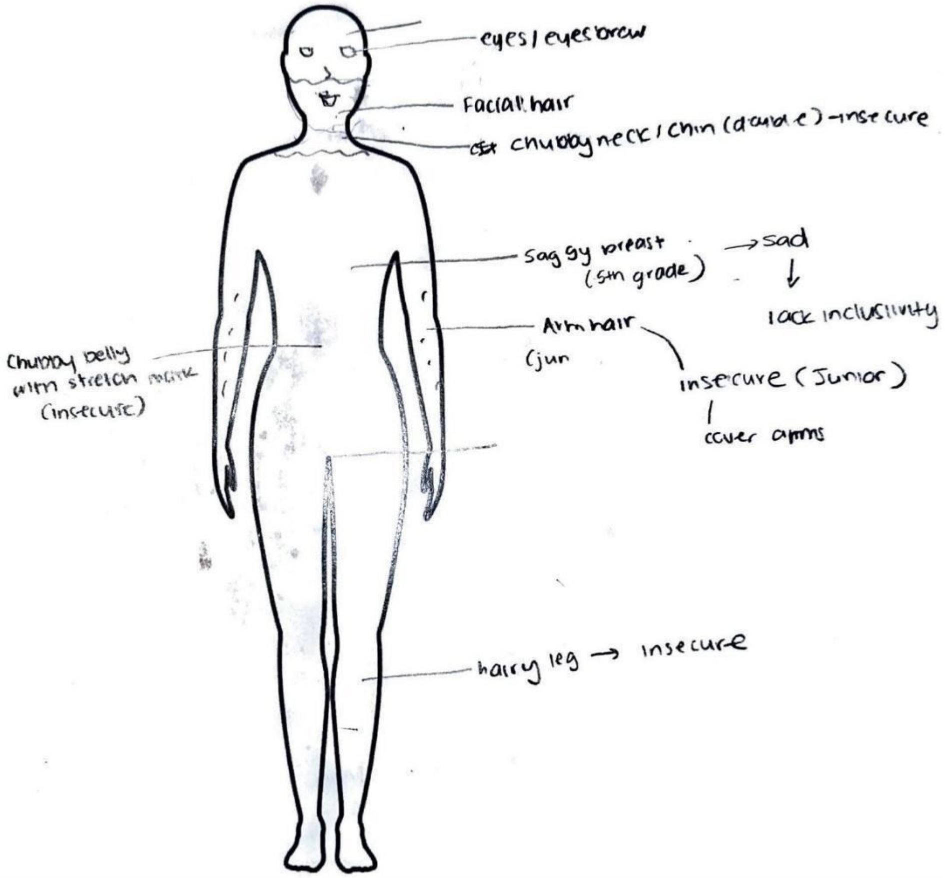
Hrithika (19 years old)



‘’Chin is definitely hair growth because it's an everyday struggle. I had to check every day in the mirror. Is it too much? Is it like, do I have to start tweezing again. I'm so tired of seeing this on my body. Like it bothers me so much. I can't do anything about it and it makes me feel like I'm gross.’’ ‘’And I can’t wear certain clothes because of the excessive body hair. And even when I do like wax and shave it leaves so many spots all over my body and like I don't feel comfortable with that either. ‘’

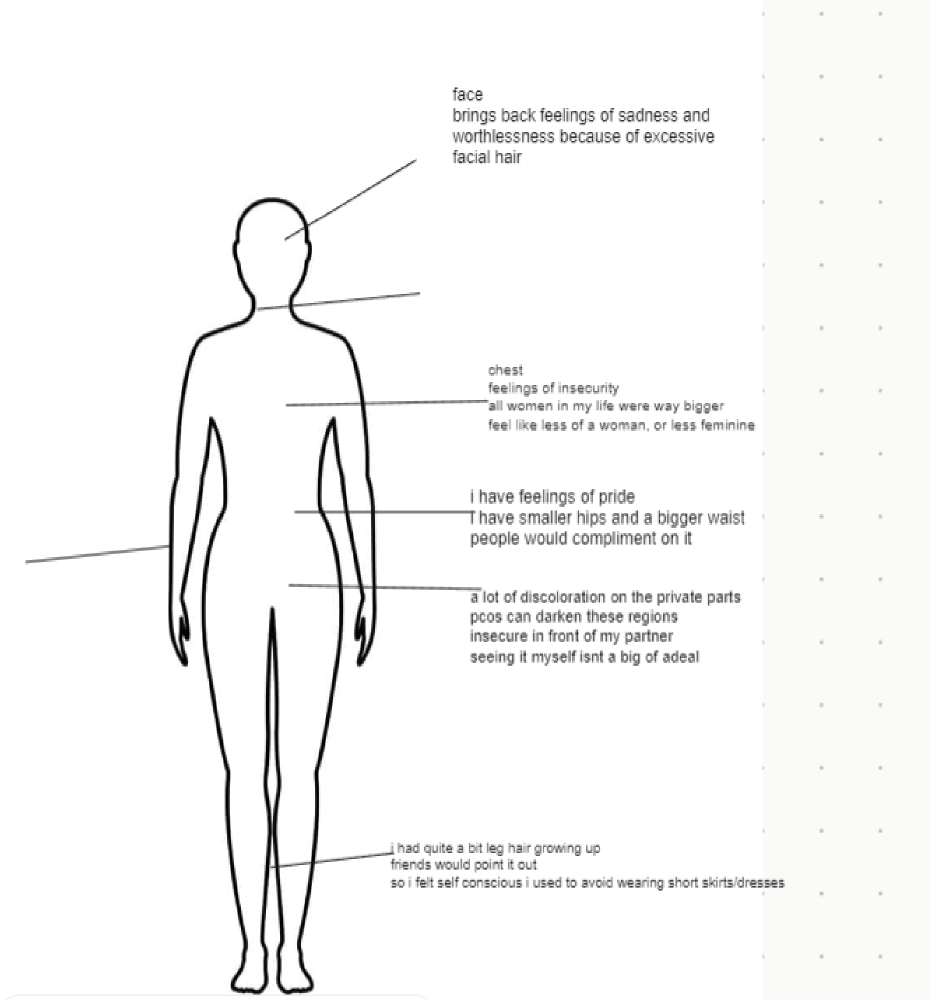
‘’My belly was something I was very, like, nervous. Not nervous, but like something that made me insecure as well, obviously, because my mom would constantly bother me with it. She said, your thighs are so big. I mean it’s not my fault that I have PCOS! ‘’

Asha (25 years old)



''These are like all my problems area of like having facial or like, like my arms here. Like I have a lot of arm hair. And I think like it's a bit more than like, my friends. I like would always cover my arms since junior high. I think even now I still like I still cover my arms. So, I like cover my arm was quite a lot. And my legs are also very hairy. Like, I think everywhere I know my body is hairy… I think my legs are like two shades or three shades lighter than the rest of my body because I never show it like I never like I don't go to like the beach or anything. So, I also think like this like makes me very insecure.'

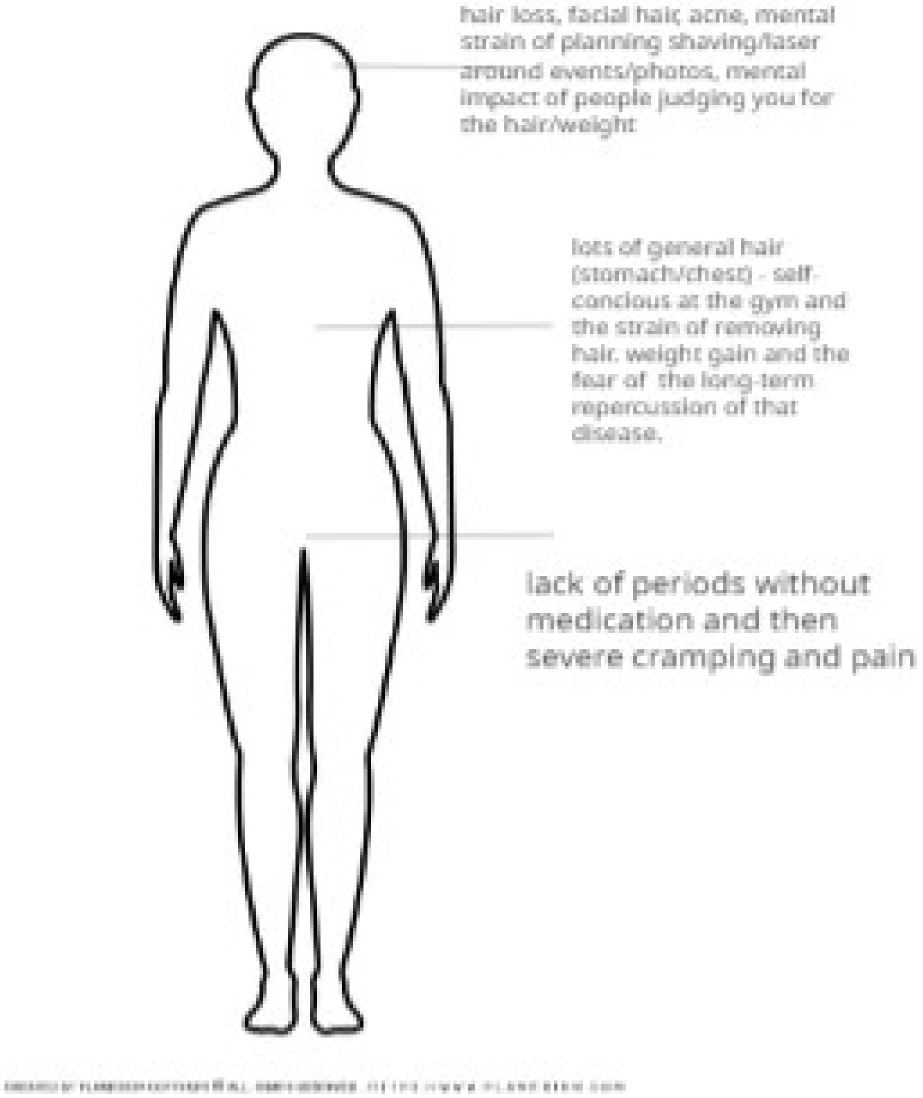
Bhoomika (25 years old)



''So, this brings back feelings of sadness and worthlessness because of like, excessive facial hair growing up, especially because not just once, like, a few times, growing ups, random aunties that we know would comment on it. So yeah, like hearing them comment on such things wasn't great for like my psyche.''

''The chest region, I associate with feelings of insecurity. Because growing up, I see all the women in my life. Like they're way bigger than mine. So, I used to think, this must be related to the PCOS. Because that's like a, you know, female, secondary reproductive organ. I used to feel like less of a woman almost or less feminine you can say''

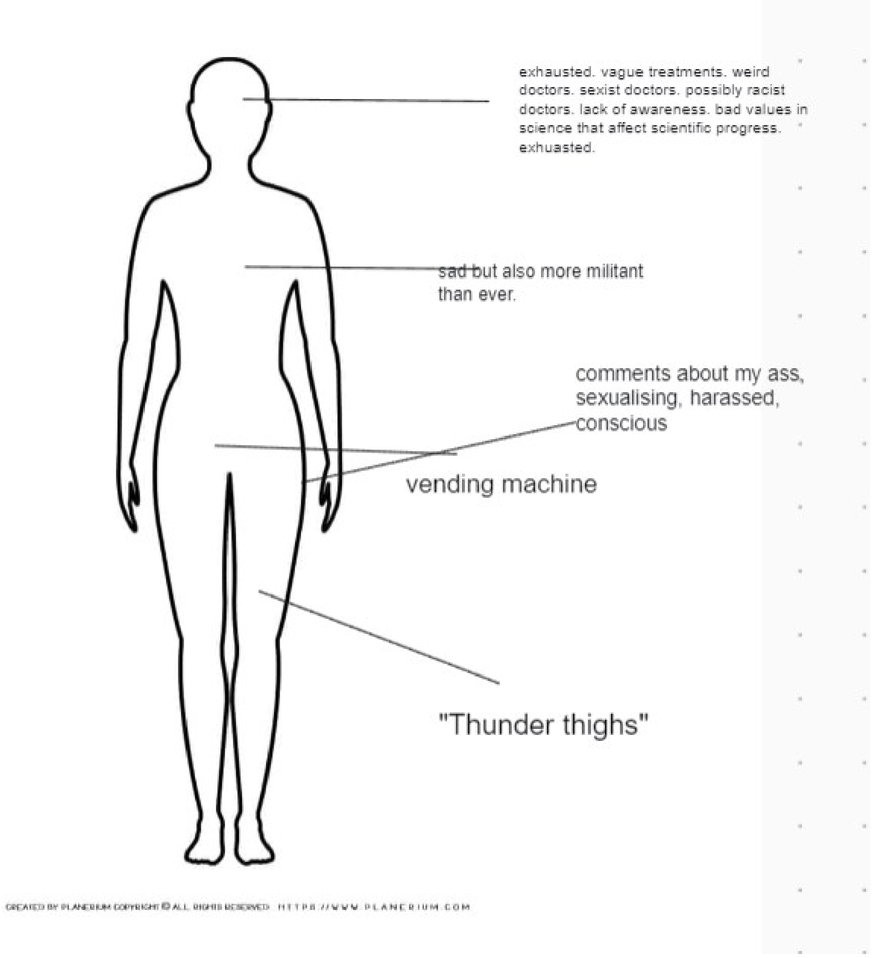
Anika (20 years)



‘’ I mean my face I can associate frustration and sadness because of the hair and acne. As I told you I did not go out because I was insecure and avoided socializing. It is also the depression that comes with the weight gain, I wasn’t comfortable in my body.’’

‘’With abdomen and vagina, I can say that the lack of periods without birth control, I mean I had extreme pain and there were irregular periods. I am also a little concerned with the pregnancy problems and maybe diabetes.’’

Ayana (26 years old)



‘’I have no thoughts about my uterus, man. But people have a lot of thoughts about my uterus. So that's my vending machine. People love to make it my vending machine.’’

‘’Thunder thighs like everyone has commented so much not everyone but yeah, so many people have commented on my thighs that like how they're so big and bla bla bla and that just saying made me really conscious of my body for sure. ‘’

‘’Then in my heart, I just feel honestly, sad, but also more militant than ever. Yeah, that's literally because it's not that I have not felt sad, I don't want to feel militant. I don't want to fight those battles. I just want to have like a safe, comforting space in my life. I don't

> *have that. So that feels really ridiculous because you can't just have those conversations all the time, every time I just feel exhausted because of vague treatments. Weird doctors, sexist doctors, possibly racist doctors. Lack of awareness, bad values in science, and yep, just exhausted''*

Discussion

These body maps are a reflection of how the women in this study view their bodies mainly in terms of how their feminine appearance and reproductivity get affected. Phrases like ''problem areas'', ''insecurity'', ''worthlessness'', ''less feminine'' were part of the conversations when asked about specific labels that these women created with regards to their own bodies which reflect how they experience stigma.

