



**(Re)Knowing polycystic ovary syndrome: from lived experience to
mediatory practice**

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Abstract

Polycystic ovary syndrome is the most widely experienced hormonal condition in women, with effects and co-morbidities apparent in bodily processes such as reproduction, metabolism and physical appearance. The syndrome is also present in social life in dimensions of perception and self-perception, emotional responses, interactions with other people, and exchanges with medical systems. In this thesis I look at the areas of everyday life, health practices and bodily being that PCOS presents in through women's subjective accounts of experience. I interviewed a diverse group of women who were in the same stage of life in that they were university students in their twenties. Each woman had different physical PCOS symptoms, varying their bodily experiences. The syndrome was present in an individual habitus for each woman, consisting of different cultural contexts, experiences with different medical systems, and personalized health practices to mediate with the condition. I trace various knowledge networks surrounding PCOS in everyday life at an individual level by using phenomenological understandings of experience. These knowledge networks contextualize how this chronic health condition is perceived and managed by women. The individual habitus of perceiving and managing PCOS is thus produced and lived through a synthesis of different knowledges generated by different modes of experiencing PCOS. The way the threads of different ways of knowing PCOS weave a habitus together are highly subjective, with women using bodily experience, knowledge, and preferences to make health choices in daily life. These health choices in practice revolve around medication, food choices, and adjusting or maintaining physical appearance. I make the case for agency, subjectivity, and individual narratives to be represented in how chronic illness and health management is studied and understood, especially in the case of a condition like PCOS that varies between individuals, is ill-understood, and affects a significant section of the female population.

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Abbreviations

AE-PCOS Society: Androgen Excess and PCOS Society

CAM: Complementary and Alternative Medicine

CT scan: Computerized tomography scan

FSH: Follicle stimulating hormone

GI: Glycaemic Index

GP: General practitioner

HRQoL: Health-related Quality of Life

LH: Luteinizing hormone

ME: Myalgic Encephalopathy

MRI: Magnetic resonance imaging

NHS: National Health Service

NIH: National Institute of Health

PCO: Polycystic ovary

PCOS: Polycystic ovarian syndrome

QoL: Quality of Life

UK: United Kingdom

Introduction

This thesis looks at the experience of a hormonal condition experienced by women: polycystic ovary syndrome, henceforth referred to as PCOS. PCOS is the most prevalent endocrine condition affecting women of reproductive age, with estimates of between 10-25% of all women experiencing it. My personal experience of the syndrome prompted my interest in studying it from an experience-based perspective. I ground my understanding of experience in the paradigm of phenomenology. My argument centres on subjective understandings of how a chronic illness is experienced and then negotiated with in everyday life. I hold that developing individual accounts of health experience are essential, as they offer a voice both alternative and supplementary to biomedical understandings of health and illness.

I see experience as dynamic, being shaped by a multitude of factors such as knowledge, interactions, and time. I also hold the body- especially the subversive PCOS body- to both inform and encapsulate experience. Accounts of embodied experience also offer representation for PCOS as a condition entrenched in ideas of illness together with womanhood. I explore women's experiences through interactions with different medical systems, interpersonal relationships, and their bodies. I find and unravel the amalgamation of this knowledge and experience in the practices that women employ to live with their PCOS.

The writing of this thesis is divided into two halves. The first section includes chapters 1-3, which lay the background for understanding the complex and multi-layered condition that PCOS is. This sets up the intent and direction of my research. The second half of this piece, from chapters 4-7, follows the results and analysis of my research.

In chapter 1, I critique biomedical perspectives towards PCOS, from the arbitrary methods of defining and diagnosing the condition to questioning standardized treatments for it. I trace the origins of the condition through a biomedical context, arriving at contemporary understandings. Chapter 2 reviews the various perspectives and domains that PCOS literature has covered. Chapter 3 follows my qualitative methodology and the phenomenological

foundations of that methodology. It is also an exercise in reflexivity, made personal by the fact that I also experience PCOS.

In chapter 4, I begin to trace women's PCOS experience from the moment of diagnosis, an encounter that is embedded in biomedicine. The implications that diagnosis begets echo throughout all subsequent themes that I explore. Chapter 5 branches into medical systems that women explored aside from biomedicine and looks at how relationship networks influence health understandings. Chapter 6 looks at the body, the ways it is experienced, and the way it informs experience. Chapter 7 ties together the strands of experience I traced, observable on a tapestry of mediation and practice.

This text adds to work on women's experiences on multiple fronts: illness, femininity, bodily function and appearance, and practice. It contributes to PCOS literature with descriptive, subjective, and emotional accounts that are otherwise rarely represented amidst predominant amounts of medical and quantitative literature. The accounts that I built with women are textured with time, interaction, opinions, attitudes, and observations. This text allows voice, personality, and story to permeate where rigid understandings of health, womanhood, and being prevail.

Chapter 1: Background

In this chapter, I will introduce what Polycystic Ovarian Syndrome (PCOS) is. I look at the most common definitions and the various criteria used to diagnose the condition. I work my way through the way PCOS has been understood over time and through different modes of medicine. The term PCOS is a curious one, with its conception and meaning evolving over time. The condition was always known as a multi-faceted syndrome, and it was initially named the Stein-Leventhal Syndrome. Tracing how the term PCOS was arrived at reflects the changes in how the syndrome was, and is, understood. Finally, I will briefly discuss the prevalence and causes of PCOS. So, to begin: what is PCOS?

Understanding PCOS

In order to describe and explain what PCOS is, this study rests on the work of medical scientists, in particular the considerable research by PCOS-specialist Ricardo Azziz and his colleagues. The predominant body of literature on Polycystic Ovarian Syndrome that has been explored in this research comprises of studies from the disciplines of biological sciences especially endocrinology, medical studies, and psychology. Studies on PCOS from within these disciplines utilize a primarily quantitative approach, tracing causality or correlations.

I will draw a definition of PCOS from medical literature. There are multiple definitions and diagnostic measures of PCOS, but to use the most commonly agreed-upon description: polycystic ovarian syndrome is a heterogeneous endocrine disorder characterized by hormonal imbalances, metabolic disturbances, and certain set of physical manifestations when other conditions and causes are excluded (Azziz, et al., 2009). Polycystic ovaries can be transliterated into the presence of multiple follicles in the ovary, observable on ultrasound. The syndrome's chief underlying factors are hormonal imbalances and ovarian dysfunction, specifically elevated androgen levels (hyperandrogenism) that are often in combination with insulin resistance and hyperinsulinemia (Azziz, et al., 2009; Azziz, et al., 2016; Rotterdam ESHRE/ASRM-sponsored PCOS consensus workshop group, 2004). The most common physiological manifestations of PCOS are hyperandrogenism,

irregularities in the menstrual cycle, and the presence of multiple follicles in ovaries (Norman, et al., 2007). Other frequently occurring symptoms of PCOS include obesity, hirsutism (increased growth of terminal hair), acne, and anovulatory infertility. PCOS symptoms are expressed differently depending on the interplay between genetic, environmental, and lifestyle factors. Symptoms vary from individual to individual by occurrence and degree of severity, making the experience of PCOS subjective and quite distinct, especially when life experiences and cultural context are considered. For some people having PCOS may be defined by a struggle with weight and obesity; for others it might be the inability to get pregnant; it may be frequent plucking, shaving, and laser sessions of unwanted hair; exhausting a range of acne treatments; or trying out a new diet.

PCOS is the most common hormonal and endocrine disorder in women of reproductive age (Azziz, et al., 2004; Carmina & Lobo, 1999). 50-75% of women with PCOS also are insulin resistant, meaning that the cellular absorption of insulin is disrupted and there is an excess of sugar circulating in the blood, which creates its own set of effects and can lead to developing diabetes type II later in life (DeUgarte, et al., 2005; Dunaif, 1997; Ovalle & Azziz, 2002). If PCOS is left untreated, the syndrome can be a precursor to health conditions such as type-II diabetes (Legro, et al., 1999; Orio, et al., 2016); cardiovascular problems (Wild, 2002); pregnancy complications; and hysterectomies. PCOS is also associated with certain types of cancers such as endometrial or ovarian cancers, especially when the condition is concurrent with obesity (Fauser, et al., 2012). The risk of these health conditions remains throughout the course of an affected woman's lifetime (Norman, et al., 2007). Alongside health implications, the symptoms and treatments of PCOS—particularly hyperandrogenism, hirsutism and infertility – significantly contribute to psychological, social, and economic ramifications (Azziz, et al., 2005).

As of yet, PCOS has no cure and it is a lifelong condition¹ (Norman, et al., 2004). Medical interventions for the syndrome contribute exclusively to symptom relief instead of eliminating symptoms (Sirmans & Pate, 2016).

¹ A possible cause and cure were discovered in 2018 (Tata, et al., 2018). I revisit this and expand on this in the following chapter.

Lifestyle interventions of various kinds are almost as important as medical treatments in managing PCOS and are often the first line of treatment (Artini, et al., 2010; Teede, et al., 2010). The most frequently recommended lifestyle changes to manage PCOS are exercise and dietary modifications (Legro, et al., 2013) as they can promote weight loss and help manage insulin resistance (Norman, et al., 2007). Obesity has been shown to exacerbate insulin resistance and PCOS symptoms. Inversely, weight loss stabilizes insulin concentrations and produces significant improvements in symptoms (Duncan, 2014).