Kitzinger & Willmott (2002) found that women with PCOS felt that the hair on their bodies, particularly on their faces, betrayed their identities as women. Similarly, facial and body hair was labelled as a negative problem in almost all of my participants' body maps. It is interesting to note how some of them, for example, Bhoomika and Hrithika, use the word ''excessive''. They describe their facial and body hair as excess—these were the primary areas with which my participants attached many negative associations and memories.

''Stigma is seen to be embedded in the interpretive engagements of social actors, involving cultural meanings, affective states, roles, and ideal types.'' (Yang et al.,2007, p.1528). The body maps reflect different interactions and experiences my participants had where they felt stigmatized and judged either because of their symptoms or because of being diagnosed with this condition. There always was a comparison of their bodies to some kind of an ideal type or an ideal role.

The women express how comments on their body parts from people further affected them and their perspectives about their bodies. Leavy et al. (2009) said, “In particular, family, peers, and the media instill constant reminders of the ways women should modify and present their bodies in order to be accepted as feminine” (p. 276). For example, Ayana states that people have made her feel that her uterus is only a ‘’vending machine’’ with the sole function of reproduction. Bhoomika shared how her friends always used to point out her leg hair that made her immensely conscious of her body. She goes on to associate her chest region with feelings of insecurity and compares it with other women around her. She attributes it to PCOS and states that it has developed in that way because it is a secondary reproductive organ and has been affected by the syndrome. As Connell (2010) described, the manner in which my participants view and interact with their bodies are significantly influenced by the specific ideals of femininity. They also interpret their subjectivities based on cultural laws that make them question their bodies. All of them stated their physical symptoms to have significant influence in their analysis of their bodies.

When it came to expressing their opinions during the body mapping exercise, all women pointed out negative experiences of their symptoms, negative interactions with other people where they felt their body was criticized and rejected, and negative emotions they had about their own bodies. During the other parts of the interview and focus group discussion, there were different narratives about symptoms, treatments, self-images and even their perspectives about themselves as a woman; however, some were positive, too. For instance, some of the participants, like Bhoomika, expressed that their treatment experience was positive since it helped them with their external symptoms. The expression of their embodied experience of the condition in these body maps shows that feminine appearance and feminine functionality, which was mainly characterized by regular menstrual periods, were more significant to these women.

Chapter Conclusion

In this chapter, I presented some of my participants' body maps where they reflected on their embodied experience of PCOS. The labels the women used for specific body parts not only showed what they feel about their bodies and identities but also what other people around them feel about them. The illness experience consists of experiences at "levels of self, others and society" (Wright et al.,2020, p. 1731) and the prevailing societal factors that shape people's understanding of illness also impact how people interpret, respond to, and act upon it. In general, most body maps were about negative emotions and experiences. The narratives about the distinct labels in the maps brought out instances of stigmatization that expose how my participants were always compared with an ideal female body. In this process, the concept of 'health' gets lost somewhere and 'being feminine and womanly' becomes essentially significant.

In the next chapter, I expand on the narratives on their embodied experiences, building on the body maps. I look at how their perceptions on how their body should look and how their reproductivity has to be maintained are based on their interactions and socio-cultural norms. In the final chapter on treatment experience, I highlight the differences in the narratives about the illness experience when I compare them with the body maps. In that chapter, I also relate the socio-cultural ideals of being a woman with Western biomedical ideas that construct an ideal image of a healthy female body.

CHAPTER V

Being a woman

''The disciplines of normality, like those of femininity, are not only enforced by others but internalized. For many of us, our proximity to the standards of normality is an important aspect of our identity and our sense of social acceptability, an aspect of our self-respect. We are unlikely to notice this until our ability to meet the standards is threatened in some way.''
-Susan Wendell, The Rejected Body (1996, 91)

In the previous chapter, I examined my participants' embodied subjectivity through their body maps and narratives expanding on them. This chapter builds onto those narratives and tries to further explore important aspects of my research questions. I focus on the lived experiences of PCOS and its symptoms (second research question), which I eventually connect with the participants' treatment perspectives (which I explore in the next chapter). I also illuminate how these experiences are based on socio-cultural ideals and expectations with regards to femininity and normal womanhood (third research question).

This chapter thus delves into one of the key aspects of the PCOS experience, i.e., stigma. Women in this study talked about feelings of being judged and excluded because of this condition, its symptoms and possible health problems they can have in the future. Most gynaecological disorders in women are stigmatized but in PCOS, the stigmatization is not limited to menstruation and bodily function, it is also associated with bodily appearance.

The chapter mainly focuses on my participants' expression of their experience and management of stigma around PCOS and its bodily manifestations. It also relates the management strategies of these women with the concept of intelligibility. According to Butler's theory, cultural intelligibility pertains to the manner in which identities are constructed, acknowledged, and controlled in cultural contexts (Butler, 1990). It describes how people and their identities, behaviours, and expressions are understood and accepted as coherent according to cultural norms. I connect Butler's concept with the coping strategies the women develop to deal with the condition, wherein they try to 'fit in' and fulfil their 'femaleness'.

I also explore how being Indian or Indo-Canadian impacts these women's perceptions. As mentioned in my literature review, Indian discourses on PCOS are mainly associated with fertility whereas, Western studies focus more on visible bodily symptoms.

Overall, this section attempts to explore how PCOS as a condition complicates ''being a woman'' for these participants. It will discuss how these women experience stigma based on the idea of what a 'healthy female body' should be and how this condition leads to ambiguity with regards to the female identity. It highlights how the struggles over stigma for these women are extensively struggles with 'being a woman'.

I begin by expanding on one of the main themes that came up during data collection, where women express how PCOS makes them feel different and not like a ''normal'' woman. I further connect it with sub-themes of bodily appearance, menstruation and motherhood where my participants talk about the various symptomatic manifestations and how they restrict them from becoming a woman. I discuss how for my participants, gender and self, develop in a cultural context, especially in terms of how they relate negative associations about their body with their ethnic culture.

This chapter mostly focuses on the embodiment aspect of PCOS both internally and externally, i.e. the experiences of dealing with symptoms that are visible and the ones that are not. It deals with how women with PCOS associate an ideal healthy female body with cultural laws that predefine what it should be. Ideas of stigma and cultural intelligibility enhance the understanding of why these women consistently try to maintain their femininity and to fit in the predetermined binary, where health and gendered ideals are co-produced. Being healthy with regards to PCOS becomes synonymous to being womanly, having full feminine bodily capacities and looking feminine as well. Women talked about correcting their symptoms to get the perfect appearance, to have regular menstrual cycles and to be able to get pregnant in the future, where they share their struggles to address these problems and be like a normal woman.

1. Becoming a ‘normal’ woman

According to Goffman, stigma suggests the contrast of a standard and a non-standard, or deviant or abnormal trait, leading to strong distinctions. These distinctions are based on the construction of binaries, which is influenced by socio-cultural, political and biomedical norms (Phelan et al., 2014). He states that stigma arises when there is a difference between a person's "virtual social identity," (as characterized by society) and their "actual social identity," (qualities or attributes they actually possess) (Goffman, 1963, p. 2). The self-imagery is based on the feeling of being stigmatized for having ‘unfeminine’ features which arises from the disconnect between the virtual social identity (in this case, the feminine state of being hairless) and the actual social identity. The symptoms become ‘markers’ that challenge the idea of a female body.

For women with PCOS, the binary of male and female becomes an important element since the symptoms lead to these women feeling ambivalent about their femininity and gender role in terms of functionality. It becomes the basis on which women with PCOS think of themselves as not a ‘normal woman’.

Participants in this study used specific terms that represent the images they have about their body. Words like ‘different’, ‘lonely’ and ‘abnormal’ often came up in the narratives. There was a clear expression of perceived stigma or ‘’internalized stigma’’ (Syvertsen et al., 2021), where women were labelling themselves but mainly in terms of their gender identity. However, women's perception of themselves aligned with the stigmatizing reactions of others, leading them to acknowledge their discredited position as legitimate (Combellick, 2023).

The following sections on bodily appearance (1.1), menstrual problems (1.2) and motherhood (1.3) expand on women's perspectives about symptom manifestations and interactions in different settings where they share experiences of stigma and how they are managing it to become a 'normal woman'. In this chapter, I explore these interactions and characterizations that made these women feel they are different from normal. These characterizations provide crucial insights into the ways in which the participants' subjectivities are shaped by their body perceptions, which in turn impact their perspectives on health and treatment.

The term 'normal' was used in different contexts. Some of them tied 'normal' to not having hormonal acne, others associated it with not having body and facial hair. They also related it with having regular periods and being able to be fertile. The comparison between normal and abnormal was brought up by one of the interview participants themselves. Twenty-seven-year-old Ayana expressed why she thinks her symptoms were not normal when compared to other women of her age.

> ''*With regards to PCOS, being healthy would be, I think in very binary terms of normal versus abnormal. People are not supposed to have acne in their late 20s or whatever. So why do I have that? I don't want to have that. A ten-day period is not okay. So why do I have that? Like, chin hair is not normal, because I never had it throughout my adult life. It was only in the past few years that I've started developing chin hair. So, this is not normal. This is abnormal.''*

The primary concern with regards to the struggles to become ''normal'' that came across in all the interviews and the discussion was the need for correcting the body. This coincides with Shildrick's (2002) concept of a ''differential body'' where it is defined as a body that defies norms of normalcy in some manner, either in terms of appearance or functionality. PCOS bodies cannot be seen just as bodies in this case, since they are results of discursive formations that not only stigmatize them because of being defined by a health disorder, but also because they defy the ideas of how a normal female body should look and function. Thompson & Stice (2001) in their research talked about how young women with PCOS started pathologizing their experiences by claiming that they were abnormal and that needed to be fixed (Thompson & Stice, 2001).

The idea of correction or ‘fixing’ their ‘’differential bodies’’ was expressed by Janki and Bhoomika in their interviews and was connected to ideas of being more ‘’feminine’’. Similar to the body maps, the women mostly used negative connotations to describe their bodily symptoms. Be it the excessive body hair, or the menstrual irregularities, the weight gain, excessive menstrual pain, or the fact that they have to take birth control pills to ‘fix’ their problem—all were reflective of how the women themselves view their body as ‘different’. All participants used the term ‘’birth control’’ to refer to the hormonal treatment they received to ‘’correct’’ (Vedika) their hormonal functionality. These were mainly pills containing artificial hormones that balanced the high levels of estrogen in their body.

Temporality is the most critical aspect when it comes to correcting PCOS. Women have to think about the symptoms that they are dealing with in the present and also about future problems that can arise if the symptoms are not managed. PCOS is termed as a "chronic" disease; that lasts for a long period of time, either continuously or periodically, and something that one must deal with on a day-to-day basis (Bury & Monaghan, 2013). Thus, my participants expressed that as much as they want it to get cured completely, they are aware that there is no treatment that can reverse the symptoms completely. Some of them like Hrithika, stated that she considers PCOS as a part of her. Similarly other women echoed her and also shared that they try to socially navigate through interactions and negotiate their identities as women.

In the women's narratives, temporality comes up in this attempt to correct their bodies to achieve their desired normality. Symptoms that are visible to everyone become the locus of insecurity whereas future concerns become more relational; i.e., it will only matter to some people involved (like family and intimate partners) and might not be as evident as the external symptoms. Participants expressed that they always have a feeling of ''why me?'', and that they compare their bodies to other female bodies and consider them 'normal' as opposed to theirs.

In the following sub-themes, I expand on the stigma narratives about experiences related to symptom manifestations and the various ways these women try to be intelligible to feel familiar with other women. I discuss how participants relate their symptom experiences with their present life, future plans and to other people around them.

1.1 Bodily appearance: Insecurity and correction

Insecurities about bodily symptoms that affected women's appearance was the most discussed and common among all interviews and discussion. As discussed in the previous chapter on body maps, women shared that there were often feelings of insecurity regarding symptoms that were visible to everyone. This section expands on narratives and builds on insights from the body maps about how those symptoms and experiences associated with them have influenced their perspectives on their body, the condition and femininity. In most body maps, the face, arms and legs were the body parts that were singled out for negative attention and emotions. Vedika who is nineteen years old stated that this condition and the diagnosis led to feelings of being 'socially isolated' because no one else was going through a similar condition. She expressed that as a woman it was extremely emotionally and physically taxing to always be conscious of her facial and body hair and keep removing it every other day.

'' But when I got diagnosed with it, it just felt very isolating. And then like, there are times when

> *I'm, like, removing, like facial hair every other day. And then I just like, break down during the middle of like, I start crying. And I'm just like, Why do I have to do this? Nobody else that I know has to do it. So why is it that it's happening to me?''*

Participants revealed having more male hormones or external physical symptoms which were similar to men (facial hair and body hair) made them feel less feminine and how they tried to 'correct' them. The women in this research typically feel that they don't meet body norms. Similar to Mishra and Sharma's study (2022), where women suffered from a "grotesque" body, my participants too shared that it is because their bodies do not meet the standards of what constitutes a woman as defined by society. Women were upset since they could not experience "normal" womanhood (p. 615).

> *''Sometimes I feel so much like, I don't feel like a man ever in my life to be compensated, I don't feel like a man. But I also feel like less than a woman sometimes, like you're having those feelings. Or they're, like, I feel like oh, like my hair's falling. Like, my face is like this, not well groomed and stuff. But then especially like, when it comes to shaving like, I have to, like, almost shave like every day, just to keep it all. '' (Asmi)*

The use of the word "have to", which came up in a lot of narratives, perpetuates the idea that they must live up to expectations out of fear of being rejected (Fahs, 2014). This observation adds a new perspective to the corpus of research (Brady et al., 2009; Farkas et al., 2014) that suggests PCOS is a stigmatising condition because of the bodily appearance (obesity, hirsutism, and acne) and lack of confidence that come from the disease's development.

Like other qualitative studies on symptoms like hirsutism, women felt more feminine when they removed their body hair and adhered to having a hairless body which is perceived as a symbol of "proper" femininity (Braun et al., 2013; Kitzinger & Willmott, 2002). Women also shared that irrespective of the fact that whether people around them knew about their diagnosis;

their physical symptoms like acne, hirsutism and even weight gain or loss had always been pointed out, and they were the subject of scrutiny and social rejection, especially by other women which essentially aligns with the characterization of stigma. These women also said that most of the interactions circled around the topic of marriage or finding a partner based on how they looked.

Participants shared their interactions with their relatives and expressed how there was always a sense of blaming them for the condition.

> *''South Asian culture is just a very difficult culture to be a part of, in this aspect. It makes things very hard because a lot of things are focused on appearance. It's always about what are people gonna say about you? Like, no one's gonna marry you, like marriage is not my only goal in life!'' (Mehekdeep)*

> *''Then all I got like, not immediate family again, but like extended family….they would give suggestions to my mom to remove the hair, and, you know, maybe get waxing, maybe this and that, but I didn't really want it at that time. Like I didn't really care about all of that. So, I think people don't really know a lot and then they keep suggesting methods to lose weight and for hair removal but don't care about my health but only how I look.'' (Aahana)*

These narratives show that stigma is not entirely internalized but experienced in these women's daily lives. Mehekdeep and Aahana point out instances where they received negative attention from people around them because of their symptoms. Some of them also stated that the various reactions and opinions from their relatives and partners, was because of the lack of awareness and sensitivity regarding PCOS. The majority women reported that insensitivity from men made them more conscious about how they looked.

> *''The guys can still be very rude. I've noticed that although in Canada people are more*

> *accepting, brown men here still make fun of hair growth. And even when you tell them like listen, like it's an actual condition, it actually makes me very insecure. I feel like awareness has to be brought especially to men, because they will take every opportunity to make women feel terrible about themselves. '' (Hrithika)*

> *''I got a lot of hair growth on my face. I got really badly bullied by men like, I don't know what I was called…like transgender and all those sorts of stuff. I got two really bad comments on that anonymous kind of thing that people usually do on Instagram. '' (Aahana)*

When it comes to bodily appearance, all the women stated that they adapted coping strategies which helped them conceal the symptoms (waxing, shaving, make up, etc),which were attempts to protect their 'threatened' gender identity and intelligibility.

Ellerman (2012) in her study stated that despite taking medicine to help "correct" hormonal imbalances, stigma associated with facial hair still remains an issue for many people with PCOS. According to Moriel, "passing" is the deliberate process of moving from a marginalised position to a more mainstream or socially acceptable position. This process includes a range of intricate survival techniques meant to blend in with the prevailing culture norms and expectations or become culturally intelligible. (Moriel, 2005, p.170).

These strategies can be complex and multidimensional, necessitating a great deal of efforts and adaptability from individuals to be understood and accepted within the dominant cultural framework. In their investigation of the relationship between hirsutism and psychological distress in women with PCOS, Keegan et al. (2003) discovered that the women they interviewed developed "passing" strategies that allowed them to conceal the outward manifestations of PCOS and still function fairly well in their social settings. They did, however, stay away from social events that would expose their bodies or interfere with their depilatory routines.

Similarly, in this study, participants talked about resorting to birth control, laser hair removal treatments, waxing and shaving as strategies to becoming more womanly, which reflects a conscious attempt to manage stigma and 'pass' as a normal woman. They talk about how they try to be coherent in relation to norms that create the definitive social understanding of what it is to be a woman. Pfister & Rømer (2017) call these "coping strategies". This can be connected to Butler's (1990) understanding of how people portray their identities in accordance to the cultural boundaries and expectations for how, which in turn defines social identity. It not only benefits them since they escape the stigma but also the society because these attempts reinforce ideals of 'normality'. Women considered these strategies to be tedious, sometimes frustrating but found them beneficial for their self and identity preservation as a brown woman.

Goffman's definition of stigma refers to a condition of the individual who is excluded from complete social acceptance (Goffman, 1963). For a condition like PCOS, this acceptance is built on cultural constructs and collective representations that decide what an ideal female body is. According to Major and Schmader (2018), collective representations are cultural standards that are shared by both stigmatized and non-stigmatized individuals. They have the direct effect of undermining an individual's "conception of the self" (Tuckett, 2001, pp. 347–348). These women explain their interactions to be spaces where they not only felt socially rejected by others but also unfit to attract men for marriage just because of the symptoms impacting their appearance. The next section focuses further on how this 'self' further gets questioned by the participants themselves as they express how their menstrual capacities make them feel different.

1.2 Menstrual problems: Dysfunction, cyclicity and pain

Menstrual irregularities were not discussed as much as bodily appearance, but were still a major concern for my participants. Women associated normal periods with having a ‘functional’ female body. Some of them also expressed that the regularity and cyclicity of menstruation made them relate themselves to other women. Pain tolerance was also another aspect that my participants brought up with regards to menstruation. They talked about how not being able to handle menstrual pain led to a feeling of being abnormal.

When I asked what does being healthy mean with regards to PCOS, nineteen-year-old Vedika says,

> *‘’I feel healthy with PCOS, for me would be just not being dependent on medicines, and still being able to function normally, normal in the sense that everyone around me is just being able to not be dependent on medicines to live their life. I don't want to have medicines to get my period. I just want to get my period normally. It's kind of running on autopilot, because I'm just taking the medicine (hormonal treatment) and it (menstrual cycle) happens, and it doesn't happen when it's not supposed to happen’’.*

She talks about how her body is completely reliant on medicines and almost compares it to a machine. The usage of the term ‘’autopilot’’ reflects the view that the medicines are controlling and stabilizing her hormones so that menstrual cycles happen ‘timely’.

Asha also talked about how she hopes that she doesn’t have to deal with the uncertainty around menstrual cycles.

> *‘’I hope that one day my period will actually start being regular and I would rather not get pregnant for that to happen, like it did for my mom. But yeah, you know, just kind of being normal, like having a period every month that's trackable. You know what to expect kind of thing.’’*

Janki kept talking about how she feels her body is ‘dysfunctional’. She said, *‘’I would say* *just having my cycles at the right time would mean that, okay, you know what, my body is functioning fine.''*

Elson (2004) in her study on hysterectomy also found out that women felt ''disoriented by the loss of this normal regulation of time and space'' (pg. 80) and missed the cyclicity of their periods that defined normality in their lives. This reflects how the social meanings of having a normal healthy female body are structured around the timings of how our bodily functions or even when our external features develop. All participants were concerned about appearance— they wanted to lose weight, wanted less hair growth and above all, wanted 'normal' menstrual cycles. Elson also stated, '' A woman's menstrual period can also be viewed as symbolic of her biological tie to other women.'' (pg. 71). Participants tended to concentrate on irregular or excessive periods when they emphasized the ways in which their bodies functioned strangely, drawing on biological conceptualizations regarding normality or health (Fabricius, 2020). Bhoomika and Asmi revealed how the regulation of menstrual cycles gave them a ''false sense of comfort'' and they felt like ''a normal girl getting periods every three to four days a month'' and counted this as a positive effect of the medication. Vedika said that, *''I'd rather handle the pain for the first two days of my period, then not have my period at all.''* Vaidehi also stated: *''And it (menstrual cycles) is one of those things that you feel like if it happens, it's good. If it's not happening, then it's concerning.''*

Kitzinger and Willmott (2002) discovered that women's perceptions of themselves as women and their sense of self were significantly shaped by their periods. Menstruation is often assumed to be present in women, even if this is often suppressed in public. According to Kitzinger and Willmott, menstrual problems served as ''reminders to women with PCOS of what they are lacking - their deficient femininity'' (p. 356). The term ''normal'' also came up when

Parthavi talked about how her experience of menstrual pain made her feel different.

> *''So, I think my biggest problem was people thinking I'm a crybaby, especially other females in my life, just because my periods were harder on me. And I would obviously complain about it, complain about the pain, complain about the excessive bleeding, stuff like that. And then there were other people, even people in my life who had the same diagnosis, but PCOS doesn't have the same manifestation for everyone. Someone might have more pain; someone might have more hair issues. And you know, like, it's just different for everyone, even within the diagnosis itself. And I've had people diagnosed with the same issue. Tell me that, oh, it's not that bad. You just don't have enough pain tolerance. ''*

This establishes how pain has been normalized to be part of the period experience and that women who are reporting or complaining about menstrual pain are either ''weak'' or do not have enough pain tolerance like other 'normal' women. Women are heavily influenced by conceptions that similarly frame menstrual pain as an acknowledged reality of women's life in order to position pain as an acceptable aspect of menstruation (Jones, 2016).

Maisha, who is thirty years old, expressed how during her teenage years and even throughout her late twenties, her female relatives made her feel isolated because according to them all women know how to handle menstrual pain which she was not able to.

> ''*Everyone's like, Oh, just you'll be fine. Like, you're just crying too much. Like, it's not that bad. I'm like, How do you know? Are you me? Oh, everyone feels that pain, and they do their work normally. So why can't you? Which makes me feel like I am an outlier.''*

In both Maisha and Parthavi's narratives, self-identities were constructed on a sense of being flawed and damaged due to their inability to do what they believe others are able to do with ease, which is a central perception with most women with PCOS.

Due to its embeddedness in a complex socio-medical discourse that views menstrual irregularities as necessitating medical intervention, the absence of menstruation can be interpreted in a variety of ways by the individual and pose a threat to gender and cultural intelligibility. (Malson & Ussher, 1996). Some women, for instance, feel ashamed and believe they are not feminine because they believe their missed menstruation is a reflection on their gendered identity (Thorpe, 2016). However, there were some women, where the menstrual regularity was not a concern, but interestingly these women had been either born or living in Canada for a longer period of time as compared to other participants.

For Bhoomika and Clarissa, the absence was not a concern for them and they were more inclined to rectify the other symptoms. They stated how getting an IUD was a huge relief for them and they did not have to deal with the effects of prolonged birth control. This cultural difference is perhaps based on the fact that contraception in India is still a major taboo and fertility is still defined by regular menstrual cycles, whereas in Canada people have been more accepting of contraceptive methods which can be more convenient and safer for women, and fertility is not only defined by bleeding every month (Babbar & Ojha, 2023).

Nonetheless, menstruation was an integral part of all my participants' narratives - for the majority of them, it defined their reproductive functionality. Because the body is an integral part of who we are, its "dysfunction" becomes crucial for these women and closely related to their overall health and identity (Carel, 2011). Feminists who have worked to promote positive perceptions of menstruation have often agreed that it is "symbolic of womanhood" (Lovering, 1995; Kissling, 1996). Menstruation is seen as a sign of femininity, reinforced by scientific and medical interpretations (Kissling, 1996). As Vedika said, birth control helped these women get regular cycles, which can be thought of as another coping strategy to be intelligible and to ‘feel’ like a woman. Medicine becomes a medium for hormonal intelligibility to escape the stigma of having a dysfunctional body and to be a ‘real woman’. The next section will explore the aspect of gender functionality and role further and connect how menstruation is also connected to future motherhood.

1.3 Motherhood: Fulfillment of womanhood

> *‘’I would say because in a few years I will probably be planning for a baby. That's the one thing that really haunts me. I don't know if I'll be able to conceive in a natural way. That is something that I really think about. And so yeah, because it's ingrained, you know, is that you have PCOS so you might have, like, infertility issues. So, these things really scare me. And I would say, that's the only thing that I really, really am scared about.’’ (Maisha)*

Infertility was a big concern for most women. When participants established that irregular menstrual periods were a huge issue for them, as a follow up question I asked them why regular periods were so important for them. Many participants expressed that they wanted to feel like normal women however, others shared that they feared that the present irregularity in menstrual cycles can affect reproductivity and fertility later in life.

> *‘’ I think it's important to get a period because it shows your fertility as well, like if you are able to get pregnant if you're not getting it means you're gonna have a high risk of infertility’’. (Asmi)*

> *‘’I am scared about not being able to fix my periods or this condition.……having children is a big part of my long-term goal. One of my goals. So, I am stressed about what if this disrupts my plans? My partner doesn't know, because….okay, so like, his goal is also to have children someday. And like things are going really, really well between us. And I don't want to put that fear in him, or doubt.’’ (Bhoomika)*

There was a commonality in all these accounts when these women talked about pregnancy- i.e., the term ‘function’ was used that reinforced the view that their bodies have to be capable of being reproductive. According to Corrigan and Watson's (2002) social-cognitive model of personal reaction to stigma, self-discrimination and stereotyping take place because people are aware of the unfavourable cultural stereotypes that apply to them. The diagnosis of PCOS made these women feel more stigmatized due to the possibility of being infertile in the future. Clarissa said, *'' I felt like a negative function within society.''* and talked about her immediate concerns after the diagnosis, stating that she felt like she had a ''defective'' body and that the possibility that she might have a hard time getting pregnant in the future made her question her functionality as a woman in society.

Some women also reported that they were not concerned about fertility as much as their parents were, but shared that there was a sudden pressure on them to be extra careful and active with their lifestyle. Aishi said that *''Suddenly, I mattered to them (parents) more. My response wasn't that bad to getting that news? But my parents, they were more like taken aback about it. Because like, they went to all the depth like, oh my god, what if she's infertile?''*

Other participants like Vedika who were in their late teenage or early twenties, expressed how the diagnosis had disrupted their lives, where they had to be immensely cautious about everything they did, so that the condition did not get aggravated and affect their fertility. She shared how she is always ''stressed about how this condition will always be there'' and that she has no control over it. She talks about how she has given up on her favourite food, tries to stay active and lose weight, so that her symptoms get better.

> *''I know I am too young to think about it....but I feel scared that I might not get the experience of being a mother. I think I'm scared to not experience motherhood....and, like the experience of having that and it sounds very special. And it sounds very, like it sounds like a very out of body experience. And it's something that I would eventually want to have. And it's sometimes scary. I*

> *don't know if I will be or I won't be able to.'' (Vedika)*

Ilana (nineteen years old) also expressed that she would want to get any form of ''actual'' treatment that would help her reverse the condition, but she did not want to risk her fertility. She says, *'' I wouldn't even mind having a surgery to even reverse it, personally speaking. But I would not want it to mess with fertility issues or, or hormones.''*

Mehekdeep brought out an important part of her illness experience which helps us understand how women with PCOS try to be culturally intelligible and how a woman should function is already predetermined. Many participants expressed how they haven't been able to approach men or deal with the anxiety of not being able to find a partner since they felt unattractive and unapproachable because of the symptoms or even the fact that the condition might impact their fertility in the future. This reflects the interpersonal aspect of internalized stigma about infertility. These women have not only developed these self-perceptions of being abnormal and incomplete as a result of their interactions in their social networks but are also acting on those perceptions that in turn shapes their formation (or not) of relationships.

> *''I think maybe a little bit, because I think it also becomes a bit for me like an attractiveness issue. I just stopped getting therapy for it. That's just like, you're just generally unattractive to people. I think it's probably just my reproductive health and like, just the anxiety of just not being able to find a partner in the future.'' (Asha)*

> *''Sometimes I do feel that if I start, like, if I talk to a man of color over here, who and this is just like all hypothetical in my head, because I clearly like to think about this quite a lot. That if I start dating a man of color, and then if I tell him that I have PCOS, and if it's going to get serious, then maybe he would just be like, Okay, so, like you can't get pregnant. '' (Ayana)*

While most participants expressed concern about having the ability to conceive, there was a minority who were not worried about having a ‘functional’ body for reproduction. Ayana and Asha stated how they were not concerned about being able to get pregnant in the future.