PCOS in Biomedical Literature

The first account of PCOS as it is recognized in modern, empirical science-based medicine appeared in 1935. Two American doctors, I.F Stein and M. Leventhal studied a group of 7 women with amenorrhea and attributed it to enlarged ovaries and the presence of ovarian cysts, with Stein and Leventhal speculating that this was linked to hormonal imbalances (Stein, 1935). The disorder was eponymously named the Stein-Leventhal Syndrome (Stein, 1958). It was mainly seen as a disorder of sterility that had 'masculinizing' features, and the very first treatments were ovarian surgical procedures such as surgically removing sections of the ovary (Geist & Gaines, 1942; Stein & Cohen, 1939). This shows that the ovary and its anatomy was seen as the site of the pathology, with both diagnosis and treatment being concentrated around it. By the 1940s and '50s, the term 'polycystic ovaries' had begun appearing in medical literature, largely in ensuing work by Stein and Leventhal (Buxton & Van de Wiele, 1954; Leventhal & Cohen, 1951; Stein & Cohen, 1939). By the late 1950s, Stein-Leventhal Syndrome was also being referred to as Polycystic Ovarian Disease and Polycystic Ovarian Syndrome (Evans & Riley, 1958; Keettel, et al., 1957), indicating that the name of the syndrome was shifting according to its characteristic morphology. Around this time and continuing over the next few decades, the syndrome was understood to encompass a wider variety of symptoms alongside cystic ovaries, including hirsutism and body weight (Leventhal & Cohen, 1951). In the 1980s the link was made between insulin resistance, metabolism, and PCOS (Plymate, et al., 1981; Shoupe, et al., 1983) and correlations with stress started being made (Lobo, et al., 1983). A strong dialogue started on the relationship between PCOS and obesity (Dunaif,

et al., 1989), prompting interest in nutritional science and lifestyle modifications, the foremost of which were weight-loss treatments. A 1992 study concluded that a low-fat diet designed for weight loss improved insulin resistance and PCOS symptoms (Kiddy, et al., 1992). The first formal diagnostic criteria was set out in 1990 during an NIH (National Institute of Health) conference on PCOS, establishing PCOS as primarily a disorder of androgen over-production (Azziz, 2006, p. 781) and bringing the focus from the anatomical morphology of the ovaries to a disorder involving the endocrine system. Over a decade later, this criteria was revised at a 2003 conference in Rotterdam (Fr & Tarlatzis, 2004), the outcome of which was a definition of PCOS that expanded on the existing NIH-criteria and included markers like the size and appearance of the ovaries, even in the absence of regular menstruation (Szydlarska, et al., 2017). The new criteria established PCOS as a syndrome of elevated androgen levels where other causes were excluded. One of the chairmen of the Rotterdam Conference, and a leading contemporary PCOS researcher Ricardo Azziz went on to publish articles criticizing the new expanded diagnostic criteria, such as 'Diagnostic criteria for polycystic ovary syndrome: A reappraisal' (2005) and 'Diagnosis of polycystic ovarian syndrome: the Rotterdam criteria are premature' (2006). He raised the concern that the diagnostic criteria might be over-reaching into who it included in the PCOS spectrum. In response, a paper appeared in defence of the Rotterdam criteria, arguing that the updated version took broadened medical knowledge into account (Franks, 2006). In 2009, the Androgen Excess and PCOS Society (AE-PCOS Society), a prominent figure of which was Azziz, published an extensive compilation of PCOS research and set out another diagnostic criterion (Azziz, et al., 2009). The AE-PCOS Society's diagnostic measure was a revision of the two main previous ones and holds that PCOS should be diagnosed in the presence of an androgen excess and ovarian dysfunction when other causes of these two conditions are excluded. The report placed emphasis on hyperandrogenism as a central feature of PCOS. However, the report also includes that some members of the task force disagreed with this focus on hyperandrogenism, calling it out as unreliable across different populations. It concludes with the acknowledgement that more research into PCOS is needed. Similarly, a follow-up workshop held by the NIH in 2012 called for increasing research on and improving evidence-based tests

for the syndrome and criticized the term PCOS for focusing too much on only one aspect of the condition: the ovaries (National Institutes of Health , 2012).

The term “polycystic ovarian syndrome” invokes controversy. The ovaries of women with PCOS do not contain what is commonly understood to be a cyst—that is, an epithelial sac inside the body, filled with fluid. Instead, a polycystic ovary contains multiple eggs, or follicles, that haven’t matured and released as happens in the course of normal menstruation (Franks, et al., 2008). When eggs do not mature as normal, it is called anovulation, and this is what characterizes anovulatory infertility in PCOS. Polycystic ovaries are larger than normal ovaries in size and contain around 12 (this figure is variable) follicles (Goodarzi, et al., 2011). These egg-follicles are referred to as cysts, which can be confusing as they are different from an abdominal ovarian cyst. It is important to note that polycystic ovaries also occur in women who display no other condition associated with the syndrome PCOS. One-fourth of the female population display polycystic or follicular ovaries on ultrasound, but they do not all have the syndrome and do not experience symptoms (Lizneva, et al., 2016). Hence using poly-cystic as the central defining word of the syndrome is confusing in multiple ways. First, it isn’t properly representative of the ovarian morphology, using the word cyst interchangeably with the term follicle. Second, it doesn’t differentiate between women who just have polycystic ovaries and those who have the symptoms of hyperandrogenism, menstrual irregularities, and metabolic features that make up the syndrome (Polson, et al., 1988). Third, and building on the latter, it inflates the role of the ovary and underplays the endocrine and metabolic side of the syndrome (Khadilkar, 2016). A 2014 study looked at perceptions of PCOS’s name and symptoms in doctors and women with PCOS in Australia. They found that almost half of women with PCOS (47%) mistook cysts as the most significant characteristic of PCOS. Both doctors (74%) and patients (48%) agreed that the name PCOS led to confusion, with 81% of doctors supporting changing the syndrome’s name (Teede, et al., 2014). These factors illustrate the criticism attached to the term, resulting in PCOS being called a misleading label (Lam & Raine-Fenning, 2009).

Constant revisions and additions to the knowledge surrounding a phenomenon are a hallmark of the scientific method and are necessary to advance the growth of medical knowledge around PCOS. However, contradictions within

these revisions, the repeated calls for a PCOS definition that everyone can agree upon, acknowledgements of the need for more research, and constant debate on the diagnostic criteria represent medical researchers' lack of consensus surrounding PCOS and may explain the general confusion surrounding the condition. It is also illustrative of how approaches within medicine are constantly subject to debate and may vary, from the identification and diagnosis of a health condition to the ensuing treatment of it. In this case, the condition under study is also varying, from the pattern of symptoms in each individual to its genetic and environmental interactions, adding to the uncertainty. Hence the identification, definition, diagnosis, and treatment of PCOS becomes even more complex.

Medical studies of PCOS from the 19th century harken to the Foucauldian ideas of medicalization and discursive formations of disease, especially concepts he explored in *The Birth of the Clinic* (Foucault, 1973; Foucault, 2002). An increase in knowledge and research surrounding PCOS and improvements in medical technologies allowed for more specialized investigations, which in turn have shaped the discourse on PCOS. The course of medical knowledge has moved PCOS from an anatomical disorder to an endocrine condition- from visible to invisible- and then has made it visible again through creating and placing it within discourse (p. 154). The medical gaze, as Foucault puts it, turned itself to the bodies of women with PCOS (pp. 8, 91): recognizing and characterizing symptoms (p. 100), weighing them in terms of what a 'good', 'healthy', and 'female' body should be, with a name, label, and discursive theme (pp. 96, 118-119) emerging as a result: Polycystic Ovarian Syndrome.

Prevalence

"Medical certainty is based not on the *completely observed individuality* but on the *completely scanned multiplicity of individual facts*." (Foucault, 2002, p. 101)

In *Birth of The Clinic*, Foucault points out that medical knowledge ascertains the validity- even the existence- of a condition through numbers. The 'frequency', the rate of occurrence, the percentage of the population affected by a medical condition is what gives it weight and importance. It also provides an interesting perspective; it is, for instance, the criteria used to distinguish what is a health

issue and what is a public health issue, taking a condition from individual experience into the social domain. An understanding of PCOS would be incomplete without examining how its prevalence has been studied and represented.

The discrepancies in diagnostic criteria before 1990 meant that PCOS was diagnosed differently between regions depending on the definition they adopted. In Europe, PCOS continued to be recognized when polycystic ovaries were observed on ultrasound, accompanied by at least one of these symptoms: irregular periods, elevated androgens, elevated LH (luteinizing hormone), or obesity. North America adapted the NIH diagnostic criteria before it diffused to Europe. North American clinics diagnosed PCOS when women had irregular menstrual cycles combined with signs of increased androgen levels, and an ultrasound of the appearance of the ovaries was not deemed necessary (Hart, et al., 2004). These differences in diagnosis also reflected in the way PCOS was reported and studied, rendering it difficult to determine a concise estimate of the overall prevalence of PCOS across populations. A 2009 study assessed the same group of women according to 3 diagnostic measures of PCOS: NIH, Rotterdam, and the AE-PCOS Society diagnostic criteria (March, et al., 2009). They found that each diagnostic measure yielded different rates of PCOS within the same population. Yildiz et al. (2012) carried out a similar study in Turkey across a homogenous population, also finding that the three different diagnostic measures resulted in different prevalence rates. This clearly indicates that PCOS prevalence rates will differ according to the criteria used. Reports of prevalence across populations are also affected by referral bias, meaning that different rates are reported in the people selected for studies in clinical settings as compared to the general population (Lizneva, et al., 2016). This suggests that the data available on PCOS, which is sourced almost entirely through patients within medical systems, might include inflations and correlations that are distorted and not truly representative (Wilcock & Taylor, 2018). On the other hand, some studies speculate that the prevalence of PCOS could be much higher than what the literature shows, as many women with PCOS remain undiagnosed (Hillman, 2018; March, et al., 2009). Research has suggested that the way the syndrome is manifested may also vary by ethnicity, as different ethnic groups display variances in the severity and degree of symptoms

experienced (Glintborg, et al., 2010; Zhao & Qiao, 2013). However, Azziz et al. (2011) contest this idea, citing the similarities in the prevalence of PCOS across ethnic groups in the UK, and North and South America. The explanation proposed for this is that the PCOS genotype predates racial differences in humans and has persisted due to certain evolutionary advantages it lent to ancient humans. On a global scale, PCOS rates consistently fall within the 5-10% range, also supporting the evolutionary explanation of PCOS (Azziz, 2016). Whilst there are conflicting views and explanations on the distribution of PCOS across different populations, what is known is that PCOS is the most prevalent endocrine condition experienced by women (Knochenhauer, et al., 1998). Around 20-25% of all women display polycystic ovaries on ultrasound, with around 7-10% of women fulfilling most of the diagnostic criteria and recognized as having PCOS (Homburg, 2008; Lizneva, et al., 2016; Polson, et al., 1988).

Causes

As with many heterogeneous health conditions, the aetiology and pathogenesis of PCOS are still unclear. Genetic factors contribute to the development of PCOS, with the condition often running in families. If a woman has PCOS it is likely that her mother or sister will also have either the syndrome (Kahsar-Miller, et al., 2001) or elevated androgen levels (Legro, et al., 1998). Another review of family-related studies on PCOS found that not just female relatives but male relatives like sons, brothers, and fathers of PCOS patients had an increased likelihood of exhibiting metabolic and androgen profiles similar to those seen in PCOS (Azziz, 2008), suggesting two things: first, this lends weight to genetics as a predisposing factor for PCOS and second, that metabolic and endocrine factors beyond the female reproductive system underpin PCOS. The closest we have come to understanding the specific genetic pathways of PCOS is identifying clusters of genes that play a role in the development of the condition (Chen, et al., 2011). Although it is known that genetics play a role, the extent and degree of that role is still not certain (Diamanti-Kandarakis, et al., 2006). Alongside genetics, lifestyle is a highly significant factor in the development of PCOS. The aetiology of PCOS looks at genetic and lifestyle factors hand in hand. Franks et al.'s (2006) hypothesis seems particularly relevant, propositioning that PCOS is rooted in genetic factors, but how it is manifested is

also affected and varies by environmental and lifestyle factors, such as diet and nutrition. Other studies also support this hypothesis (Diamanti-Kandarakis, et al., 2006). Metabolic disturbances, foremost amongst which is insulin resistance have emerged as pivotal factors in the pathogenesis of PCOS (De Leo, et al., 2016). An interplay of genetic, lifestyle, and environmental factors is the most comprehensive understanding of PCOS aetiology that can be gleaned so far (Dumesic, et al., 2015).