> *‘’Having kids is going to be a problem, which, you know what? That's okay. I've had a massive fear of childbirth since I was eight. So, I think it worked out for me in that case, I don't think I could ever physically want to be pregnant. I would give (sic) a surrogate if I had to or even adopt one frankly.’’ (Asha)*

> *‘’I'm not really keen on giving birth or not giving birth. I'm like, It's vague. It's out in the open, we'll see. As and when it happens, if it happens. And, like, in my head, I've always thought that okay, even if, like, my parts don't work. And then I can just go and try for adoption, or do something. It's not like the end of the world.’’ (Ayana)*

Both of them expressed that they are not stressed about fertility but talk about motherhood. Their approach to fertility and motherhood does seem to be influenced by choice and alternatives to conventional forms of motherhood; however, it is somehow affected by the possible infertility stigma they might face later in their life, which results in an unconscious navigation to future plans to become a mother- the focus may not be on the internal or bodily functionality but is centered on the social role.

The social role of becoming a mother becomes central. The narratives from this study reaffirm that having children is still expected of women at some point in their lives; failing to do so puts them in danger of being called "defective" (Arendell, 2004). Clarrissa in her interview shared that it is frustrating for her because her friends do not understand that pregnancy might not be an easy process for her and how she is scared about the possibility that it can be financially and emotionally draining for her. She expressed that she feels excluded when it comes to conversations about pregnancy. For her fertility is something that is natural for every woman, but for her, it might be something she will have to fight for.

> *‘’I have friends who don't have PCOS. So, when they talk about having kids, like, you just stop taking birth control and have kids and I'm like, well, not that easy for some people. And that was incredibly frustrating for me where it's like, it felt like people didn't completely understand, like, how difficult it's going to be for me if I want to. I mean the possibility of like, a lot of struggles to get pregnant….this is going to be hard and frustrating and a lot of money for me if I want to have kids, and so it's not that easy.’’*

She also expressed how she is confused how she can ‘’be a woman’’ if she doesn’t get to be a mother in the future and compares her life with other women around her, who are mothers.

> *‘’I'm in academia, and some of the women I know too, came out of high school, started having kids and they were stay at home moms. And I'm like, but that's not how I'm living my life. How do I be a woman in this situation? I don't know what that's like’’*

The condition not only interferes with her aspirations to become a mother, but it also makes it difficult for her to relate with friends who are parents, which undermines her self-perception as a woman, which is another example of the interpersonal dimension of internalized stigma. But it also goes beyond stigma and becomes a concern for intelligibility. Being a mother or having full capacity to conceive (in the future) is an essential part of being a woman. For most women with PCOS, the ability to be a mother is closely linked to women's sense of self-worth; if they are unable to do so, they believe that they are not contributing to society or are not valuable in any way.

According to Kitzinger and Willmott (2002) infertility is socially framed as a “cultural disorder” and not only threatens a woman’s familial aspirations but also her gendered sense of self. As Hrithika says, in Indian culture ‘’it is the one and only concern when it comes to PCOS’’. Anthropologist Emily Martin contends in her book *The Woman in the Body* that the dread associated with the childless female body stems from a "lack of production: the disused factory, the failed business, the idle machine" (2001, 45). The concern stems from the fact that an infertile woman is "not reproducing, not continuing the species, not preparing to stay at home with the baby, not providing a safe, warm womb to nurture a man's sperm" (47).

Most women in this study were extremely concerned about future problems with pregnancy and the fact that they might never get to experience motherhood. All of them talked about feeling incomplete as women since one of their significant abilities might be affected by this condition, fertility was central in these women's lives irrespective of their age. Vedika and Ilana, who are only nineteen, talk about treatment that will help them with their reproductive capacity. According to studies on sexual behaviour and reproductive issues in teenage females with PCOS, young women with the condition stress about getting pregnant 3.4 times more often than their healthy peers (Trent et al.,2003).

For women with PCOS, stigma goes beyond the purview of health and influences women's perspectives on womanhood. They do not find themselves as properly gendered in their embodiment according to the gender binary and are consistently trying to fulfill their gender identity to be culturally intelligible (Butler, 1990). In terms of fertility and reproductivity, they are always in a state of uncertainty because they are aware that this condition can lead to infertility and risk in pregnancy but are unable to do anything about it in the present.

Ayana and Bhoomika expressed that as brown women they felt a lot of pressure when everybody (family and relatives) came to know that they had PCOS. They stated that pressure about reproductivity is something that was very distinct about Indian culture, where they felt that their bodies were reduced to machines that had to fulfill the role of bearing children.

> *''I think in India, when you talk about PCOS, everyone just starts talking about fertility. Like, if you're talking about PCOS, you are talking about just fertility, like your whole body just goes to*

> *die. And just you just get reduced to a vending machine, and my parts are not working. That's very odd. Like, why is everyone talking about my fertility, because then, at that point of time, you're also talking about my sex life as an adjacent narrative. I don't want to have those conversations with random aunties.'' (Ayana)*

> *''I think if they find out that they'll be just more judgmental, or gossipy, and will make more conclusions based on this one piece of knowledge. Oh, she might not be able to have kids. So, I think they'll be more annoying about it than folks here (Canada)... that culturally it is and will be a bit of a taboo, if a woman is having any reproductive problems at all. Yeah, and there's a lot of blame that goes around the woman, even if she has a medical diagnosis. That kind of impacts me.'' (Bhoomika)*

This is a representation of how the socio-cultural ideals prevalent in society get related with a health condition, where reproduction is the primary function that the female body is supposed to entail. Ussher (2006) states that "the reproductive body is central to the process by which women take up the subject position 'woman'; central to the performance of normative femininity" (p. 3). PCOS bodies get conceptualized based on the ''failure or the breakdown of the reproductive system'' (Fennercioglu, 2017, p.48). According to research on women with PCOS, individuals show significant feelings of hopelessness and stress due to the possibility of never having children (Deeks et al., 2010; Jones et al., 2011; Trent et al., 2002).

Bhoomika has hidden the fact that she has PCOS from her partner fearing that the knowledge that it might affect her fertility, can in turn make her partner ''doubt'' her and their relationship because she might not be able to conceive in the future. She describes her infertility as possibly preventing her from leading a "standard" life as a woman. For her, being a mother is closely associated with her self-worth and identity. Zaidi (2019) in her study found that Pakistani women with PCOS perceive themselves as less valuable or as unable to achieve their social role when they get their diagnosis, fearing that they will be unable to become mothers.

The women in this study elaborate on how interactions with other people ‘otherized’ them since this condition might disrupt the normal expectations of how their bodies should be, how their life should unfold. Firstly, these women have a syndrome that affects their fertility, and hence they get stigmatized even before they try to get pregnant. Secondly, the symptom manifestations do not align with the ideal imagery of what a woman should look like. These interactions or the people in these interactions act as the ‘guardians of normalcy’ who keep on reminding these women that there is something wrong with them- they are incomplete as women. They also credit the infertility stigma conceptions to their cultural background, blaming the foundation of this otherization on Indian culture.

Expanding on Goffman’s theory on stigma, Link and Phelan (2001) discuss the construction of stigma. ‘’Stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics -- to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of ‘us’, from ‘them.’’’ (p. 367). For women with PCOS, the physical and physiological symptoms lead to the distinction based on negative cultural stereotypes.

Within PCOS discourse, the phrases ‘’more’’ or ‘’less’’ are always constructed as problematic. Starting from having more body hair or facial hair, more body weight, too much menstrual pain, less hair, menstrual periods that last for more or less number of days- everything gets labelled as abnormal but not in the context of heath but more in terms of a normative female body. The participants confessed how they go through a constant internal struggle to become more normal but indirectly refer to being more womanly.

Chapter Conclusion

Women are constantly exposed to heteronormative conceptions of the ideal female body. They talk about making decisions, choosing specific feminine technologies and body-management practices that are influenced by these ingrained constructions that help them 'fulfill' their gender identity and maintain the gender intelligibility matrix.

This chapter provides insights about how women characterize their PCOS bodies according to these conceptions. Participants stated that their struggles with PCOS were mainly struggles to become a 'normal woman'. Sub-themes in this chapter explored how they try to fix their bodily symptoms, menstrual cycles and their concerns about future motherhood. I integrated these sub-themes with the primary theme of 'being a normal woman' to represent how these in turn consist of coping strategies to manage stigma and be more intelligible in regards to their culture and gender.

The women in this study always mention about not being able to determine where they stand- they want to feel like a woman, but are not able to for two reasons. First, they experience incoherence with an ideal healthy female body (both in terms of appearance and abilities). Second, they constantly have to try to reshape their bodies (either hormonally or other measures to address visible symptoms), signifying that they are in fact always trying to be a woman, authenticating their internal sense of gender. Whether it be their strained relationships with female friends, or the difficulty in finding a partner or negative interactions with relatives and friends where they felt socially rejected- all expose the fact that PCOS as a condition does not only impact their bodies and perceptions but also their equations with others around them. Women also use culture as a rhetorical device and associate negative experiences with it. They connect most instances of stigma to be rooted in their ethnic culture and express the pressures they face to conform to be a woman. They use cultural norms to interpret and make sense of their experiences—particularly the negative ones. This entails expressing their sentiments, defending their choices, or criticising their circumstances using cultural allusions, expectations, and ideals.

In the next chapter, I will connect the embodied experience of the condition with the embodied experience of the treatment, and also discuss how the medical system reinstates the problematization of PCOS bodies.

CHAPTER VI

Treatment and Correction

‘’The discipline and normalization of the female body [...] has to be acknowledged as an amazingly durable and flexible strategy of social control.’’
-Susan Bordo, Unbearable Weight, 1993, p.166

The previous chapters dealt with symptom experiences of PCOS and how those impacted my participants’ lives, especially as they grapple with being a ‘normal’ woman. I discussed how bodily appearance and menstrual issues in the present and possible infertility in the future heavily impact their self-perceptions as a woman. In terms of gendered embodiment, these women questioned their self-worth and often found that this condition structures their interpersonal relationships.

This chapter will discuss the treatment aspect of their PCOS experience. Treatment narratives demonstrate how healthcare systems influence patients' experiences. They shed light on the intricate interactions between personal experiences and larger social, cultural, and institutional settings. First, I explore women’s internalized ideas about the ideal healthy female body and treatment. I connect these perspectives with Western biomedical ideas and show how medical encounters with doctors have an influence on how PCOS is viewed. I highlight narratives of these encounters where medical doctors’ focus was on the ‘problem’ of possible infertility. In the second main findings section, I explore the treatment experience of these women to understand how the internalized ideas and the biomedical notions in turn affect the treatment process.

I adopt a Foucauldian approach to understand the imposition of body norms and ideals through institutions and structures, and how those intersect with a body that is non-conforming.

Bartky (1990) argues that the disciplinary power that regulates femininity in female bodies cannot be limited to only one institution. The previous chapter showed how family and social networks play an important role in this regulation but now I will discuss how a major part of this disciplinary regulation of femininity is also rooted in the medicalized ideas of the healthy female body.

I will refer to the concept of medicalization to expand on how medical professionals reinstate biomedical ideals and essentialization, especially when it comes to women's capacity to reproduce. According to Riessman (2010), medicalization consists of two interconnected processes: First, a medical definition is applied to particular behaviours or circumstances, defining them in terms of health and disease. Second, in order to ensure obedience to societal norms, medical practice turns into a tool for eradicating or managing experiences that are defined as deviant.

As McKellar wrote in her study of PCOS, ''The increase in medicalization is problematic in that the line between what is "normal" and what is a mild "disorder" has become blurred'' (2015, p. 17). This chapter explores that blurred line where participants develop preferences based on these medicalized ideas of health. They view being healthy as having the ideal female body and medicalization as a concept helps to understand why women in turn internalize these ideas and self-discipline their bodies as well.

The chapter will begin with how women view and approach treatment, and how they prioritize the treatment of specific symptoms over others. I argue that women unconsciously create two kinds of hierarchies: one based on symptoms of PCOS and the other where they prioritize certain health problems over others. In the first kind of hierarchy, they prioritize symptoms of the present—those that are visible to everyone--based on internalized ideas about the female body. The second hierarchy places a priority on correcting symptoms through hormonal treatment and dismisses the side effects of medication. I did not ask details or the dosage of the medication however, all my participants used the word ‘’birth control’’ or ‘’contraceptives’’ to describe the hormonal treatment they were prescribed.

In the second section I examine women’s interactions in medical settings and elaborate on how these are of central significance when it comes to their analysis of the treatment process. I highlight narratives of these encounters where medical doctors’ focus was on the ‘problem’ of possible infertility. For most women, their encounters with doctors made them feel that they were unheard and would be only taken seriously if pregnancy came into question. Their concerns about other symptoms that were appearance based, were not paid much attention to. As a result, many participants expressed that they were not given the right treatment (which was mostly hormonal medicine).

In the third and final findings section, I discuss two narratives that are specifically about the assessment of hormonal treatment. While some women positively framed it as helpful, others did not. I relate these two contrasting views to the fact that women looked to treatment to ‘’fix’’ their physical symptoms (primarily adhering to feminine appearance). As much as they express concern about possible fertility issues, they are secondary and come up in the assessment of treatment but only as a concern for the future. These two contrasting perspectives deepen understanding of how, with regards to PCOS, women associate a healthy body with a female body fulfilled in its feminine capacities.

1. Women’s ideas about treatment

As mentioned above, this section will primarily highlight the two hierarchies that become evident in the women’s narratives. The first sub-theme expands on women’s prioritization of certain symptoms over others whereas the second one discusses more about health issues where side effects of hormonal treatment are ignored because they view symptoms of PCOS more important. However, both hierarchies are essentially influenced by their attempts to manage stigma and be more intelligible.

1.1 Symptom Hierarchy: Visible symptoms vs future problems

During the focus group discussion, participants were discussing the symptoms that impacted their lives the most and also talked about how there were other symptoms that did not affect them as much. Most participants discussed that they wanted to get rid of the physical manifestations, specifically hirsutism, acne and the weight gain above anything else. This section demonstrates this hierarchy these women have created based on which symptoms they want gone first. By symptom hierarchy, I want to establish how women's preferences of symptom treatment are founded on their interpersonal experiences of being stigmatized. Due to the visible symptoms being clearly evident to everyone, these become more important.

Fabricius (2020) in her study on women with PCOS claimed that medical discourses on PCOS and how knowledge is situated and internalized by women with PCOS ‘’shape not only their social and material practices, but their very subjectivities.’’ (p. 110). For my participants too, their perspectives about treatment were influenced by socio-cultural constructs of embodied femininity. The participants expressed that those were the ‘visible’ symptoms and felt constantly judged and criticized because of them. In this study, although infertility was a major concern for many women, the majority stated that at the moment, they want to correct the symptoms that make them ‘’relate to other women’’ (Vedika).

When asked about what kind of treatment would be ideal for them, most participants in this study expressed that they wanted to ‘fix’ their appearance.