Chapter Summary

Allopathic medicine's symptom-specific approach is especially interesting when syndromes are considered. A syndrome is a constellation of heterogeneous symptoms that amalgamate into a spectrum, along which individual experiences vary. For a syndrome, allopathic medicine does not hold one cure-all and its approach breaks down and addresses one symptom at a time. This is particularly evident in PCOS treatment, which is divided into three domains: medication, diet, and lifestyle. The medications prescribed for PCOS depend on what symptoms are experienced. This is pragmatic, considering that symptoms vary so widely between individuals; if someone with PCOS has regular periods, for instance, there is little point in her taking contraceptives to regularize her cycle. However, this specialized approach also limits biomedicine from addressing the condition in its entirety. Lock and Nguyen (2010) problematize this approach in biomedicine through what they term "decontextualization" of the body, where health or illness are limited only to the parameters of the body without considering the environment surrounding the body. Interestingly, biomedicine also tends to break down this parameter of the body, separating it into parts, processes, and symptoms. In biomedicine, a syndrome is defined precisely as being an aggregate sum of its parts. Biomedical approaches to PCOS focus on treating its parts singularly, whilst regarding the whole as an incurable lifelong condition. The implications of this reverberate out of the body and into multiple other spheres of life.

Chapter 2: Literature Review

The writings on PCOS I engaged with can be divided between two disciplinary approaches: the medical and beyond the medical. The epistemological objectives of science-based medical knowledge are grounded in generating empirical information that can translate to practical applications (Malterud, 1995). For instance, establishing causal pathways of illness, or assessing the effectiveness of certain treatments. Medical research is based on biological science and the experimental method. Medical studies on PCOS have been occupied with defining it (Azziz, et al., 2006; Azziz, et al., 2009; Dewailly, et al., 2013), discovering how it develops, its aetiology and pathogenesis (Chen, et al., 2011; Sirmans & Pate, 2016), and treatments for symptom relief (Badawy & Elnashar, 2011; Goodman, et al., 2015; Harwood, et al., 2007). It is difficult to overlook that in medical literature's perspective on PCOS- and indeed any illness- the focus has been exclusively on biological bodies, and part, processes and functions of the bodies: on ovaries, hormones, skin, hair, periods, and pregnancy- largely overlooking the presence of health and illness beyond the body (Harari, 2001). Schepers-Hughes and Lock (1987) call this the "Cartesian dualism" of medicine, where the mind and body are seen as separate and almost diametrically opposed. Specialized knowledge inadvertently reproduces these dualities- a reflection of which is obvious in medical literature on PCOS, and which has seeped into PCOS representations outside the biomedical domain as well. This is because PCOS itself is a phenomenon defined and recognized through biomedicine, so it cannot be studied independently of it. Attempting to separate or downplay the biomedical aspect of PCOS would in fact reinforce the very Cartesian dualism that limits the scope of inquiry in other dimensions. So, I read a large body of medical studies on PCOS, the bulk of which is discussed in the previous chapter and which surfaces throughout my writing. Following from dualism, medical literature has also inherited, and then built its epistemological foundation on empiricism and positivism (Bunniss & Kelly, 2010). I found PCOS literature to be laden with a predominantly

positivistic² approach, even beyond medical studies. PCOS was framed as a disease, a disorder, an abnormality, and a problem, resulting in a telescoped and unidimensional exploration of what is, in my perspective, a multifactorial phenomenon, proliferating through multiple dimensions over the course of a lifetime. This heavily positivist perspective sees PCOS as a sum of its symptomatic parts and correlates the syndrome and its symptoms (such as obesity, hirsutism, or infertility) with other constructed compartmentalisations such as sexual health, depression, anxiety, or quality of life.

To find accounts of PCOS that explored subjective, individual, contextually-situated experience, I turned to literature that differed from medical science in terms of philosophical, epistemological, and methodological approaches: qualitative, phenomenological works on PCOS within social science. Apart from psychology, social sciences like anthropology and sociology have barely engaged with PCOS. I found only two sociological studies that looked at the experience of PCOS in depth and used purely using qualitative methods (Kitzinger & Willmott, 2002; Snyder, 2006). In anthropology, I found only one ethnographic account of PCOS based in India (Pathak, 2015). Smith-Tran's (2018) study was a refreshing mix of the auto-ethnographic method and sociological analysis.

In this literature review, I will look at studies that have chronicled the effects and experience of PCOS. I begin with quality of life studies on the impact of PCOS. Then I look at literature on the co-morbidities of PCOS that are experienced on a mental and emotional level, like depression. I then move on to studies interested in the individual experience of PCOS. Finally, I look at what the literature says in terms of managing and living with PCOS. To begin, I will look at psychological studies on quality of life, which intersect quantitative and qualitative approaches: generally, with quantitative methods employed to study qualitative phenomena.

PCOS and Quality of Life

Quality of life (QoL) is a concept constructed to understand how individuals feel about their lives; life here is seen as the compound of multiple dimensions, one

² Positivism is a paradigm, a framework of thinking, where reality is objective; knowledge is aimed at uncovering patterns and causes governing objective reality; and methods are based around measurements, statistics, and testing hypotheses.

of which is health (Whoqol Group, 1995). Specifically, in qualitative and quantitative studies looking at quality of life of women, the effects of PCOS are broken down into dimensions such as the physiological, the mental or psychological, the emotional, the social, and the performance of roles (Jones, et al., 2008). These dimensions are then studied in relation with PCOS as a whole and also by its individual symptoms to measure the impact of each on quality of life. For instance, Bernard et al.'s (2007) study used a specific scale adapted to PCOS to assess health-related quality of life (HRQoL). This scale used symptoms like hirsutism, acne, and infertility to determine their separate effects on HRQoL. Specifically in quantitative QoL studies, such dimensions of inquiry almost always aggregate into concluding that PCOS has negative effects on quality of life (Amiri, et al., 2014; Elsenbruch, et al., 2003; Hahn, et al., 2005; Li, et al., 2011). Similarly, Coffey et al. found that women with PCOS had a decreased health-related quality of life as compared to women without the syndrome, and in comparison with women who had other serious health conditions (Coffey, et al., 2006). However, this almost perfectly unanimous result is debatable. These studies seldom delve in-depth into subjective experiences, assuming that experience can only be framed in one way and that experience, as well as the recollection of it, remains static and inflexible over time. Amiri et al.'s (2014) study took a qualitative approach to examine Iranian women's subjective experience of living with PCOS in terms of quality of life. Their participants spoke of shame, embarrassment, body image issues, distress in interpersonal relationships, feeling less feminine, and subsequent social withdrawal. Williams et al.'s (2016) study on PCOS's effects on quality of life analysed visual content thematically. They found that their participants also perceived themselves as unfeminine or 'less' feminine. Simultaneously-and contrastingly- they also observed an optimistic approach and positive reframing of PCOS by their participants, as a means of making sense and coping with the condition. This indicates the complexity of PCOS; from producing conflicting emotions to reactionary mechanisms. To me, such findings highlight the importance of studying PCOS's experience beyond clinical settings and multiple-choice questionnaires, and in the intricate realm of individual, multi-layered, lived experience.

I see the way quality of life studies break down PCOS and assess it symptom by symptom as a reductionist attempt to classify PCOS neatly through its symptoms. It is reductionist towards the overall experience of someone with PCOS, and even to the experience of a single symptom. These symptoms cannot be compartmentalized so simply and looked at in isolation. They are complex on multiple levels. The ways these symptoms develop and manifest on the level of the biological organism are interwoven. For instance, insulin resistance leads to elevated androgens, which cause hirsutism. The symptoms may be heterogeneous, but they are still interlinked. That connection is precisely what characterizes a syndrome³. On the social level, experiencing a symptom that alters one's appearance is layered with social meaning and consequences. I argue that PCOS is more than a Frankenstein-like mix of physical symptoms. PCOS is multidimensional in more than just its range of symptoms. It manifests on multiple levels: from the sensorial experience of one's own body; to the place of one's body in the social world and its semiotics; to positionality and identity; in terms of power structures; and in predominant thought surrounding health and the body.

Depression, Anxiety, and Mental Health

PCOS has a long-standing association with an increased incidence of mood disorders such as depression, anxiety and bipolar disorder (Deeks, et al., 2010; Dokras, et al., 2012; Rasgon, et al., 2003). The hormonal profile of women with PCOS includes elevated levels of certain hormones, and this hormone pattern has been linked to depression (Weber, 2000). Himelein & Thatcher's (2006) review of PCOS and mental health found significant links between PCOS and general psychological distress, impaired body image, effects on sexual health, and a decreased quality of life. The review also found that PCOS was highly correlated with depression, especially when coupled with obesity, and that women with PCOS were at a higher risk of being depressed compared to those without it. This finding has been echoed in multiple other studies (Bhattacharya & Jha, 2010; Kerchner, et al., 2009; Rasgon, et al., 2003), with Dokras et al.'s review on depression (2011) finding that women with PCOS are four times likelier to have episodes of depression in comparison to women without PCOS.

³ In medicine, a syndrome is a health condition comprising of different symptoms occurring together which have the same underlying causal pathway (Miller-Keane & O'Toole, 2003).

Similarly, Månsson et al. (2008) found that women with PCOS had higher incidences of suicide attempts, eating disorders, social anxiety, and depression as compared to age-matched controls. Studies on depression and PCOS often disregard the cause of this depression, overlooking the complexity of both conditions. How are these women experiencing depression? Is it purely biological, an endocrine imbalance interfering with brain functions? How does it interact with a person's circumstances, life events, social and cultural values? How does it interact with the individual person? Some studies attribute this depression and distress to physical manifestations of PCOS and the effects it creates on one's body and appearance such as obesity, hirsutism, and acne (Hahn, et al., 2005). These visible bodily effects can create complex feelings about the body such as dissatisfaction and embarrassment (Pastore, et al., 2011). However, there is no conclusive evidence to draw a definitive causal relationship between the altered body image PCOS can result in and depression (Dokras, 2012). Considering the pervasive and serious nature of mental health issues, these studies leave large gaps unexplored. Studies on PCOS and depression are overwhelmingly statistics-based, which restricts the depth and detail they can achieve towards chronicling depression and mental health problems. It must be noted that these studies are not claiming to represent experience; their aim usually is to establish correlations and rates of incidence. Nonetheless, they indicate lacunae in experience-based, subjective, and qualitative understandings of PCOS and its relationship with mental health.