‘’As superficial as it sounds, I would want to fix the external part of it. Because my insecurity

> *stems from very much being outward appearances of PCOS. So, if I could change that, if there was a medication to change that I would probably take it in a heartbeat.'' (Naina)*

> *''I think, you know, the physical like hair growth, that was just, you know, a texture thing and how you see yourself where it's like, you don't always feel comfortable in your own body where you look like how it should look. I look kind of masculine. But I'm, I'm female, like, this is very weird. I would want that to go away. That makes me feel so uncomfortable'' (Clarissa)*

> *''If someone asked me in the spur of the moment, I would say I want my external symptoms to get treated soon, because that affects me a lot. But then I want to stop taking the medication, because I am scared it might affect me in the future…with conceiving and all that.'' (Aahana)*

Participants like Asha, Asmi and Alia did express their concerns about other conditions like uterine cancer and diabetes in the future, but the focus regarding the future was more centered around fertility. However, Hrithika talks about how infertility is ''a problem for the future'' and for now she wants to focus on following a better lifestyle so that her external symptoms (excessive body hair and weight gain) can be controlled.

> *''I do want to have kids in the future. It's not that I don't want to, I feel like this is something I kind of go into denial about. I'm like, yeah, it's a problem for the future, not now. So, because obviously, I'm not looking to have kids. Now. I don't think about it as much. But I do want kids in the future. So, I feel like it could bother me more in the future than now. For now, I'll try my best to do whatever I can. So, it's easier for me in the future. But moment, infertility doesn't bother me as much''*

Fabricious' research shows how PCOS bodies are negotiated intersubjectively and are relational to others (Fabricious, 2020). All the above statements make it clear that in the present they want to correct the symptoms that can be seen by others. Fertility is a major concern for them, but it is again something relational, i.e., for most of them it is not a problem that they have to deal with now, but in the future which would again impact people close to them. As discussed in the previous chapter, they want to cope with stigma that according to them cannot be avoided, since the external visible symptomatic manifestations will always be evident to others and thus arises the need to treat these first so that they can maintain their feminine looks.

According to Foucault (1995), messages that demand changes or improvements from bodies—what he refers to as the "modality of docility"—implicate "an uninterrupted, constant coercion, supervising the processes of the activity rather than its result" (p. 137). Through messaging from the media, news, friends, family, doctors, and the general public that push women to control their bodies—with little regard for whether that control is even possible for all women—women with PCOS are continuously forced into surveillance (of the self and others) and regulation of their bodies (i.e., technologies of femininity, medical intervention). The preference to treat visible symptoms over others is a reflection of this self-surveillance. The next section will explore another important sub theme- that of health hierarchy, wherein I touch upon how based on these messages of control, women also unconsciously create a hierarchy of health problems.

1.2 Health hierarchy: Regulating toward normality

The interviews and discussion brought up another interesting aspect of priorities and treatment preferences. The majority of participants reported that they had faced prominent and sometimes severe side effects of taking birth control, but they still continued with it. By health hierarchy, I refer to the clear prioritizing of less body and facial hair growth, less acne having and ‘normal’ menstrual cycles over the side effects and other health problems that could have been caused due to the treatment. In this section, I illuminate how the possible risks of hormonal contraceptives are seen as “worth it” because they enable the person with PCOS to regulate their body so it becomes more “normal”.

Most participants expressed that they knew that taking birth control could lead to severe side effects. There were many participants who claimed that they experienced intense mood swings, huge weight gain, immense hair loss, increased menstrual pain and other side effects after they started taking birth control but still chose to continue with them because they helped them ‘get’ their periods, or restored their clear skin and controlled hirsutism.

Clarissa shared how she plans to remain on birth control in the future since it is an ‘*’easy option”* for her and that *‘’the only adverse effects would be I'd be hormonal or nauseous or have extreme mood swings for about a month or so until I settled, and then I'd be back at the normal’’.* For her, less facial hair and the periods are more important than experiencing the negative side effects of birth control. This shows how women have internalized a constructed hierarchy of health problems, where their priority should be femininity and fertility. Some women who were facing these side effects also expressed that they continued with the treatment hoping that it would help them eventually.

> *‘’I think I was just scared at the time. And I was just doing it because I thought maybe it'll help eventually. Or I even was scared because getting off birth control people gained like 20 pounds instantly, and I didn't want that to happen to me. So, I was just scared because why I was just stayed on it.’’ (Sana)*

The hierarchization of health problems depends then on the relationship between risk and the power dynamics that influence lived experiences. Based on the consideration of health problems ranked according to what becomes primary and needs to be treated or corrected in a woman’s body, these women agree with the possible risks of hormonal contraceptives because they are seen as worth it. The side effects of hormonal pills become secondary to the regulation of

womanhood inside the body. This can be related to Irni's approach of ''relationality of risk'', where the risk of not taking these pills supersedes the risks of taking them (Irni,2017).
Chrisler (2013) expands on Foucault's theory that medicalization defines and upholds standards of femininity and health by extending the power of medical authority into daily life. Following Chrisler's argument, women typically follow strict social norms in an effort to fulfil and maintain conventional notions of femininity which in turn make them prioritize certain health aspects when it comes to treatment. Women who experience PCOS symptoms seek treatment through biomedicine to normalize their bodies according to the internalized gendered and medicalized notions of femaleness.

The participants state how the treatment has affected them mentally, sexually and even physically too, but they focused on being more womanly rather than healing their health.
Ellerman (2012) stated that ''biomedicine is so deeply entrenched that it permeates myriad aspects of our everyday existence, becoming a ubiquitous presence.'' (p.24). It serves as a tool of the medical institution that determines what is deemed healthy/unhealthy. But it does not only get limited to that. It also influences women which health problems they should prioritize and which ones they should tolerate to preserve their feminine capacities. The internalization of socio-cultural ideals and norms of gender and womanhood and the medicalized control of women's bodies have made a hierarchization of health problems, where for a woman, the primary concern was maintaining their feminine appearance and functionality, especially their capacity to reproduce.

2. Experiences with Treatment in Medical Settings

Till now, I have talked about women's perspectives on treatment and symptoms they want to get treated first, overlooking problems they are facing or might face due to hormonal treatments.

The following section will specifically address the interactions of my participants with their doctors and medical professionals. It will connect the perspectives these women have with regards to the condition and treatment to the institutional realities of medicalization. The previous sections elaborated on the hierarchies that women create in terms of fixing their bodies but in the next sections, I illuminate a hierarchy that originates outside the women with PCOS, in the perceptions of medical practitioners.

The first sub-theme will explore how in the interactions with doctors, there was an imminent hierarchy of health problems, where these women's perspectives and their voices are not heard. The other sub-theme, responsibility and blame, will also cover medical encounters wherein these women express that they were considered to be responsible for their health. The sub-themes will be related to ideas of medicalization as well to connect these interactions to the larger structure of Western biomedical framework.

2.1 Health Hierarchy in the medical system

In this section I elaborate on how a health hierarchy for the female body also is pre constructed in the medical world. Here, by health hierarchy, I refer to how in patient-doctor interactions, doctors focused on reproductivity as the only concern. The construction of health hierarchy typically happens because most illnesses or conditions are viewed from biomedical perspectives that perpetuate the standard of normalization. The medical model is implicitly based on mind/body dualism (i.e., the body is distinct from the mind and is treatable mechanically). Biomedicine is composed of hierarchical, ranked, and binarized lateral associations that prioritize one over the other; frequently, the subordinated term represents a state of difference that is typically viewed negatively (Grosz, 1994). Differences in terms of health, especially when it comes to conditions, where a physiological problem is diagnosed, it is explained from a biomedical standpoint as a distinct clinical entity or a category of illness, where the patient would need to be monitored, treated, or managed in order to get their body back in line with what is deemed normal (Shildrick, 1997).

Fertility gets intertwined in the first step of diagnosis. When the participants (especially those who were diagnosed in India and later shifted to Edmonton) were asked about their diagnosis and consultation experience. Most women stated that after knowing that they had PCOS, they consulted only a gynaecologist. Clarissa expressed how she assumed that this condition can only be dealt with by a gynaecologist when she got diagnosed with the same.

> *‘’I specifically chose a gynaecologist because I didn't know there were other people that dealt with it. I was like, oh, gynaecologist, like they deal with women's health and periods. So, they would probably know, like something more than family doctors. And then later after I found out about PCOS, about like, the endocrinologist who like we're more specifically about that. And I was like, Oh, I didn't know that. ‘’*

Maisha expressed that she consulted a gynaecologist because she had ‘’*successfully dealt with other cases of PCOS where women were able to conceive*’’.

The decision to get diagnosed by a gynaecologist was essentially based on the irregularity of menstrual cycles. However, even after knowing that they had PCOS, that the problem with ovaries were just part of the larger hormonal endocrine disorder, these women preferred gynaecological treatment over endocrinological ones, which shows how the focus of these women has always been on restoring femininity and on the gynaecological aspects of the condition. On a broader level, these accounts connect this focus and approach to treatment with the fact that PCOS is mostly classified as a reproductive condition.

> *‘’Honestly, I did not even know that I had to refer to an endocrinologist, I came to know about it recently. Why am I confused? When I think of PCOS treatment? Why do I not know that I can go to a gynecologist and an endocrinologist both? Why don't people tell me that? By people I mean fucking doctors. ’’ (Ayana)*

All of the participants in this study expressed how they have been extremely frustrated, confused and anxious because of their encounters with their doctors. Some participants complained that practitioners failed to appropriately address other symptoms because they placed too much attention on the issue of reproduction. Reiterating a similar observation made by Kitzinger and Wilmott (2002), some of the women in my research also reported to me that they believed their doctors either under- or over-diagnosed PCOS. For instance, Ayana shared how the doctor made her feel like a ‘’baby producing machine’’ and talked about the trivialization of appearance-based symptoms like acne by the doctor.

> *‘’I feel it's sort of like a double-edged sword that sometimes I feel people don't take PCOS seriously. Or sometimes people take it like, way too seriously. I went to see the University doctor and I told him that my PCOS is getting really flared up….my chin hair just erupting, I started getting a lot of acne. And my periods were getting a bit irregular. And then he asked me, ‘’Are you planning to get pregnant anytime soon?’’... He was like, if you're not planning to get pregnant, then we don't need to do anything about it. I was like, it's still messing up with my life and my body. He literally said if you decide to get pregnant at some point in future, then we can do a treatment. That was my Canadian PCOS journey, because for some reason, I thought maybe it would be better in Canada in some ways, maybe, but apparently not. That was very difficult, because it just made me feel like I'm like a baby producing machine. ‘’*

Ayana’s narrative reflects that the focus is always on restoring fertility which led to the dismissal of other health problems. She states, *‘’ At one point, honestly, I was thinking, should I tell him that I am thinking of getting a baby? Because then maybe he will treat it?’’*

Alia, who is nineteen years old, shared how the University doctor ‘’was forcing’’ birth control on her, even though she did not want to take them. She also stated that the doctor did tell her about certain side effects but did not consider them as serious.

> *‘’They (doctors) casually tell you -oh, you might get a migraine and stuff. You may be prone to getting this and that but it's okay, fine. You can take birth control. And it's just like not done! No, that's not something that's very casual for us.’’*

Similarly, Janki also shared how her doctor also told her that the side effects won’t be a problem until and unless she decides to get pregnant. She stated, ‘’*They said that everything has a side effect, but like, there is no harm in taking the pill as long as you're not planning to, you know, conceive and stuff.* ‘’Twenty- year- old Naina talked about how the negligence of the doctor led to her delayed diagnosis. She expressed that her irregular menstrual cycles were not considered as a big deal in her initial teenage years, because she was young and didn’t need to get pregnant. She expresses that as a woman she was not heard and her concerns did not matter to the doctors just because her concerns were not as serious as fertility.

> *‘’I was pretty frustrated for the most part….it just kind of sucked having to go through like our healthcare system, the Canadian healthcare as a woman because you are always brushed off as it's just stress, you're in school, like you're anxious, that's why you have irregular periods and all of this. But the main reason is that you are young and you don’t need to get pregnant. So, it's really frustrating having to go to a doctor to say like, it's not just irregular periods, the weight gain and the excessive hair, like it's all of these other things that are also contributing, and still being brushed off and like having to advocate yourself, even when you shouldn't have to be doing stuff like that. And you should be, you should be taken more seriously.’’*

Parthavi’s consultation experience also made the prioritization very evident. After being on birth control, she expressed to her doctor that her menstrual pain had become intolerable, which according to the doctor was not an issue. She said that it seemed that the doctor was not identifying that the increased menstrual pain had become a problem and had prescribed more painkillers to her.

Asmi, shared that her doctor did not consider her cultural background during consultation and treatment prescription. She expressed that conventional treatments follow ‘’Western standards’’ and the dietary suggestions from medical professionals had taken ‘’away the culture from her’’. She expressed that she was disappointed with how her doctors asked her to give up all kinds of food that she used to eat and asked her to follow a new diet that did not include things that were part of her culture. When I asked her what would be some advice that she would want to give to someone who will be starting their PCOS journey, she said,

> *‘’Make sure when you're doing all of these things stay embedded in culture and like who you are as a person. Because, like, if you're changing everything about who you are, you will struggle with that later on. Right? So, like, even like, like when you've cut down like certain foods, like I suggested by dietician, nutrition, or like anyone that makes sure like you advocate for yourself and do not change everything about you, you're gonna get more sadness. Nowadays PCOS women are always advised to eat food that are not Indian culture friendly.’’*

Wright et al. (2020) say, ‘’Traditional western medicine dichotomizes body and mind and uses reductionism to exclude social, psychological and behavioural facets of illness.’’ (p. 1730). With regards to PCOS, the dominant Western biomedical framework excludes the cultural facet too. The reductionism was also evident when Alia talked about how her present doctor had a predetermined mindset about medicine. She had communicated to her doctor in Canada about vitamins prescribed before coming to Canada which was completely dismissed by her present doctor. She said,

> *‘’I tried getting prescribed here telling them this is a medicine that they gave me. And they were*

> *like, Oh, these are just vitamins and stuff. And I'm like, Yeah, but they helped me! But they didn't care at all. They were just forcing birth control on me. I think it's basically an attempt to promote contraception amongst university students. He did not even consider about how I feel about it.''*

Alia's experience shows how alternatives to birth control like vitamins are dismissed by doctors, under the impression that they are of no use when it comes to reproductivity.

Buddhavarapu (2019) stated that referencing PCOS only when fertility is threatened "is an act of dismembering the patient from her womb" (p.422). In order to address the risk to society's future generations, the patient's own experience and perceived health risks are disregarded. Rather than serving as a location of lived experiences where the body actively participates, the living body is seen as nothing more than a biochemical machine (Fennercioglu, 2017). For PCOS bodies they are also reduced to reproductive gendered machines.

A very clear health hierarchy of symptoms was evident in the women's narratives about their interactions with doctors, where there was a clear prioritization of fertility. Alia, Ayana and Vaidehi said that because of their consultation experience, they rejected birth control. They felt their concerns were overlooked. Their voices remain excluded in the treatment process. The following section is an expansion of such interactions with medical professionals where their voices are not only excluded but they also get further stigmatized in terms of being responsible for the condition and its treatment.