The Lived Experience of PCOS

A review-based study arguing for the importance of qualitative research for PCOS found only six studies on PCOS that were qualitative in their methodology and approach (Ma, et al., 2014), indicating the lack of qualitative studies on PCOS. Five out of the six reviewed studies used phenomenology as their theoretical groundwork. This supports the utility of phenomenology for studying PCOS as the majority of qualitative studies on it so far- albeit limited in number- have gravitated towards the same framework. Qualitative explorations of PCOS experience can yield candid insights into how the condition plays out in everyday life.

Wilmott's prize-winning piece "The Experiences of Women with Polycystic Ovarian Syndrome" (2000) used in-depth interviews that revealed a

predominant theme of feeling different. Women with PCOS felt 'freakish' and unlike other women because of PCOS- it resulted in aggravated infertility, hirsutism, and irregular period patterns. Wilmott and Kitzinger followed up and expanded the depth of this work with a study called, 'The thief of womanhood': women's experience of polycystic ovarian syndrome' (2002). This work was the first, most comprehensive, and remains the most well-known study done on PCOS that combines qualitative, interpretative, and feminist frameworks. Akin to the preliminary work, it focuses on analysing three prominent PCOS symptoms- body and facial hair, menstruation patterns, and infertility. The study found that women saw themselves as 'freakish', 'abnormal', 'weird' and 'unwomanly' (Kitzinger & Willmott, 2002, pp. 352-355). They felt differentiated from 'proper' women who had, in their view, bodies that were ovulating, hairless, and fertile. The study concludes that PCOS significantly challenges women's perception of themselves in terms of their womanhood and femininity.

Snyder's study, 'The Lived Experience of Women Diagnosed with Polycystic Ovary Syndrome' (2006) is the most prominent phenomenological exploration of PCOS I found, and it revealed similarly recurring themes such as feelings of being different and 'less' feminine. The women participating in this study didn't use terms like 'freakish' or 'abnormal', but they did express a desire for 'normal' womanhood. Another theme was about control: PCOS brought uncertainty into women's lives, especially surrounding fertility, which resulted in feeling out of control and attempts to reclaim control.

Ekbäck et al.'s study (2009) explored the bodily experience of hirsutism. Hirsutism⁴ is an androgenic expression of PCOS, although it is not exclusively a PCOS symptom; women may be hirsute without having PCOS. It is one of the most distressing and troubling symptoms of PCOS (Khomami, et al., 2015), as it creates powerful feelings about one's body. The women Ekbäck et al. spoke to were persistently concerned with their hirsutism. It was a consistent, distressing undercurrent to their thoughts. The excess hair was an unwelcome invader, in both body and mind, and left women with a negatively altered perception of their

⁴ Hirsutism is defined as the growth of dark and coarse hair on areas of the body where men typically have this type of hair, such as the face, chin, neck, arms, belly, back, buttocks or legs. Hirsutism also refers to the changing of fine hair already present of the body to thicker terminal hair (Azziz, et al., 2000).

bodies and their selves. They expressed feeling a loss of femininity, reduced self-esteem, feeling entrapped in their body, and shame. This piece highlights how potent the impact of just one symptom of PCOS can be, and how multi-layered the experience of a visible symptom on the body can be. In a more PCOS-specific piece, Pfister & Rømer (2017) studied a group of women with PCOS in Denmark. Their interviewees were considerably affected by PCOS symptoms that were visible. These visible symptoms, most prominent amongst them being hirsutism, contributed to feelings of abnormality. Respondents used words like “abnormal”, “unfeminine”, “masculine”, and “different” to describe how hirsutism made them feel (Pfister & Rømer, 2017, p. 174).

William et al.'s (2015) Skype interview-based study of lived experiences was the first to discuss how women managed PCOS and life changes alongside co-morbidities such as other chronic illnesses and depression. Their participants highlighted the importance of support networks ranging from personal relationships to health care providers, as well as PCOS's impact on feminine identity. Crete and Adamshick (2011) point out the lack of literature on the experience of PCOS management. Their study's primary findings were that women with PCOS felt frustrated and confused, especially by healthcare practitioners' attitudes towards PCOS care, management, and future risks. As a result, women turned to self-learning as a means of controlling and managing PCOS.

Weiss and Bulmer's (2011) study looked at young, college-going women experiencing PCOS. Their participants described feeling anxious about the future, in particular worrying about their ability to conceive. The women were conscious of their appearance, attributing the embarrassment or frustration they were feeling to hirsutism and weight gain. They were also affected by their relationship with health care practitioners; despite receiving information on PCOS, they felt it insufficient when the chronic nature of the condition was considered.

The relationship between medical practice and PCOS has seldom been directly explored in social science literature, and the intersection of formal biomedicine, health practitioners, and lived PCOS experience is a particularly interesting domain in which to ask questions. Whilst the healthcare provider and PCOS

relationship has not been not the central focus of investigation, a few studies touch upon this in accounts of lived experience; for instance, William et al.'s (2015) study talks about health professionals' advice to have children sooner being a factor in women's fertility-related planning. This study, alongside Kitzinger and Wilmott's (2002), Snyder's (2006), Crete and Adamshick's (2011), and Ellerman's (2012) studies highlight how women feel that there is inadequate support and information being offered for PCOS by medical professionals. Participants in Snyder's (2006) study also related feelings associated with a lack of information from doctors and control, where regaining control was associated with attentive and informative health care practitioners.

Smith-Tran's (2018) piece on PCOS was laden with personal experience, resulting from her use of autoethnography⁵. She related the distress of finding out one has a chronic condition, and consequently feeling a loss of control. She unpacked experiences with medical practitioners, from diagnosis to treatment plans. She was recommended the standard treatment for PCOS: metformin. Instead, Smith-Tran opted for only exercise and diet as management methods. In particular, she began lifting heavy weights. This enabled her to manage her PCOS and feel empowered as a female. Most interestingly, she proposes reimagining exercise as medicine, arguing for it to be recognized on the same level as medical treatment.

Pathak's (2015) ethnography on PCOS is set in Mumbai, India and notably frames PCOS as a 'lifestyle disease'. As far as I know, this study is the only anthropological work that focuses on PCOS. This ethnography shifts the lens of experience; instead of only examining subjective experience from an individual's point of view, the experience of PCOS becomes a means to examine 'modern' lifestyles that are created by the large-scale processes of globalization and urbanization. Pathak poses the PCOS body as 'plastic', moulded to normalized standards of both health and femininity, for instance through bodily practices and reproductive technologies. She situated the experience of PCOS and the processes surrounding it within larger cultural and global processes. The body experiencing PCOS became representative of

⁵ Autoethnography is a method used in social sciences. The researcher records and uses their personal experience as a source and means of understanding cultural experience (Ellis, et al., 2011).

evolving lifestyles, with PCOS demonstrating new and old norms, disorder, and change. Hadjiconstantinou et al.'s (2017) study also supports the role of culture in the experience and perception of PCOS. Their interviewees were of different ethnic backgrounds, which reflected in their narratives of PCOS: some experiences were shared by all interviewees, and some were culturally-specific. There is a definite gap in PCOS literature when it comes to culturally grounded studies of experience.

Feminism in PCOS Literature

It is impossible to read experiential PCOS literature without engaging in ideas about womanhood, the female body, and feminine identity, making pertinent the feminist perspective in studying PCOS. The rare works tackling PCOS from a feminist perspective have argued against positivist perspectives on the condition. Feminist critiques on PCOS question the epistemological stances and constructions of the female body in dominant narratives like biomedicine: from self-help books (Willmott, 2000) to diagnostic measures to medical interventions, to terming testosterone and androgen 'male' hormones when all adult bodies produce the same sex hormones, just in different ratios (Ellerman, 2012). The seminal feminist work on PCOS is Kitzinger and Willmott's (2002) piece, which challenges ideas of 'normal' womanhood and the female ideal, asserting that women with PCOS feeling different is a result of socially entrenched ideas of femininity.

Ellerman's thesis "Don't Blame it on My Ovaries: Exploring the Lived Experience of Women with Polycystic Ovarian Syndrome" (2012) calls out the disparity between PCOS in medical practice and PCOS in life and experience. She attributes this divide to the silencing of women's own narratives of experience by patriarchal structures, leading to the subjugation through discourse and of discourse itself. Discourse is a significant tool in placing PCOS contextually; in fact, I will argue that given the multiplicity of epistemologies, norms, ideals and attitudes surrounding PCOS, a discursive approach is well-suited to distilling from the cacophony. Foucault's ideas on bio-power (1972) are essential when discussing the role of discourse in embodiment and of control in social phenomenon, including health conditions like PCOS. I understand this through Csordas' (2015) interpretation of Foucault and the application of his ideas to phenomenology. According to Csordas, the Foucauldian concept of

bio-power sees agency being filtered through, and inhibited by, discursive structures of power, trickling down from the world to the body (Csordas, 2015, p. 52; Foucault, 1972). This world-to-body direction of power and control is also reflected in feminist thought, where external power structures demarcate the parameters of gender, womanhood, and the body as a site of power struggles, especially through the subjugation of the processes of reproduction and sexuality (Sawicki, 1991). Feminist writings have contributed to, and laid the groundwork for, experience-based understandings of PCOS. They also emphasize on lending voice to the individual experience of health and illness over an institutional view.

Living with PCOS: Management and Lifestyle

In 2018, a spate of articles announced that a 'cure' for PCOS had been discovered⁶. A friend who knew my area of research sent me an article circulating on Facebook: "Finally, Scientists May Have Found the Cure to PCOS". I immediately went online to find out more. I found that these articles were citing a study published in *Nature medicine*, which didn't exactly tout a cure for PCOS; instead, it found a highly probable cause of the condition (Tata, et al., 2018). The study found that PCOS could be caused by foetal exposure to anti-Müllerian hormone (AMH). A drug treatment was pioneered based on this finding and tested on mice. The results were triumphant: the drug eliminated PCOS symptoms. This treatment is set to begin human trials by the end of 2018. There are multiple barriers between clinical drug trials and treatment options becoming available to the public. To name just a few: knowledge, time, cost, accessibility. It is still viable to say that PCOS has no cure- it *could* be cured, and fairly soon. However as of yet, there is no one pill to pop that can make PCOS fade away- mice being a notable exception.

In the absence of a miracle cure, the buzzword in PCOS treatment has become lifestyle. Lifestyle here refers to the pattern of choices that an individual consistently makes. For instance, PCOS is linked with obesity and insulin resistance, which are keyed back to two main factors: genetic predisposition,

⁶"Finally, Scientists May Have Found the Cure to PCOS", Reader's Digest, 25th May (2018); "Hopes for PCOS cure as scientists reveal cause in mice", Bio News, 21st May (2018); "Polycystic ovary syndrome: Scientists closer to understanding cause", BBC, 15th May (2018) "Cause of polycystic ovary syndrome discovered at last", New Scientist, 14th May (2018)

and individual lifestyle (Duncan, 2014). One may be prone to obesity because of a sequence of inherited genes that one has no control over, or obesity may be a product of what they eat and how they move, or don't move. Pathak's study calls this 'medical individualism' (pp. 106-108), where medical practitioners combine an understanding of factors beyond a person's control (genes) and those within their control (lifestyle) both producing health, as well as ill health. There is an element of individual responsibility attached to ill health, especially when a 'lifestyle disease' is considered (Farshchi, et al., 2007; Pathak, 2015). Seeing an individual as responsible for their health has the potential to create stigma- for instance in Smith-Tran's experience when a doctor assumed that she was not physically active as she had PCOS (2018).

The interest in managing lifestyle to treat PCOS was spurred by its correlation with obesity, insulin resistance, and metabolic disturbances. The two most prominent lifestyle factors in PCOS discourse are exercise and lifestyle, with some studies also including alcohol, drug usage, smoking, and environmental factors (Norman, et al., 2006). Exercise and dietary changes are often the first recommendations cited to counter insulin resistance and reduce weight (Norman, et al., 2002; Moran, et al., 2006).

Insulin resistance and metabolic issues govern the mechanism affecting the hormones implicated in PCOS, especially androgens. High levels of androgens are responsible for symptoms like acne, hirsutism, and anovulation. Changes in lifestyle have been shown to reduce the severity of these PCOS symptoms. Lifestyle modifications like diet changes and exercise can improve insulin sensitivity (Holte, et al., 1995); regularize menstrual cycles and improve fertility (Huber-Buchholz, et al., 1999); balance hormone profiles; and decrease the future risk of developing diabetes and cardiovascular problems (Moran, et al., 2013). Lifestyle changes, therefore, are significantly linked to ameliorating the symptoms of PCOS.

There is no particular PCOS diet, although there are general dietary guidelines that are recommended. These are based around principles from nutritional science and suggest a diet that is low in carbohydrates which have a high impact on glucose levels (low-glycaemic index), high in carbs that are low on the glycaemic index and release energy slowly, low in fat, and often based on

eating lean protein and vegetables (Douglas, et al., 2006; Farshchi, et al., 2007; Marsh, et al., 2010). The diet recommended for PCOS can be summed up as a high-fat, low-GI⁷, low-carb diet. There are recommendations for the frequency of meals as well: smaller meals to be eaten 3 or 4 times a day. Insulin resistance is a mechanism that underpins PCOS as well as pre-diabetes and diabetes type II; therefore, dietary recommendations for both conditions often overlap, as well as the use of the drug metformin to regulate insulin resistance (Glueck, et al., 2008; Liepa, et al., 2008). Eating along these guidelines is rigorously linked to symptom relief, although the studies doing so repeatedly call for more substantial, concrete investigation into this (Herriot, et al., 2008; Moran, et al., 2006).

Farschi et al. call PCOS a “disease of over-nutrition” (p. 769), harkening back to its association with obesity- a problematic association, as many women with PCOS are lean and still have symptoms like insulin resistance (Morales, et al., 1996). Whilst I have a rudimentary understanding of the biochemical processes involved between PCOS and nutrition, I propose that instead of looking just at over-nutrition vs. inefficient nutrition, the everyday processes surrounding PCOS should be looked at. Daily practices, especially those that are persistently linked to PCOS through tropes of biomedicine and lifestyle, serve both as an insight into the lived experience of PCOS and as means of illustrating the contrasts between PCOS in everyday life and PCOS as represented in the aforementioned tropes.

In the literature on the lived experience of PCOS, diet is fleetingly mentioned. It is never the focal point but is present in women’s narratives. Williams et al.’s (2016) piece, for instance, mentions diet as something that is used as a strategy to control PCOS whilst simultaneously being regulatory, as women have to abide by the diet to reap benefits. In Ekbäck’s (2009) study, diet was mentioned as having a modified or “abnormal” (p. 361) way of eating to lose weight and manage hirsutism, but this is left unexplored as the study narrows its focus to other aspects of embodiment. I see this as an interesting example of diet being

⁷ GI: glycaemic index- a value that indicates how foods (such as carbohydrates) affect blood glucose levels. Foods low on the GI release energy slowly, meaning blood glucose levels do not vary greatly and remain relatively stable. Foods high on the GI raise blood glucose very quickly, resulting in periods of excess circulating blood sugar and then lowered blood sugar- instability. In PCOS, insulin resistance, and diabetes, the aim is to keep blood glucose levels stable.

mentioned by participants as a practice in relation to their experience of their bodies- of both being a body and producing a body.

Management practices for PCOS, including the ones I have mentioned, are influenced by the chronic nature of the condition. As a syndrome without a cure, having PCOS can mean having to constantly manage it throughout the course of a lifetime (Elizabeth, et al., 2009). This makes it important to chronicle and understand the management practices women use for PCOS.

Mediatory Tactics

Everyday practices are not limited to diet and exercise regimens. They also include medication, and cosmetic processes like shaving, plucking, threading or laser treatment for hair removal (Ekbäck, et al., 2009; Hadjiconstantinou, et al., 2017; Kitzinger & Willmott, 2002). Pfister & Rømer (2017) and Hadjiconstantinou, et al. (2017) call these “coping strategies”. Aside from bodily practices, women use discursive and cognitive practices as coping mechanisms for PCOS as well. For instance, some women used humour to diffuse the chronic nature of PCOS, especially in social settings (Pfister & Rømer, 2017). In Williams et al.’s (2016) study, some participants were optimistic and hopeful, having positively reframed and rethought of PCOS as manageable.

What I conclude about lifestyle management in PCOS is that despite lifestyle being frequently mentioned in PCOS literature there is not enough qualitative and individual exploration of this, even in the handful of phenomenological studies on PCOS. To apply a model of studying everyday practices for a health condition, I looked at work on diabetes. Diabetes is similar to PCOS as they share the underlying pathologies of insulin resistance and unstable blood glucose levels, and PCOS can be a precursor to diabetes type II. Beyond that link what interested me was a concept I encountered in experiential works on diabetes: everyday tactics. I was interested in pieces on diabetes looking at how people engage in management tactics for self-care (Mendenhall, et al., 2016). I draw from Guell’s ethnographies of Turkish people based in Berlin (Guell, 2011; Guell, 2012): she builds accounts of people with diabetes navigating culture, tradition, and biomedicine to arrive at everyday practices, or ‘tactics’ that are unique individual ways of managing their illness and health. For instance, eating

tactics such as selecting food types, meal timings, and portion sizes, were sourced from biomedicine and negotiated to fit social needs (Guell, 2012).

I borrow from Guell and look at what I term mediatory tactics in the study of PCOS. I take mediatory tactics to mean everyday practices that combine knowledge and practices from multiple social spheres, from biomedicine to culture to everyday practicalities, to negotiate with a health condition- in this case, PCOS. I will develop this concept in a subsequent dedicated chapter.

Chapter Summary

PCOS literature suggests that the effects of the condition are as much of a constellation as the biological symptoms of it. PCOS influences the way women feel about their bodies. It can affect the way women interact with other people and their relationships. It influences identity and selfhood, in terms of both health and gender. Women with PCOS struggle with constrained ideas of womanhood and femininity. Throughout qualitative pieces on PCOS, the notion of being different recurrently stands out. Sometimes this is expressed as feeling abnormal, sometimes a desire for 'normal' womanhood, and through everyday actions of conforming to dominant narratives on womanhood. Qualitative studies on PCOS have repeatedly revealed the aforementioned themes, but there is still a scarcity of in-depth, subjective, and contextual data. Methods such as ethnography that are well-suited to understanding phenomena interpretatively and phenomenologically are scarcer still in PCOS literature.

Chapter 3: Methodology

I began my research in May 2018. I had originally planned to situate this research in Pakistan, where I am from. As a Pakistani woman with PCOS, and knowing of multiple other women's PCOS experiences, I was familiar with the cultural presence and perception of PCOS in Pakistan. I was also accustomed to medical attitudes there, having been through multiple different medical systems numerous times. My research plan was to live in Lahore for some months, carrying out participant observation and ethnography within a local network. However, a few months after I arrived in England, my research field and with it my methodology shifted. Research, in particular fieldwork, is highly pliable to practical factors, and in my case the change was made to account for time. I had to finish the project much earlier than initially anticipated, and no longer had the time to travel back to Pakistan for ethnographic fieldwork. Since I wanted to commence research as soon as possible, the most accessible location became simply where I was based for the duration of my Masters: Exeter, in the South-West of England.

In this section I begin by outlining the theoretical frameworks that inform my study and my own position, and how these accommodated the changes to my research plan. The research paradigm I draw from is phenomenology. I then move on to how this framework translated into my methodological practice, from the recruitment process to interviews and data collection. Finally, I discuss my position and reflexivity, which I will continue throughout this thesis.

Objectives and Research Questions

The central aim of my study is to chronicle a slice of the lived experience of PCOS by developing an understanding of what having PCOS means and feels like for the women experiencing it. My first, and primary, research question is:

- 1) What is the individual experience of PCOS?
 - i. How do women feel about PCOS?

This question takes individual experience to largely mean perception, and subjectivity within perception. After reviewing a large body of PCOS literature, I felt that the few qualitative studies that existed had only served to emphasize the lack of individual narratives of PCOS. So, I became interested in

representing women's personal narratives, attitudes, and feelings regarding PCOS and their own experiences. To explore this, I was interested in a range of experiences: from narratives, memories and emotions surrounding PCOS to more literal bodily experiences, such as symptoms. This informed the sub-question regarding feelings. I was curious to see how women thought of their PCOS, and whether/how they felt the condition's presence in everyday life.

I decided to look at experiences that women attributed to PCOS themselves, so I kept this question and sub-question (and subsequently my interview approach) very open and flexible. Since I have PCOS as well, I did not want my own experience to create biased assumptions of PCOS experiences. However, I did use my personal experience as a springboard for asking and developing questions. For instance, I have a set of practices that I use to manage my PCOS. This made me think of what other women were doing to manage PCOS, and whether they were doing anything at all. This led to my second research question:

- 2) What is the lived experience of PCOS?
 - i. What experiences did women have with medical systems?
 - ii. How is PCOS managed in daily life?