2.2 Responsibility and blame

The majority of the women narrated how their interactions with medical professionals always consisted of patient- blaming and putting the responsibility of the condition on them. They felt that since their goal was not to get pregnant, the doctors did not provide them with a treatment that could actually help them and only asked them to lose weight, making them feel like they are at fault for having this condition. This is similar to the findings from other qualitative studies on PCOS. ‘’Physicians and researchers generally frame women with PCOS as being responsible for the state of their poor health, especially in relation to fatness, which is generally believed to influence symptom expression and severity’’ (Fabricious, 2020, p. 91).

Some participants also reported how physicians asked women to lose weight and constructed it to be the reason for everything. For women who started gaining more weight after being on hormonal treatment, the blame seemed to be a never-ending cycle.

> *‘’I think this also had something to do with the fact that she (the doctor) was also a brown woman, like, South Asian. And that sort of, like, made sense to me. In our culture, it's very, like usual common to blame the weight gain or like the girl for having these issues, you know, I was just like, Oh, screw this, I'm not going to her anymore.’’ (Bhoomika)*

> *‘’Growing up, I kept going to my family doctor, about the missed periods and the weight gain and the facial hair. He would do blood tests and she would you know, tell me basically like you just need to lose weight. This is common among younger girls, but if you lose weight, it all kind of fixes itself. Yeah, so I would do that but I still couldn't lose the weight because of birth control. So, I think at a point I got fed up of that one doctor because I was not comfortable going with going to her anymore.’’ (Vaidehi)*

The participants’ discussions are filled with obvious signs of frustration, discomfort, and a loss of control. As Crawford (1977) argues, for those who fail to have healthy bodies according to normative ideals, their bodies are portrayed as different and as reckless for not caring for themselves more. The latter becomes more enhanced in case of PCOS because it is accompanied with cultural fears. The focus on fertility and pregnancy by doctors undermines all other problems these women have and eventually shifts the responsibility to manage this syndrome on the women themselves. This is similar to what Mehekdeep expressed, *‘’I feel like they make it more like our responsibility. And I feel like that's true for many disorders in women. ‘’*

The concepts of standardization, health, and abnormality that underpin biological understandings of PCOS were evident in these medical encounters. Women felt their concerns were not addressed and they were examined based on Western biomedical ideals of treatment. In the case of PCOS, it gets more complex since women are not only examined or judged as patients but also as female bodies. If pregnancy was not an issue that these women reported to, all other symptom corrections were shifted under their own responsibility.

3. Narratives of treatment

In the previous sections, I have represented themes that are more related to how treatment is viewed from both the patient and doctor perspectives. Here, I look more specifically at narratives around the most common treatment option advised to women by doctors: hormonal contraceptives. Women in this study judged hormonal contraceptives based largely on whether and how they helped them with symptoms associated with aspects or manifestations of femininity.

Overall, there were two distinct narratives held by different women about treatment that were very clear throughout. The first and most prominent one was that they did not think the birth control treatment method was useful for them, since they still felt ‘’unfeminine’’. The other, secondary, narrative was that they felt and looked healthier and considered birth control to have improved their conditions and controlled the symptoms, where being healthy was often synonymous with womanhood. Women who were not satisfied with the treatment expressed that even after going through the treatments they were prescribed by the doctors, still did not feel like a ‘’normal’’ woman. For both perspectives, most of these conceptions were focused on whether the treatment addressed the external symptoms that were visible. Women who thought that birth control did not help them also talked about the side effects of birth control but this concern was secondary; even when they talked about side effects, they mostly referred to how they might affect reproductivity.

The concept of health gets complex because primarily, these women examine the efficacy of birth control with regards to how it helps with maintaining femininity, without talking about ‘’being healthy’’. Their rejection of birth control or labelling it as ineffective because of side effects that make them feel ‘unhealthy’ now or in the future seems to be a secondary reason for them to dismiss this form of treatment.

3.1 Narrative 1: ‘’Birth control was not useful’’

When asked about why she did not continue with birth control Maisha mentioned that the treatment did not help her with her symptoms, especially with hair growth and mood swings.

> ‘’ *I had like courses and courses of birth control pills. And even after that my problem was not fixed. I mean the bleeding was normal most of the time, but the hair growth was still there, I was still getting mood swings, I was very irritated, even though I was on medication. I was really scared, to the point that I really wanted to burn all my medicines, and throw them out of the window. I wasn't really happy. I got severe acne; I couldn’t go out even after taking birth control. It made me really stressful about everything .... I was conscious all the time. And yeah, there are a lot of risk factors about taking birth control pills that nobody talks about. It can actually cause breast cancer….and also it can risk pregnancy in my future. Even after six months, then getting an ultrasound, it just gets right the first time then again, the symptoms come back. So yes, I think it (birth control) didn't really make any difference and I am scared if it affected me in terms of the future, like if I’m trying to get pregnant.*’’

Bhoomika and Ilana’s experience of the treatment process had commonalities with

Maisha’s, especially with regards to how the birth control impacted the external symptoms and its side effects that can have serious repercussions in the future. When they talk about the treatment in association with PCOS, their concerns are about the conventional feminine appearance (slim and hair free). Comments about the side effects of birth control, like Maisha, are stated later and are focused on health problems that can happen in the future.

> ‘’*Contraceptives were not really useful for me. I got laser treatment done. About a year ago, that was quite expensive. But honestly, my mental health has really benefited from the lack of facial hair. Yeah, birth control, I was on it. But I found that it like, like hindered my weight loss goals. And I was just very moody. I honestly don’t mind spending money on something that actually does something with my symptoms rather than adding more problems in my body. I am scared, like..fear of long-term effects. I also studied the effects of prolonged birth control like cancer, heart issues, and whatnot.’’ (Bhoomika)*

> *‘’When I think about treatment for PCOS, it’s like a lot of birth control or a cure, most likely that because like I have been put on birth control many times, it just messes up my periods. And I put on a lot of weight. I just don't feel myself on birth control…. you don't need to put things that could be full with other things with side effects. For me, I wouldn't even mind having a surgery to even reverse it. Personally speaking, but I would not want it to mess with fertility issues or, or hormones. Yeah, I'm trying to stay away from pills and everything because I don't know what it could cause, like it could cause some cancer or whatever. ‘’ (Ilana)*

In all of these testimonies, birth control was seen as an unsuitable form of treatment. Most of my participants expressed that there is a lot of vagueness around this condition and they are very confused specifically about how it can be ‘’actually’’ treated.

Some women who chose to take birth control shared that they expected it to help ‘’control’’ their symptoms but reported that their condition did not improve. They felt that they had not been given the correct treatment. Maisha did agree that the heavy bleeding stopped when she started birth control, but while describing her treatment process, she focused more on how birth control was not helpful since her external symptoms were still there. A part of her treatment experience was also focused on how birth control can impact her fertility and future pregnancy, which was again more influenced by her desire to ‘maintain’ or ‘preserve’ her femaleness and motherhood. Ilana also had a similar approach when she talked about how she did not prefer birth control since it could ‘’mess’’ with her fertility and hormones. In terms of body weight and external appearance, Ilana and Bhoomika did complain that birth control made them gain more weight.

When it comes to physical appearance, a person's level of satisfaction with their look is frequently influenced by how much they internalize what they consider to be "ideal" and how they view their appearance (Thomas et al., 2014). The approach to treatment in these cases is not an attempt to get a healthy body but more of a body that is fulfilled in terms of femininity and womanhood, that is essentially based on ideas of feminine gendered embodiment. The transformation that is desired is not from an unhealthy to a healthy body, but to a female body that is fertile. Ilana did mention that her periods got more regularized but there were no changes in terms of the hair growth. She said, *‘’Because of my hormonal problems and on top of that birth control is there now, my laser treatment doesn’t work for me. I think I have put on more weight’’.* In the case of all these women, when they were assessing the treatment, they overlooked how it possibly helped them with other symptoms and stressed more on how their feminine appearance was not ‘’fixed’’ by it. The only time they mentioned health was when they talked about side effects, which were again mostly future possibilities.

Participants expressed that irrespective of whether they were accepting or rejecting birth control, they felt helpless. They shared that it was frustrating to get prescribed birth-control pills as the only solution because it did not seem like a choice or the opportunity to control their bodies but as the only option to reduce the symptom effects.

All my participants agreed on one point- that there is no clarity with regards to treatment options or even causal factors which eventually lead to the doctors shifting the responsibility of having a healthy lifestyle to the women and only focusing on reproductive capacity. Asmi and Ayana talked about the dismissive attitude of doctors and Canadian healthcare in general and said that there isn't enough effort to understand their concerns or perspectives because it is essentially a woman's illness. Birth control seems to be the most easy and conventional form of treatment because the idea of a healthy female body in both Indian and Canadian discourses is centered around disciplining the bodies for reproductivity.

3.2. Narrative 2: ''Birth control helped me''

Just like the participants who expressed that birth control was not helpful, the participants who reported that birth control was a helpful treatment option in their PCOS journey focused on the femininity aspect more than health. For these women, the fact that the visible symptoms got ''fixed'' was the most important part. They were definitely satisfied that their menstrual cycles became regular but their contentment was more concentrated on immediate physical symptoms. Participants stated how PCOS symptoms did get better after they started taking birth control pills; however, the focus was more on how these 'markers' were either less or gone and how it made them feel like a normal 'woman' during these phases when they were on medication.

Asha and Mehekdeep were both happy with birth control as her treatment mostly because it helped with getting regular menstrual cycles. The reduction in facial hair, acne and menstrual cramps made them satisfied with their treatment. Both expressed that their body had become dependent on birth control, and even though their periods were not natural they were overall happier with the treatment that was prescribed to them.

> *''I just have the birth control to go over the PCOS. I stopped it in April, just to kind of see what would happen. I didn't get my period all summer. And then I got it in August when I started the birth control up again, which was like…. I had to wait to like to like the sugar pills and four days into that, which is the usual to actually start coming out. I think it's been helping me pretty good so far. Um, I've noticed that I've lost a little bit. I've gotten less hair growth, which is nice on my face. I prefer it that way, frankly. Else, my cramps are not as bad, which I really like. I can finally be a girl with no worries about my menstruation. '' (Asha)*

> *''It was like the first treatment my doctor gave me like, the cure for it basically, or the way to hide my symptoms. But I've honestly had like a positive experience with birth control. I'm like, very lucky in that way. Because I've heard like horror stories about how you get mood swings issues which are awful. But yeah, luckily, I haven't had anything like that. It's fixed. Like most of my, at least my outward symptoms… like, okay, I feel the only thing that's fixed really is my acne. I used to have really bad acne problems and my birth control fixed it. And my periods. Now they're basically just like, fake synthetic periods, but it works, whatever. '' (Mehekdeep)*

Janki on the other hand stated that she personally did not like taking pills but still preferred this treatment because her acne was in control. As an international undergraduate student, birth control actually helped her even though she did not like to be on medication all the time. She expressed that her academic life and shifting to a new country was very stressful for her and the contraceptives ensured that she got her periods every month and was not hindered by hormonal imbalances due to her stress. In general, she said that being on medication was annoying for her, but since her symptoms were in check, she preferred to continue that treatment.

> *''If I don't take the pill, and I also see like, Okay, I have a lot of acne, as soon as I leave the pill,*

> *like, or if I'm missing pills, I can see that, you know, those differences in my skin. So, I'm now, I'm of the thing that okay, you know, what if, if I have to take it, I'll probably take it, it's gonna fix my other problems as well. Because I think it's all about, you know, the hormones. And I mean, there's hormones in it, right. So, it's balancing the stuff that I my body is not able. I would say, just having the pill actually manages the symptoms that I'm having, or for PCOS. So, for example, like, you know, I can feel that I am not having that much hair fall, I'm not having that much acne. Like, my facial hair growth is like, balanced, and my periods are on time.''*

Anika reported that she got diagnosed back in 2019 in India and was prescribed birth control pills but did not actually take them since her parents were scared of its possible side effects. However, after coming to Canada and consulting the university doctor, Anika decided to go for birth control. She claimed that her experience with birth control has been a positive one since all her symptoms got better. She expressed, *''Coming to Canada has been the best decision, I guess if I had the same freedom to choose my treatment back in India, I wouldn't have had to deal with my symptoms for such a long time.''* She also said that she was aware of the side effects that birth control can have, but since she was not experiencing any negative effects of the same, she was satisfied with the treatment she was going through.

> *''I plan on continuing the treatment until I decide to get pregnant. I now have clear skin, my periods are regular, I do not have coarse hair on my face anymore and I have finally lost weight. I do not care what other people think or say, but contraceptives have been very helpful for me. I can now socialize with people; I am not conscious of how I look anymore. I have even stopped doing make up! I knew the side effects, I mean all medicines have them, I did not face anything so yeah, I feel beautiful now. I definitely feel better, like normal. So now I would say birth control helped me, I am healthy now ''*

For these women, the side effects of birth control were not a very big issue. Their experience was more centered around the fact that their appearance got better after they went through this treatment and since they did not face any negative side effects at the moment, they were willing to continue birth control. The possible health problems in the future did not stop them from taking the contraceptive pills. It comes down to the fact that for both groups, femininity and womanhood is integral and the most important thing in the entire illness and treatment experience. If the birth control did not ‘’correct’’ their symptoms, they stated it to be not helpful and only then do they talk about rejecting them for the possible health problems that it can lead to in the future. Even then, pregnancy and fertility become major concerns and supersede other health problems like diabetes and uterine cancer.

The above discussed themes and narratives show how medicalized ideas of bodies and socio-cultural constructs are connected. Surveillance, normalization and categorization of bodies through medical authority, social relations and other institutions reinforce disciplining of PCOS bodies. As Thanem (2011) stated, power relations discipline the body which is essentially gendered and perpetuate through different institutions. Treatments for these women not only serve as pathways for well-being based on ideals that are culturally influenced but are also essentially ways to discipline their bodies according to medicalized notions of a healthy female body. Women in this study unconsciously discipline their bodies according to the cultural, social and biological laws that are based on the heterosexual matrix which gives meaning to bodies. Health risks get intertwined with risks of not being feminine.

Chapter Conclusion

This chapter discussed both women’s and medical doctors’ perspectives on treatment decisions. It explored how these women develop symptom priorities and a health hierarchy, wherein they want certain symptoms to get treated first, and are prepared to face any side effects and health problems caused by hormonal pills to get the desired female appearance and normal menstrual experience. These were heavily influenced by their interactions with others and their strategies to deal with the stigma associated with symptoms.

The chapter also covered the medical encounters of my participants with doctors where their illness perspectives and concerns get overshadowed by the placed importance of fertility over everything. In the previous chapter we saw how women are developing strategies towards a predetermined idea of a healthy female body, where ‘health’ becomes secondary and becoming ‘female’ is the primary concern. In this chapter, too, we see that the female body is medicalized in such a way that ‘female’ and ‘healthy’ are not exclusive to each other. For women their priorities are focused to make their body look more feminine and fertile. For doctors, the female body is healthy only when it has the capacity to procreate. All other concerns apart from fertility are considered to be the patient’s problem.

I finally present two contrasting perspectives on treatment results, where I highlight my participants’ narratives that build on themes from previous sections and chapters. Most women seemed satisfied with hormonal treatment only when their visible symptoms and menstrual problems were regulated. Others who rejected the treatment also based the treatment’s effectiveness on the same factors. However, these participants also talked about how side effects of the contraceptives played a major role in their perceptions, but it seemed like a secondary reason to their concerns about maintaining the ideal of a feminine body. The treatment was assessed more on the fact if it made them more womanly and not healthy.

CHAPTER XII

Conclusion

‘’The body can never be regarded merely as a site of quantifiable processes that can be assessed objectively, but must be treated as invested with personal meaning, history, and value that are ultimately determinable by the subject who lives ‘within’ it.’’

-Susan Bordo, Unbearable Weight, 2003, p.74

Let us return back to the research questions I asked at the beginning of my research.

(1) What are the treatments that Indo- Canadian women prefer with regards to PCOS?

(2) How do these preferences arise from their lived experience of PCOS?

(3) Do these preferences and experiences connect to the broader biomedical and socio-cultural ideals of femininity? If so, how?

With regards to the first question, in chapter six, I explored treatment narratives and medical encounters of my participants which exposed their preferences in treatment in terms of PCOS. Hormonal treatment (stated as birth control or contraceptives by participants) was the primary mode of treatment that was prescribed to all the women. Few of them shared that they considered it to be useful. Some of the women expressed that even though they were unhappy with their bodies’ dependence on this medicine. they still preferred being on birth control since it made their symptoms (especially appearance-based symptoms) go away.

However, most women rejected the treatment and stated that for them, this line of treatment did not help with their symptoms (again, focused more on visible symptoms) and brought up side effects of treatment, but these seemed to be secondary to their concern about maintaining their femininity and becoming intelligible as a woman. These decisions were based on their efforts to avoid stigma, related to their visible symptoms.

Coming to my second research question, my findings (chapters 4,5,6) outlined the lived experiences of my participants that explain why they had these perspectives about treatment. Chapter four demonstrated body maps of the participants where they relate their body parts with negative associations, negative emotions and stigma experiences- most of them related to body and facial hair growth and body weight. Expanding on the body maps, in chapter five, I discuss women's embodied insecurities and the influence this condition has on their lives.

As seen in the maps, bodily appearance was the primary theme that came up. Although women talk about reproductive functionality and express concern about menstrual problems and possible infertility, these do not become as significant since they are not known or visible to everyone. These relational and futuristic aspects of their symptoms become secondary to their strategies to fix their appearance in the attempt to be a ‘‘normal’’ woman and become intelligible with regards to their gender identity and cultural norms.

The stigmatization my participants experience and internalize influences how they view this condition as a part of their lives and their approach to treatment. Intelligible genders, according to Butler (1990), are those that establish and sustain relationships of "coherence and continuity among sex, gender, sexual practice, and desire" (p. 23). Because the intelligible genders are based on discursive norms that regulate deviance, their primary impact is to restrict any kind of incoherent embodiment. Women in general struggle with phenotypical normative femininity norms (Esteban-Gonzalo et al., 2020). Similarly, women in this study try to get rid of any ‘unfeminine’ symptoms which benefit them and maintain the predetermined norms of what the ideal female body is. These discursive norms are not only cultural but also medical where the concepts of ‘’healthy’’ and ‘’female’’ get intertwined, which I also explore in chapter six.

Chapter six builds a connection between the social imagery of an ideal woman and the medicalized ideal of a healthy female body, both of which are constructed on the basis of the gender binary and expectations. We see that femininity in forms of reproductive capacity becomes integral for doctors. Women with PCOS are viewed only in terms of their bodies, which are again medicalized and viewed as machines for reproduction. My participants were asked if they plan to get pregnant any time soon and only then they are taken seriously. If not, it seems like all other symptoms don't raise concern and hormonal pills are prescribed to ensure women are regularly menstruating, which is again a sign of being able to be fertile. Hormonal treatments reduce their body to a vessel that produces and circulates hormones, and focuses on 'optimizing' its balance aimed at providing menstrual regularity which in turn optimizes the normative physicality and functionality of women (Balsamo, 1996), which brings me to my third and final research question.

PCOS is related to broader biomedical and socio-cultural ideals of femininity, so much so that for my participants, health and normative femininity get conflated. Chapter five shows that participants always refer to feeling different than other women, but they never bring up that they feel unhealthy. The body maps acted like a converging space for all women in terms of bodily experience of PCOS. Irrespective of what they thought about birth control and its impact on their treatment, they all focused on negative feelings and experiences about their body parts, which were again mostly related to appearance-based symptoms which made them insecure about their connection to womanhood. Fahs (2012) talks about western notions of femininity and that they are pervasive and hard to modify. Women are exposed to cultural messages about how they should seem, preferably as slender and hairless, from a variety of sources, including family members and the media. 'Looking feminine' and adhering to these cultural norms was the most important aspect of my participant’s PCOS experience. According to Bartky (2010), a woman's identity is often closely linked to ideas of femininity and that it takes "skill" to sustain gender normativity. Since people are currently only perceived as male or female, having a body that is perceived as "feminine"—that is, a body that has been socially constructed through appropriate practices—is typically essential to a woman's sense of herself. (p. 91)

Women also talked about menstruation and reproductive capacity but the major concern with regards to bodily function was associated with a broader gender role of motherhood. Mishra and Sharma (2022) discuss that in Indian culture, having children is a social identity issue. As mentioned before, a woman is deemed to be complete only after giving birth, and if she is unable to do so, she is referred to as a "barren" woman. PCOS presents a significant obstacle to individuals with the condition and much more so to married women who are still unable to conceive. Therefore, the greatest stigma associated with this illness in Indian discourse may be the inability to procreate. Not only does this condition cause a woman to feel incomplete, but it also makes her socially distant.

Even though fear about infertility was expressed as one of the major concerns after getting the diagnosis, it seemed that women were more scared of not being able to fulfill the motherhood mandate. Interestingly, two participants shared that infertility did not scare them as much since they were eager to try other forms of motherhood, which again revealed that the focus was more on the social role rather than the biological role.

In general, women in this study equated ‘’healthy’’ and ‘’feminine’’. They were more apprehensive about how their appearance and internal functionality differs from what is expected of a ‘’normal’’ woman. Even when participants talk about treatment results in chapter 6, they refer to symptoms affecting their feminine appearance and reproductivity. Anika for instance, said, *''I feel beautiful now….I feel healthy''*.

In terms of identity, women in this study express that they always experience a state of liminality, a condition of ambiguity and uncertainty in which they feel difficult to categorize themselves. They are always trying to ''be a woman'' which reflects how with the symptoms and treatment they are not already a complete woman. They have internalized the belief that other women can do things with ease but they (women with PCOS) can only do them with great effort and pain. With the diagnosis and treatment some of them cannot decide if they are healthy or not; if their symptoms get better with hormonal treatment, they still are concerned about whether they will be able to be pregnant in the future, if they have regular menstrual cycles after treatment, some question themselves and think their body has lost its natural feminine capacities.

Strongly held beliefs about femininity, beauty, fertility and "being a woman" may be called into question since symptoms of PCOS not only modifies the body in the present but leaves the possibility of future "dysfunctions", particularly with regards to pregnancy. Identity and self-perception of these women are therefore defined by ambiguity, and body image issues are frequently cause for discontent. Challenged by having to maintain femininity in conformity with society's norms, interviewees worked persistently to adjust their body to intelligible ways of doing gender (Butler, 1993).

Culture plays an important role in this study. As discussed earlier in my literature review, I wanted to see if women's ethnic culture influenced their illness experience and how the discursive differences in Indian and Western cultures as discussed in previous studies, came up in this research. It was interesting to note that all women in this study blamed their ethnic culture- they leveraged cultural references as a rhetorical tool, consistently attributing the negative perceptions and experiences of stigma associated with PCOS to Indian culture.

However, specifically in terms of consultation and treatment experiences they attribute negative experiences to the medical culture. They express how doctors do not take their ethnic culture into account and dismiss it during the treatment process. Alia shared, *'' I asked the doctor if I can continue with the Ayurvedic supplement…it was helping me you know, but he said no, he completely ignored it.''* Asmi on the other hand expressed how she felt she was forced to change herself- *''I was instructed to stop eating more than half of the things that are there in our culture. Suddenly, how can I change everything in my diet?''*

Culture also comes up as a significant conceptual tool in explaining why there were differences in how women view fertility. In chapter five, I discussed the key difference in the demographics of the women who did not consider regular menstruation without any complexities as a symbol of reproductive ability. These women had been living in Canada for a longer period of time. Perhaps the exposure and acceptance to new forms of reproductive technology in Canadian society was one of the primary reasons that cyclicity of periods did not matter to these specific participants. On the other hand, women who had just immigrated or had been living in Canada for a comparatively shorter period were preoccupied with their menstrual irregularity, which is probably because Indian discourse focuses on regular menstruation as the reflection of a normal and necessary reproductive function (Buddhavarapu, 2020).

This also brings up the question that is central to this study- why did these women prioritise bodily appearance over everything, even fertility? Is it only because appearance-based symptoms will be evident and hence need to get treated first? Based on my findings, I argue that it is not the only reason. Perhaps here is where the Western notions of femininity and normal womanhood get precedence over the Indian views they encounter in their families and communities. Exposure to the Western imagery of the ideal female body influences their approach. But fertility still remains a fear for the future.

Crawford (2006) argued that in the neo liberal setting where health consciousness is becoming more and more inevitable because of the constant perpetuation of individual responsibility, healthy persons must seek out, evaluate, and act on a never-ending stream of information on health threats—a backdrop that feeds fear about problems. Rose states that the 'advanced liberal' governmental and medical technologies are characterized by 'marketization, autonomization and responsibilization' specifically in the context of health (Rose, 2007). Following Scharff's (2016) argument, women with PCOS have been positioned as subjects with agency and of capacity in public, media, and policy discourses who can live responsible, self-managed lives through ''self-application'' and ''self-transformation'' but in reality, women are not really given agency or choices but are only scrutinized from a medical and cultural lens. Sybylla (1997) also highlights the issue of hormone therapy, pointing out that while women may perceive this as a freeing decision to take charge of their bodies, the "be what you want" rhetoric really has a hidden normalizing and patriarchal agenda that is intertwined with power dynamics; where the main concern is to control women's appearance and fertility.

Asmi expresses her frustration about there being no progress with regards to treatment when it comes to PCOS.

> *''I think it feels a bit annoying and frustrating. Because I feel like they have as pointed out to be like the only solution. I'm in engineering, more in the biomedical side of engineering. So, I know like, in life, there cannot be just one concrete solution. But since women's health and maternal health in those sectors are like very under represented and researched. And, corporations as well, like, there's not a lot of companies that cater to women's health. If PCOS would have been men's illness, we would not have so much confusion.''*

It really does make us wonder where PCOS is situated in the complex intersection of a chronic health condition and a problem about normal womanhood. Why is hormonal treatment the only option used as preventive care? The PCOS body cannot be correctly or decisively classified in terms of binary male-female categories of hormonal functionality because of its imbalance associated with this condition, and thus emerges the need to ‘correct’ and ‘discipline’ it. Thus, women with this condition deal with the stigma of being both ‘’unhealthy’’ and ‘’unfeminine’’.

Illness narratives over the last few decades have demonstrated the importance of patient accounts in expanding the body of knowledge (Bennett et al, 2020). The experiences of their patients have the ability to both question and positively impact the medical paradigm, even if doctors are still a primary source of health knowledge. The accounts of female patients who have historically been repressed by the medical establishment hold particular significance in the field of Western medicine. Thus, these stories can act as instruments to support our critical analysis of these establishments (Stone-Mediatore 2003). This research study provided a platform for self-reflection to these women and on the other hand is also a scholarly exploration of themes that emerged from it. Biomedical knowledge gets enhanced when experiential knowledge is included in understanding illness.

I hope that the findings of this research will be of interest to members of the academic community who concentrate on feminist perspectives on health systems and gendered illnesses. The research can also be beneficial for the healthcare system in general, where issues regarding the hierarchization of health concerns can be examined, in addition to understanding the diverse problems of hormonal and gendered therapies. It might be helpful in providing a new perspective of illness, which will prioritize women and patients and not only the body or the disorder.

However, a new way to interpret this area of study might be to examine how social categories like gender, sexual orientation, age, social class, and ethnicity intersect in the experiences and narratives of women with PCOS by utilizing the concept of intersectionality. In addition to the stigma associated with PCOS, women from minority ethnic backgrounds may additionally experience marginalization as a result of the intersections between their gender, race, and social status. Intersectionality is a concept that may be used to investigate the meanings associated with various social categories and how these meanings shape social hierarchies and power structures (Crenshaw, 1991). Buddhavarapu (2020) pointed out that PCOS presents a distinctive opportunity for examining intersectional concerns because of its characteristics and the difficulties they provide for gendered medical discourses that control women's lives. This study did focus on ethnic categories but if we try to focus on the intersections of other important social realities like class, socio-economic status, geographical locations, ability and sexuality, we would be able to understand and capture the experiences of a diverse group of women and examine how these intersectional identities get connected with PCOS.

My personal vision and aim in general is to question how we define normalcy and what it means to be a woman. Oksala suggests that “Power inscribes the limits of normal bodily experiences, but it is exactly the existence of these limits that makes their transgression possible” (2004, p. 108). Perhaps PCOS bodies will be one of the many ways to challenge notions of health and womanhood. Anne Fausto-Sterling, states that ‘’In order to shift the politics of the body, one must change the politics of science itself.’’ (2000, 8). We need to question the binaries, and how depending on them gendered health models are creating and labelling conditions and producing the hierarchy of risks, based on the very practice of inducing artificial hormones into PCOS bodies, we can expose medicalized control and at the same time challenge it.

In closing I would like to say that it is time that women with PCOS reclaim their power through embodied knowledge. A diagnosis cannot decide if we are normal women or not. We have the potential to challenge not only medicalized notions of women's bodies but also social expectations that devalue PCOS bodies. We can start by asking a simple question-

‘’What do I want to be? Healthy or feminine?’’