The first question is about experience as individual perception, and the second question is about lived experience as individual practice- things that women do with and for PCOS. Here, I take lived experience to be practices and routines in day to day life. Once again, I decided to keep this question very broad and open so that my research could be an inductive process, generating insights as I conducted it. With this question, I was interested in what influences, produces, and affects the lived experience of PCOS in everyday life. The first sub-question is concerned with medical systems and PCOS. I anticipated that women must have had at least one encounter with a medical system, and I assumed this to be a useful starting point for narrative. I was especially interested in the role of biomedicine in how PCOS is perceived and managed, as biomedicine is the institution through which PCOS is recognized. To look at health practices, medical systems were an essential contextualizing medium. The second sub-question is directly about daily actions and practices that women might be using to live with PCOS, such as medication or diets.

The central aim of this study and these research questions was to develop detailed and personalized descriptions of how women experience and live with PCOS. I have taken experience here to be two-fold, with one tier being perception and attitudes and the second tier being the embodiment of these perceptions through practices and actions. I take these two aspects of experience to be inseparable, and I do not assume a hierarchical or causal relationship between perception and practice. However, for the purposes of clarity, and to narrow down what I explore within experience, I have settled upon these two main questions.

Whilst these questions are very broad in their scope, their outlook is narrowed by the frameworks I adapted in my approach towards them: phenomenology, and embodiment.

Theoretical influences: Phenomenology and Embodiment

The ontological and epistemological foundations, as well as the analytical approach of this piece are based on the paradigm of phenomenology. I have used the terms 'subjective' and 'individual' throughout this piece; phenomenology is the paradigm that I draw and define those terms from. Phenomenology eponymously investigates a phenomenon, usually by developing detailed and descriptive accounts that are subjective in nature. Subjectivity in phenomenology refers to a subjective consciousness; every individual's experience of consciousness is layered with meaning and intentionality. The philosopher Edmund Husserl's work is the building block for the phenomenological paradigm. He developed the ontological stance in phenomenology and the ideas of a subjective conscious as the locus of meaning-making. Husserl's ontological legacy underpinning existential phenomenology is that reality is understood through- and thus constructed through- consciousness and perception (Husserl, 1958). Phenomenology does not assume an objective reality external to the perceiver, and it assumes no objective truth, putting it in opposition to the positivism that dominated in the early days of social sciences. This allows the paradigm to examine experience without prejudice and presupposition. Following Husserl, Alfred Schütz expanded the application of phenomenology to sociology, specifically to the domain of everyday life (Schutz, 1967). Schütz, alongside Luckmann (1973), built upon Husserl's idea of the 'life-world'. For Schütz and Luckmann, the

lifeworld comprises the subjective conscious, intersubjectivity, interactions, institutions, culture, patterns and ways of being that form the experience of everyday mundane life (p. 53). Thus, the life-world should be the centre of investigation for social scientists (Costelloe, 1996; Schütz & Luckmann, 1973).

Phenomenology and the concept of the lifeworld are fitting for the study of PCOS. I take the condition to be a multifactorial phenomenon that is a part of everyday life and that draws influences from multiple other domains. Since phenomenology is essentially the study of experience, it aptly lends itself to studying the experience of PCOS. Phenomenology's attempt to understand an experience through subjective accounts is relevant as the way PCOS takes effect varies from individual to individual. The shared experience of PCOS is not enough to generalize about the combination and severity of symptoms different women will experience. Phenomenology allows the study of PCOS from a subjective perspective and does not attempt generalizations across a group. In the case of PCOS, medical and biological aspects cannot be overlooked- again, phenomenology is useful as it doesn't disregard those sides. Instead it sees those dimensions as part of the phenomenon, recognizing that natural science's descriptions together with individual experience are important in understanding a phenomenon (Englander, 2012). This approach also recognises the role of the researcher in the process of meaning-making, acknowledging that whilst the objective is to capture the participants' subjective experiences, the researcher cannot disregard their own position and perspective (Hammersley, 2005). This is particularly relevant in this study, as I am researching a phenomenon that I experience myself. Attempting to separate my experience would be difficult, possibly an exercise in futility, or even reductive. Whilst I have not included personal accounts of experience, I rely on consistent reflexive positioning. Phenomenology has been the dominant theoretical approach adapted by most qualitative studies on PCOS, also validating its suitability for the study of PCOS (Ma, et al., 2014).

Husserl and Heidegger established phenomenology within existential philosophy and as concerned with consciousness, the nature of phenomena and the life-world (Groenewald, 2004). Schütz expanded on this, emphasizing on a phenomenology of everyday life (1967). Merleau-Ponty, both drawing from

and departing from these thinkers, positioned experience as a deeply embodied phenomenon (1962).

Embodiment is another framework and methodology I draw from. I engage with Merleau-Ponty, Foucault, and Bourdieu's ideas to inform my understanding of embodiment. According to Carman's (1999), Husserl sees the body as occupying a kind of middle realm between the subjective and outside worlds, between consciousness and reality, and as one facet of conscious experience. It is the site of physical sensation and cognitive schema and 'bodily intentionality', meaning innate bodily agency, such as reflexes and motility. However, for Merleau-Ponty, the body is the primary grounding medium for sensory experience and thought. In *Phenomenology of Perception* (1962), Merleau-Ponty situates the body as a background for perception. The body is the locus of sensation and experience and of precognitive schema; the body is a point of origin for perception. The body is an active presence and process, constantly interacting with and inhabiting the world and in turn informing experience. The body is also intersubjective, allowing for the understanding of other bodies. For Merleau-Ponty the body renders the world intelligible just as the world makes the body intelligible (Carman, 1999; Davidson, 2000). Csordas' (1990; 1999; 2015) works on embodiment illustrate the approaches of Bourdieu, Merleau-Ponty, and Foucault. Csordas (2015) reviewed phenomenology in anthropology to present a configuration of perspectives on embodiment and relationships between the body and world in terms of agency and the direction of agency. In the text by Csordas, the body and the world are initially discussed as separate but symbiotic. Csordas' own approach to embodiment rejects the duality and division of mind and body, holding that bodies are included in and not separate from the perceptive process. Studying both the habitus and cognitive perception through embodiment blurs the lines between subject and object (Csordas, 1990). According to Csordas's interpretation, Bourdieu holds that agency is exercised through everyday practice, in a co-producing synergy between body and world, and agency and structure (p. 51). In contrast, Foucault's view on bio-power sees agency being filtered through and inhibited by discursive power structures, trickling down from world to body (Csordas, 2015, p. 52; Foucault, 1972). Both of those views are relevant to my line of inquiry. The Foucauldian approach is useful towards understanding body norms

and ideals, the imposition of the former through institutions and structures, and how those intersect with a body that does not conform. Foucault's ideas on agency inform my interest in management practices and choices, framing their connection to culture and society. This study uses everyday practices as a reflection of the embodied experience of PCOS. Unlike Foucault, and in order to allow my participants to map out their own experiences and accounts, I do not presume a linear and deterministic direction between cultural influences and management practices. To understand associations between everyday practices and one's bodily experience of PCOS, I find Bourdieu's ideas on an individual habitus significant. Bourdieu defines habitus as an amalgamation of internalized dispositions and practices influenced by, and in turn influencing, experiences and social structures (Bourdieu, 1977; Bourdieu, 1990). The habitus connects cognition, experience, embodiment and the social world through internalizations, habits, and everyday practices. I see the embodied experience of PCOS as part of individual habitus, situated within, and possibly reproducing, a collective habitus that informs practices and attitudes surrounding PCOS. The collective habitus of PCOS that I anticipated was based on previous studies and my personal experience, including intersections of the medical sector which is responsible for the recognition, diagnosis, 'measurement', and treatment of PCOS; cultural attitudes towards health; cultural ideas of gender, femininity, and masculinity; and subjective, individual experience.

To explore the embodied experience of PCOS, I used in-depth interviews. The 'data' that interviews elicit is discursive- a conversation, in this case verbal and in-person, transcribed into text. The use of discourse to accurately or sufficiently represent lived experience elicits varying opinions. One point of view holds that discursive representations of lived experience are reductionist, or performative; the lived moment and the recollection of the lived moment are different experiences, and so narratives might be inadequate in capturing the entirety of a lived experience, especially that of someone else's experience (Denzin & Lincoln, 2005; Polkinghorne, 2005). In a similarly critical vein, narratives might take on a performative aspect and lose gist of the lived experience in terms of time and space, taking on an entirely new character that merits separate study (Silverman, 2013). Wolputte (2004), paraphrasing Csordas (1990) says that

embodiment lies within lived experiences instead of discourse. However, Csordas's central argument arrives, alongside those of Merleau-Ponty and Bourdieu, at the abolition of dualities that delineate between mind and body, thought and action, subject and object (Csordas, 1990). Whilst I concede to the narrative of experience and a moment of experience itself differing in terms of temporality and spatiality, the representations of both forms of experience can be concurrent in narrative accounts. In my research, I could not anticipate or access moments of lived experience pertaining to PCOS as they were being experienced. First, this would have required imposing a host of presumptions on my part; from defining what a PCOS experience was, to anticipating when it would occur, to positioning myself within in, and assuming that being present in the moment was enough for me to fully understand someone else's experience. Second, it was practically impossible, especially in terms of embodied experience. How could I experience someone else's bodily experience- especially one that is not observable- unless the person experiencing it *told* me of it. Hence, I was already limited in terms of accessing a lived experience as it occurred and- assuming that the body is the locus of experience- *where* it occurred. As a woman with PCOS, I had some idea of bodily experience, but it was key for me to allow my participants' experiences to be subjectively represented. So, I turned to accessing those moments through conversation and narrative. Which brings me to another perspective on discursive representations of experience: experience is not static, or inflexible. Experience need not be separated from the recollection of it. To quote Treadaway (2009):

“Perceived experience is also influenced by memory of previous experiences; we bring to the present personal and cultural influences that have been previously sensed or learnt. What we perceive is “the product of past experience and future expectations” [17]; our perception of experience is dynamic, changing and modulating through sensory stimulation and the merging of memory.” (2009, p. 233)

Even if experience must be temporally situated, what is perceived in the present is imbued with everything that happened before (Desjarlais & Throop, 2011). Schütz and Luckmann argue that lived experiences are not just meaningful in the moment, but when recollected a layer of reference is added to them, which in turn creates meaning (Schütz & Luckmann, 1973, p. 16). Using Merleau-

Ponty's ideas, Belova and Munro (2009) argue that the body is crucial towards what linear time and linear narrative is. Whilst temporality situates a body, temporality itself is also bound to the body experiencing it. For me therefore, the need to separate a moment of embodied experience and the narrative of that experience dissipates. I find this echoed in Cunliffe and Coupland's (2012) piece, where they propose that embodiment and discourse, retrospect and prospect, the everyday and the unusual all come together for 'sense-making', to understand the dynamic and ongoing process of experience. Returning to Merleau-Ponty's ideas on embodiment and perception, the body is a medium of communication and inseparable from communication itself. Communication, in turn, is an exercise in the embodiment of thought, and so it is a valid representation of experience. For Merleau-Ponty, speech and articulation are not representations of thought that are separate from thought itself; they are manifestations and expressions of thought through a bodily act (Csordas, 1990, p. 26). To draw from Paul Ricoeur (1992), narratives are an active process of relaying not just an occurrence or story, but of expressing- and making intelligible- one's identity and self.

Interviews

To explore someone else's experience using discourse⁸ and communication quite literally allows them a voice. The narrator can choose how to shape and convey their experience. Oral narratives contain memories, descriptions, emotions and gesticulations that come together to try to communicate experience (Legard, et al., 2003; Polkinghorne, 2005). This may also mean that participants rearrange their experiences, perhaps leaving out or exaggerating details. My argument here is not that discursive representations can capture experience in its entirety; instead, I argue that discursive representations allow for experience to be relatively free from external impositions, such as the researcher's preconceived notions, values, and attitudes. It is not value-free, but it reflects the values of the subjects it claims to represent. During the course of a conversation or interview, experience is both narrated and recollected. The moment of experience is accessed and verbalized. This also allows participants

⁸ I use discourse here in lay terms and not as discourse analysis, which is a separate research methodology. I also do not use it here as the Foucauldian concept of discourse. In this section I use discourse, narrative, and communication almost interchangeably to reflect the conversational nature of the interview process as well as the content it generated.

to decide on what a PCOS experience actually is. My method of inductive interviewing allowed participants to choose what constituted their PCOS experience. For instance, I asked what PCOS symptoms they had, instead of asking whether they experienced hirsutism or irregular periods. It is possible that the women I spoke to had symptoms/experiences that PCOS had influenced- say, a mood swing, or abdominal pain- but which they did not attribute to PCOS. In this case, it didn't matter. A PCOS experience only counted if it was perceived as such, whether in the moment or in retrospect. The key here for me was that the person having the experience perceive it as related to PCOS.

The ideas and assumptions underlying my approach in this study are thus: that the paradigm of phenomenology is well-tailored to the study of the experience of PCOS. Theories of embodiment are applicable to the bodily experience of PCOS, illustrating it from multiple points of view. Finally, that the experience and embodiment of PCOS can be understood through discourse and descriptions.

Modifying the Research Plan

I began this chapter with the mention of practical considerations and a time constraint that shifted my original research plan from ethnography to interviews. Due to personal reasons, I had to complete the project within the span of six months instead of eighteen. Changing the research plan was a pragmatic decision to ensure that this project was completed on time. Here, the qualitative and phenomenological underpinnings of my project worked to my advantage. Qualitative and inductive research is quite flexible, with the design being able to incorporate modifications at most stages (Maxwell, 2008). Instead of using these factors as 'controls', inductive research allows itself to be shaped by the field, context, researcher and participants (Maxwell, 2012). The data collection method in phenomenological research is interview-based, with analysis being centred on deriving themes and meanings from this data. Using phenomenological, in-depth interviews for my study became an adjustment grounded in both practical and theoretical factors.

Locating the research in England, where I had arrived only a few months ago, put me outside the context of my own culture, where I had known the cultural

terrain and could anticipate some PCOS experiences. In phenomenological research, however, there is a concept of 'bracketing' the 'natural attitude' (Husserl, 1958). This means that the researcher attempts to understand different experiences outside the domain of their own personal, cultural and social experiences. This does not mean ignoring or downplaying the researcher's position. Instead, it means suspending preconceived assumptions to allow for notions and ideas generated by the research to be understood in more dynamic, sensitive, and nuanced ways, without presuppositions and bias (Desjarlais & Throop, 2011). As this theoretical aspect aligned with changing the study setting, I came to another realization: I could speak to people from a wide variety of cultural backgrounds. I no longer had to ground my research in one specific culture. Instead, the phenomenological paradigm allowed me to build subjective and individual accounts, including my participants' accounts of their own cultural backgrounds and influences. Instead of cultural specificity, my project became delineated by parameters of geographical space- simply the place where I was located. My 'sample' was demarcated through the experience of PCOS, with the condition being the only common thread I had presupposed between my participants. Anthropological approaches to embodiment have widely adapted using the body and "bodily experiences, forms of knowledge, and practice" (Desjarlais & Throop, 2011, p. 90) as the grounding medium for experience. The condition of PCOS and its bodily presence became the grounding factor for experience in place of a common cultural background.

This sort of cultural non-specification could allow for a diversity of experiences to be included and represented. The role of culture is not rendered any less important, however. I still explored cultural and social influences and contexts surrounding each PCOS experience, just without assuming them beforehand. My approach allowed me to leave the framing of their cultural experiences, heritage, and knowledge to my participants- which I would access through how they discursively represented and relayed it to me during interviews and conversations.

Recruitment Method and Participants

My theoretical approaches informed the method of participant recruitment that I chose. I had two different approaches towards my recruitment methods. The

first approach, draw on my sociological training, was purposive sampling. The second approach was through simple, spontaneous word-of-mouth.

Purposive sampling is the characteristic sampling approach in phenomenology, as it allows a sample to be drawn based on their experience of the particular phenomenon under study (Robinson, 2014). In purposive sampling research participants are selected based on whether they fulfil certain criteria or possess specific characteristics (Etikan, et al., 2016), so this approach is a non-probability method of sampling and widely used in qualitative studies. For studying the experience of PCOS, it was necessary that my participants be women who had PCOS. I limited this sample to women who had PCOS for purposes of physical homogeneity⁹, as this homogeneity was a contextualizing element in my study. I specified no age range, but I excluded post-menopausal women as menopause has overlapping or exacerbating symptoms in conjunction with PCOS.

In March of 2018, I printed out a call for participants, alongside a brief description of my project and posted flyers around the University of Exeter's Streatham Campus. Initially, I put up flyers on noticeboards in the main building on campus, the Forum. I called for participants who had experienced PCOS personally in any capacity. No financial inducements were offered; although I did include that there would be tea and coffee. A couple of weeks passed, and I received no response. I then put the flyers up in the ladies' bathrooms in the same building, with the intent that women would be able to view and respond to them without being observed. Within a week I heard back from three people. It is possible that my first flyers got lost amongst the gaggle of other notices jostling for attention on overcrowded noticeboards. It may be that a single flyer in a bathroom stall drew attention while people cast around for something to look at. Or, as I suspect, women may have felt more comfortable reading and responding to a call for participants with 'PCOS' blazoned across it when they didn't feel observed- perhaps indicating stigma or embarrassment associated with PCOS. It also indicates the nature of places where you can and cannot be

⁹ Meaning that the participants should have a physical trait- here the diagnosis of PCOS- in common (Teddlie & Yu, 2007).

observed; like public and private spaces. I revisit themes of visibility and observation later in this piece.

Since I wanted to chronicle subjective accounts of PCOS, I initially estimated interviewing between 10-12 participants. Such a number would work for practical factors, such interviews and transcription being conducted by one researcher over limited time. It would also allow for an individual voice and expression for each participant (Robinson, 2014). However, during data collection practical factors often influence the sample size (Silverman, 2013). In my case, I was limited to the number of people who answered to my call for participants. I interviewed a total of seven women. Three of them responded to my flyers. Four of the women I spoke to became interview subjects simply by chance. One woman approached me after a conference presentation, offering to share her PCOS experience. The other two were fellow Masters students who I met at university. In a hallmark socialization ritual of graduate students, we discussed our research topics when we first met. Following my description of my Masters project, in separate ensuing conversations, two women told me they had PCOS and offered to participate in my study. Out of the women I spoke to, five had an active diagnosis and symptoms of PCOS; one woman had an ambiguous diagnosis, where she wasn't quite convinced as to whether she had the syndrome or just polycystic ovaries; and one had cystic ovaries and related complications- however she did not have the syndrome, or any symptoms related to it. We discovered this after beginning the interview. She had polycystic ovaries (PCO), which she and her doctors referred to as PCOs, the plural of polycystic ovary. The term is easily confused with PCOS, the acronym for the syndrome, and my respondent thought she had PCOS. I continued my interview with her but have not included it in the analysis. My final sample consisted of six women with PCOS.

The study was located in Exeter, so the participants I interacted with were all based there; however, they hadn't grown up there. The study was set at the university, and all my participants were students at Exeter who had moved here from other places. Although I was open to interviewing staff members at the university and locals from the city, I did not come into contact with any. So, my final sample consisted only of students. Some were from different parts of the UK, and some were from other countries. The women were between 20-28

years of age. All of them were unmarried and had no children. All of them were living as a single unit, either in university accommodation or shared student houses. My participant group was multicultural, had varying experiences with PCOS, and had interacted with different medical systems.

Interview Method and Data Collection

My main methodological tool was in-depth interviews. In phenomenological research, qualitative and in-depth interviews are the primary research method for collecting data (Bevan, 2014). Phenomenology values descriptions over causal explanations towards understanding a phenomenon. The researcher elicits descriptive accounts of lived experiences from the participants and then, drawing from Husserl's phenomenological reduction, creates a discussion around the meanings in those descriptions (Sadala & Adorno, 2002). In order to access these descriptions of experience, in-depth interviews are significant.

My interview guide was semi-structured, with the objective being to facilitate organic conversation but guide it to specific areas of inquiry and interest. I adapted a form of 'active' interviewing, where the interview process itself is seen as a medium for generating meaning (Holstein & Gubrium, 2004). The participant is not seen as a vessel containing meaningful experiences waiting to be poured out. Instead it is recognized that both the participant and researcher create meaning and knowledge through an interactional process. Since my subject of investigation was quite specific, I began the conversations with contextualizing questions, largely to orient myself to the participants. The starting point of my interview was asking participants when they found out they had PCOS. Contextual questions allow for accounts to take a narrative structure and provide necessary backdrop (Seidman, 2013). My participants' narratives were not chronologically ordered. Instead the accounts ebbed and flowed between timeframes and memory, with participants adding thoughts and incidences as they remembered them. I found myself trying to piece chronological order into the accounts as I was transcribing the interviews but settled for verbatim transcriptions.