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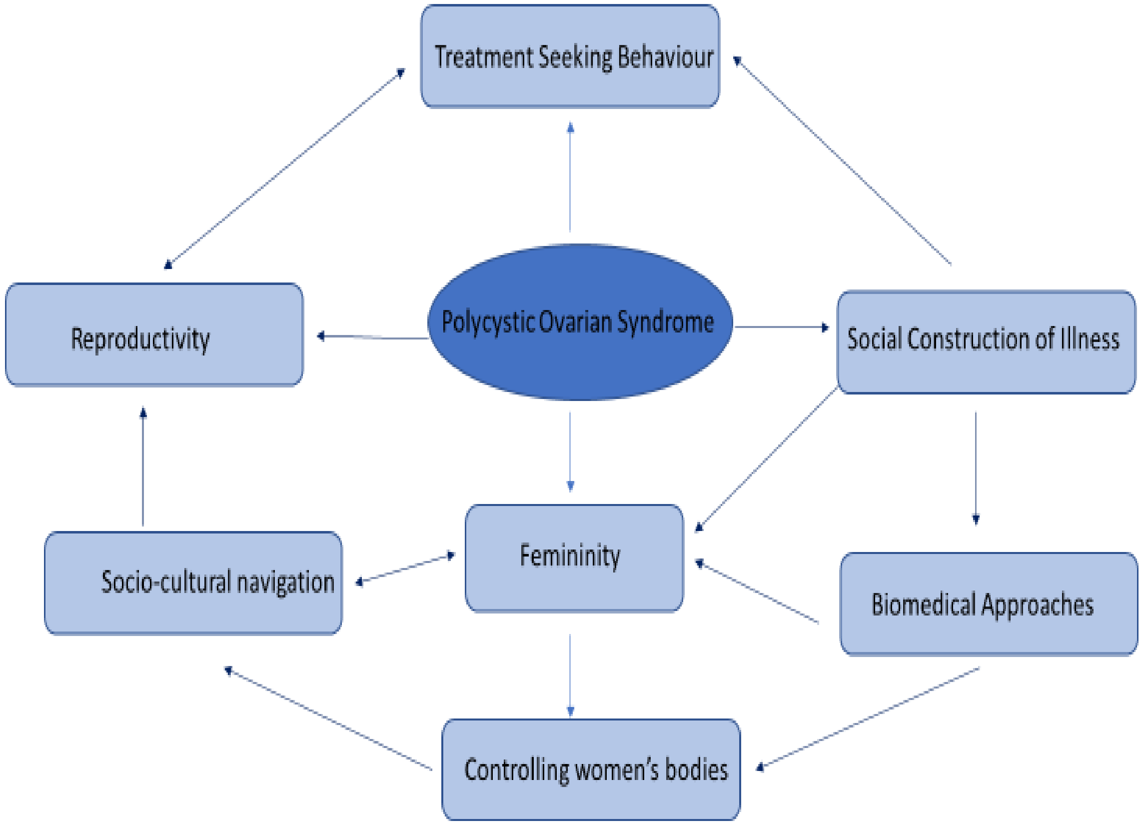
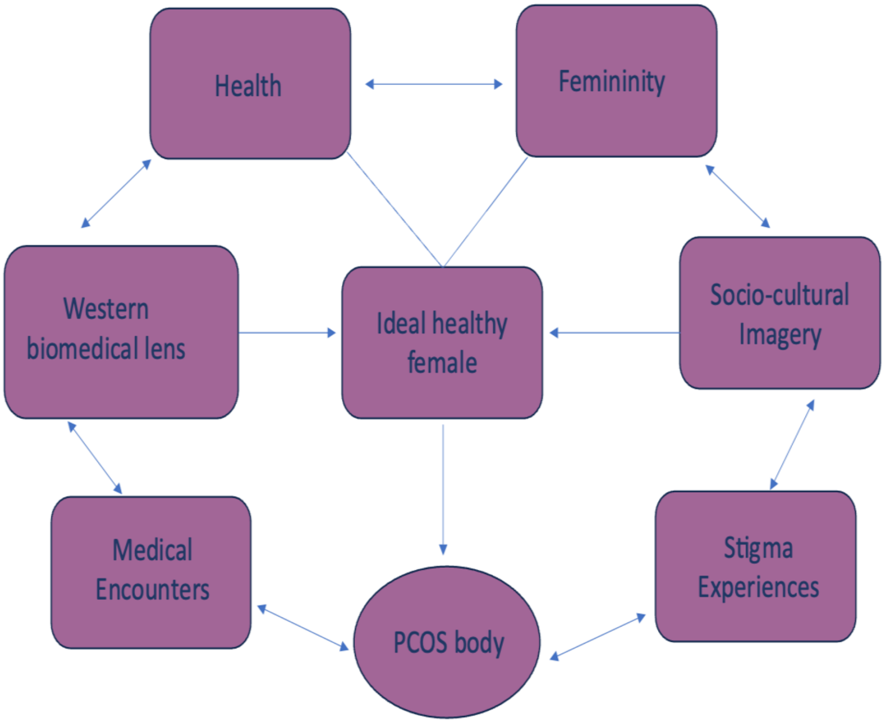
APPENDIX A

Conceptual Framework 1 (Based on Literature Review)



Conceptual Framework 2 (Based on Thematic Analysis)



APPENDIX B

Interview Guide (Interviews)

Hi, my name is Samadrita.

It's really nice to meet you. I'll be asking you some questions about your experience of dealing with polycystic ovarian syndrome and its treatment.

General question-

Can you tell me your story of PCOS?

Topics to be covered

1. Can you tell me when you first thought you had PCOS?

   (For me it was when I started to have acne on my face. I became very conscious because of it and my dermatologist advised me to go for the tests).

Prompts

- Which symptoms affected you the most?
- Was it your decision to get diagnosed?
- What were your concerns when you learnt you had this condition?
- How did you feel about it once you were diagnosed?

2. How was your diagnosis experience?

Prompts

- What kind of a medical professional did you go to?
- How was your experience with that medical professional?

3. How has this condition affected your life?

Prompts

- social life?
- mental health?
- sexual health?
- work life?

3. Are you going through any kind of treatment or do you plan to go for any form of treatment?

If YES-

-What kind of treatment/s are you going through or wish to take for PCOS?

-what are the reasons for you to try it?

-are there any references (Prompts- people who have the same disorder, social media, other resources, family?)

-was the decision entirely yours?

IF NO

-what are your reasons to not get treated?

- was the decision entirely yours?

-how are you managing PCOS?

4. (For those, who answered YES to the last question)

What effects are you experiencing or expecting because of the treatment?

-How do you think it has affected or will affect your life?

-Do you plan on continuing the treatment?

5. Let's talk about how and from where you get your information about the condition

-which sources do you prefer when it comes to information about treatment?

- which are the ones that you don’t count on?

6. How do you think others see you because of this condition?
   - Family
   - Intimate partners
   - friends
7. Do other people’s perceptions about you affect you?
8. Do you think the effects of this condition have affected others’ perception about you?
9. Has this condition affected how you see yourself as a woman?

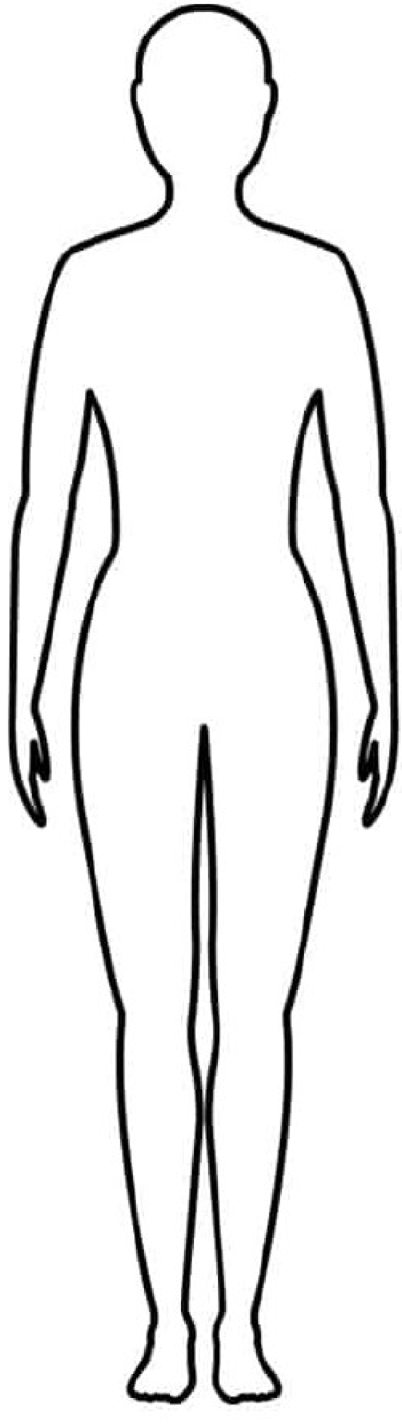
Prompts

- Symptoms
- Interactions
- Treatment

10. Is there anything else you would like to discuss?

APPENDIX C

OUTLINE FOR BODY MAPPING



APPENDIX D

(CONSENT FORM FOR INTERVIEWS)

Understanding women's experience of Polycystic Ovarian Syndrome and treatment-seeking behaviour

Research Investigator:
Samadrita Chowdhuri
University of Alberta
Edmonton, AB, T6G 2H4
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(587)9685458

Supervisors:
Dr. Amy Kaler and Dr. Sara Dorow
University of Alberta
Edmonton, AB, T6G 2H4
akaler@ualberta.ca
sdorow@ualberta.ca

Background and Purpose

In recent years PCOS has become a very prominent health concern for women. The incurable nature of the condition has led to varied types of debates and discussions regarding the forms of treatment for this disease. For this study, I examine women's experience of PCOS in connection with women's treatment seeking behaviour.

Study Procedure

The interview will take 45 minutes to one hour. It will be a face-to-face interview scheduled at a time and place that is best for you. If it is okay with you, I would like to record our interview. You may request a copy of your interview once it has been transcribed.

Risks and Benefits

At this time, there are no known risks to you through your participation in this study. However, if at any time you feel uncomfortable or the topic is uncomfortable for you, we will take a break from the interview. There are no immediate benefits for participants but I hope that you will benefit from this experience by reflecting upon and sharing your experiences.

Voluntary Participation

Your participation in this study is completely voluntary. If you feel uncomfortable responding to any question(s) or continuing with the interview, you have the right to not answer the question(s) or end the interview. You may also withdraw any information you have shared with me up to that point. If you wish to do so, please let me know within two weeks of your interview.

Confidentiality and Anonymity

All materials collected in this interview will be kept confidential. Your name will not appear in any of the transcripts, findings, or results. If you wish to have your name appear in the transcripts and/or final results, please let me know. In this case, I will share a copy of your interview with you. All recordings and notes will only be accessible by me or my supervisors.

Further Information

The design of this study follows the rules and recommendations provided by the University of Alberta Research Ethics Board. The plan for this study has been reviewed for following the ethical guidelines given by the University of Alberta Research Ethics Board. The ethics approval number for this project is Pro00094014. If you have any questions regarding participant rights and ethical conduct of this research, contact the Research Ethics Office at (780) 492-2615. If you have any questions regarding the interview or the project, please feel free to ask me any questions during the interview or following the interview to samadri2@ualberta.ca**.**

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

(Interviewee's Name) ______________ (Researcher's Name) _________________

(Interviewee's Signature) ______________ (Researcher's Signature) _________________

Date ______________ ______________

If you wish to receive a copy of the interview transcripts, please initial here: _____________

APPENDIX E

INTERVIEW GUIDE (FGD)

Hi, my name is Samadrita. It’s really nice to meet you all. I will be your moderator today for the discussion and will be asking you some questions about your experience of dealing with polycystic ovarian syndrome and its treatment. PCOS has become a very prominent health concern for women in recent years, and it is important that all of your voices be heard. All of you have been invited here since you have consented to be a part of this discussion and it would be really great if you could share your experiences.

Some guidelines before we start-

-There are no right or wrong answers, and we have to be respectful of each other’s views.

-We are tape recording, so I would appreciate it if only one person speaks at a time.

-Please put your phones on silent mode. If you must answer a call and are unable to do it quietly, please do so and return to us as soon as you are able.

-My role as moderator will be to guide the discussion.

So, let's get started. To make it easier for us to remember each other's names, name cards have been put on the table in front of you. Let's go around the table and learn more about each other. Please tell us your name and a little about yourself.

1.How about we start talking about when you first learned what PCOS is?

2.What led you to get diagnosed?

Prompt- How was the diagnosis experience?

3. How has this condition affected your lives?

Prompt-Which aspects were the hardest for you?

4. Are you going through any kind of treatment /plan to go for any form of treatment/ are you considering getting treated?

If YES-

-what are the reasons for you to try it?

- what are the pros and cons, according to you?

-where are you getting your information?

Prompts- people who have the same condition, social media, other resources, family?

IF NO

-what are your reasons to not get treated?

-How do you manage or plan to manage your PCOS?

5.What effects are you experiencing or expecting because of the treatment?

-How do you think it has affected or will affect your life?

6. How do you think others see you because of this condition?

7.Has this condition affected how you see yourself as a woman?

8.Lastly, has the condition or the treatment affected you with regards to sexuality or intimacy?

APPENDIX F (CONSENT FORM FOR FGD)

Understanding women's experience of Polycystic Ovarian Syndrome and treatment-seeking behaviour

Research Investigator:
Samadrita Chowdhuri
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Supervisors:
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Background and Purpose

In recent years PCOS has become a very prominent health concern for women. The incurable nature of the condition has led to varied types of debates and discussions regarding the forms of treatment for this disease. For this study, I examine women's experience of PCOS in connection with women's treatment seeking behaviour.

Study Procedure

The group discussion will last between 60 to 90 minutes. It will be scheduled inside the university premises at a time that is best for all the participants in the group. If it is okay with you, I would like to record our interview, which will be later transcribed by me for my research.

Risks and Benefits

At this time, there are no known risks to you through your participation in this study. However, if at any time you feel uncomfortable or the topic is uncomfortable for you, we will take a break from the discussion. There are no immediate benefits for participants but I hope that you will benefit from this experience by reflecting upon and sharing your experiences.

Voluntary Participation

Your participation in this study is completely voluntary. If you feel uncomfortable responding to any question(s) or continuing with the discussion, you have the right to not answer the question(s) or leave. You may also withdraw any information you have shared up to that point. If you wish to do so, please let me know within two weeks of the discussion.

Confidentiality and Anonymity

All materials collected in the group discussion will be kept confidential. Your name will not appear in any of the transcripts, findings, or results. If you wish to have your name appear in the transcripts and/or final results, please let me know. In this case, I will share a copy of the transcript with you. All recordings and notes will only be accessible by me or my supervisors,

Further Information

The design of this study follows the rules and recommendations provided by the University of Alberta Research Ethics Board. The plan for this study has been reviewed for following the ethical guidelines given by the University of Alberta Research Ethics Board. The ethics approval number for this project is Pro00094014. If you have any questions regarding participant rights and ethical conduct of this research, contact the Research Ethics Office at (780) 492-2615. If you have any questions regarding the interview or the project, please feel free to ask me any questions during the interview or following the interview to samadri2@ualberta.ca**.**

Consent Statement

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(Interviewee's Name) ______________	(Researcher's Name) _________________
(Interviewee's Signature) ______________	(Researcher's Signature) _____________
Date ______________	______________

If you wish to receive a copy of the interview transcripts, please initial here: _____________