In an active approach to interviewing, although participants' narratives are guided by the researcher and the topic being discussed, participants hold the autonomy to steer the conversation, to dip into intimate areas or veer away from

certain topics. In practice, I found that my participants were relying on me to guide the conversation whilst we were in 'interview mode' with the recorder on, often continuing to talk to me after I stopped the audio recording, which allowed 'rambling', as one girl put it. I also found that gentle prompts when participants seemed hesitant or awkward encouraged them to open up and share experiences that were laden with meaning and emotion. Rapport-building was essential for this. The longer and more frequently I spoke to someone, the likelier they were to share meaningful experiences with me. I found the limited time and frequency of a single interview slightly inhibiting towards establishing a rapport and trust with the participants. Even though the interviews were an hour or so long, this was not enough time to cultivate a close relationship. Verbal assurances of confidentiality could only go so far. This returns me to the temporality that phenomenology acknowledges; human experience is embodied and made sensible through layers of space and time. An hour was hardly transcendental. To facilitate our interaction and rapport-building, I relied on sharing my own experiences with PCOS. Establishing that the phenomenon under study was a shared experience significantly contributed towards rapport-building. I also tried to do a second interview with those participants who were interested. This proved very useful. I found that during the second interviews girls were more relaxed, and often gave more open emotional responses to similar questions I had posed during the first interview. This illustrated the importance not just of rapport-building, but of building an interpersonal relationship with the participants.

Some of the richest nuggets of conversation emerged when the researcher-interviewee divide dissipated. For example, in ongoing conversations with the participants after I turned the recording off, I found that people would speak about things that they had held back during the interview, perhaps feeling they were unrequited or unnecessary. With the recorder off, participants used more sentences beginning with "I think", and people would offer opinions and thoughts on things they were not certain of, or the source of which they couldn't place or legitimize. For instance, things that were supposed to be common knowledge but had no clear substantiation, such as the idea of there being "hormones" in animal products such as meat or milk. The awareness of being recorded, combined with the researcher-interviewee dynamic seemingly had an

authoritative effect, almost inhibiting the sort of open conversation sought by a qualitative researcher.

Most of my interviews were conducted on the University of Exeter's Streatham Campus. A few interviews took place in cafes in town. The interview locations were decided over email or messages with the participants, selecting a convenient time and place. It was important that the location of the interview be such that we could not be overheard. The interview location needed to be neutral, safe, and private. This was to ensure privacy, confidentiality, comfort and to avoid disruptions during the interview process. I was acquainted with two of the participants outside of the capacity of this research, so their second interviews took place in their homes. Interviews with each participant lasted for about an hour to 90 minutes. I collected audio recordings entirely on my phone, and immediately transferred them to a laptop or computer afterwards. I stored the audio recordings on the university's cloud storage. All these devices and mediums were password-encrypted.

Analytical Approach

As I was conducting interviews and writing transcripts, the analytical dimensions of my project started to take shape. In qualitative research, analysis emerges from, is concurrent with, and can influence data collection; if unexpected themes or areas of interest begin to emerge, they influence the kinds of questions asked (Maxwell, 2008). I adapted a similarly flexible and inductive approach and as data collection progressed, my interviews grew less and less structured as I realized that a flexible approach was better at generating the kind of information useful for my study. In phenomenological analysis, interview data is transcribed into text and then commonalities in the texts are identified. The researcher zooms out their lens of perspective, from an individual's experience to patterns in the group's experience. The commonalities this perspective creates condense into themes that are broad descriptions of the phenomenon under study. The analytical process then telescopes into individual perspective again, to support the thematic categorization (Starks & Trinidad, 2007). I loosely followed this inductive pattern. Whilst I did organize the data by common themes, I found an immense overlap and connection between themes, such that I was at times reluctant to segregate data into

categories. In my writing, these themes often overlap, emerging and re-emerging at various points.

Ethics

I outlined my research plan and gained approval from the University of Exeter's ethics review board before commencing research. The other ethical considerations in my study were informed consent and privacy and confidentiality. This study has not received funding from any parties.

Informed Consent

Before the beginning of each interview, I gave each participant a consent form. This served both as a record of consent and contained a brief outline of my research, so that women would know what the study was about before the interview. Verbally, I assured the participants that everything they said would be kept confidential and that they could withdraw from the interview any time.

Privacy and Confidentiality

Since PCOS as understood in this study is a health condition, like any health condition it can hold associations with shame, stigma, or a simple desire for privacy, depending on the person, their experiences, and the sociocultural context. To avoid any issue related to shame, embarrassment, health-related privacy, interpersonal relationships, or a risk to reputation or social status, I kept respondents anonymous. Starting from the transcription stage of the data, I assigned each participant a pseudonym which I used throughout the rest of the research and write-up. I involved a few participants in the process of choosing their own pseudonyms, usually to hilarious results. However, in the end I assigned each pseudonym myself. All information including interview audio recordings, transcripts, and email exchanges were stored on encrypted platforms, mainly the University of Exeter's cloud storage.

Reflections and reflexivity

In qualitative and inductive research, the researcher is an active participant in data collection and the process of meaning-making (Holstein & Gubrium, 2004; Maxwell, 2012). It is important for the researcher to recognize this role. However, the defining factor for my position in this study is not just that I am the researcher, although it began as such. For me, the defining feature is that I am also a woman with PCOS, who has experienced PCOS in very tangible ways

over several years. From the conception of my research proposal, to the last interview and throughout writing, I kept returning back to my own experience with PCOS throughout the course of this project. In qualitative research, reflexivity is an introspective process employed by the researcher where they attempt to recognize and place their own role and position in the research (Guillemin & Gillam, 2004) . This means being aware and critical of their own experiences, knowledge and ideas and being cognisant of their role in generating interpretations, meanings and knowledge. Reflexivity is both an exercise in ethics and a process of self-positioning. I position myself as a woman with PCOS and a researcher in the context of this project. I also acknowledge the influence the research process had on me.

During the course of data collection, I couldn't help but repeatedly turn the lens onto myself. I did not keep a research journal in the traditional fashion. However, I collected informal field notes in a notebook. I scribbled down a variety of things, from analytical observations to to-do notes for myself. The interview process made me think about my own PCOS experience in ways I hadn't considered before. First, there was the reaction to similar bodily experiences. I found some of the experiences and feelings I had with my own body because of PCOS being articulated by my research participants. I had two responses to this. The first was sharing my own experience, and the second was to check that I was not projecting my experience; after all, this was about the participants' experiences. I shared enough that the conversation would still remain focused on them, but that I was still engaging with what they were telling me. For example, by adding "me too" after someone told me about their symptoms or showing the hirsute hair on my neck and cheek. After one such instance during an interview, the girl I was speaking to visibly relaxed her shoulders and exhaled before continuing to talk, her conversation taking on a much more open tone. When I opened up about my experience, it resulted in conversations acquiring an empathetic, much more confidential tone and a sort of intimacy born from similar experiences. I persistently found a therapeutic aspect to the interview process. This affect was two-way, felt by me and my participants. For the participants, it made them relax and share more. Most of my participants thanked me at the end of our conversation, which I found

heartening. For me, each time I spoke to someone and found my own experiences reflected in theirs, I felt relief in knowing that I was not alone.

Before beginning research, I knew that my participants and I would share a diagnosis of PCOS and anticipated some of us having the same symptoms. I had not anticipated the powerful effect speaking to people with the same experience would have on me. My personal experience with the bodily manifestations of PCOS have often made me feel different from other women, despite the statistics on PCOS asserting that it was 'common', and despite me personally knowing many women who have PCOS. However, during my research process I felt that I was regularly engaging with people with whom I shared very similar experiences and concerns, including some symptoms. For instance, one participant gave a term to a symptom I also experienced but never knew how to articulate: "brain fog". In such instances I felt myself normalizing my own feelings and experiences through seeing them reflected in other women's accounts. This normalizing also occurred through vocalizing my own PCOS experiences; I felt that between me and my participants there had sprung a shared discursive space where I could speak as freely as I was encouraging them to.

I felt that where our bodily experiences were in common, we also shared how those made us feel, despite the cultural, social, and experiential variances in our experience I identified with the experiences they related. What strikes me here, as I write, is my use of the word *us*. Knowing that other women had felt similarly and seeing reflections of my experience elicited emotional reactions and memories in me. Some interviews took me back to the day I was diagnosed- a memory that I shared in turn with some participants. Some stories reminded me of the various tactics I had employed over the years to manage my PCOS, especially the medications.

Some of these effects translated into my everyday actions towards managing my PCOS. A very concrete effect of my conversations with one of my participants was that I resumed taking a supplement called Inofolic. I had last taken it years ago without much affect and discontinued it after some months. I was reminded of the supplement during an interview and began taking it when I had a late period. I was incorporating information from interactions with my

participants. For me, this highlights the highly interactional nature of PCOS, present in the researcher-participant dynamic that my study created.

Between sharing and similarity of experience, one instance put me in an ethical conundrum. In one interview, a participant described symptoms that I recognized as insulin resistance. I identified the condition because I have insulin resistance myself. She had mentioned these symptoms to her doctor without getting any response. The doctor had either failed to make the diagnosis of insulin resistance, or not mentioned it to her. Naturally, she was not taking any medication for it. In my opinion, insulin resistance is not a condition that should remain unchecked. High levels of circulating blood sugar can wreak havoc in the system, and it is a precursor to diabetes type II and other health complications. I didn't know what to say- even if I recognized the condition, I could be wrong. As someone outside the medical profession, was I qualified to talk about it? I was also afraid of causing alarm or distress during the interview, which would be an ethical violation in itself. I decided to mention insulin resistance to her without saying something alarming like, "you have insulin resistance". Towards the end of the interview, I casually asked her if she had ever heard of the term insulin resistance. She told me she had not. I told her it was something commonly experienced by women who had PCOS, so it was worth asking her doctors about it at her next appointment.

Chapter Summary

In a departure from the intended ethnographic design of this study, my methodology was moulded to practical factors and took on a more sociological approach. Instead of the anthropologist travelling to a different place, living with participants, and engaging in an established 'field', a field of sorts sprung up around the anthropologist. In a place where I was not from but where I was living at the time, I became the locus around which my participants aggregated. The interactions between me and my participants, in the form of in-depth interviews, form the base structure of this study's methodological approach. I have concluded this chapter with my own experiences. In the following chapters, I explore the PCOS experiences of the women I interviewed.

Chapter 4: Diagnosis and Doctors

In my flyer calling for participants, I had specified that I was looking for women with a personal experience of PCOS. I did not specify that the respondent needed to have a medical diagnosis of PCOS. I did this on purpose for a number of reasons. First, I was uncomfortable with using the word 'diagnosis' to validate an experience of PCOS. It was possible that women had never consulted or been diagnosed by a doctor but still, through other sources, knew of PCOS and were experiencing it. Secondly, despite having a diagnosis sometimes women did not have symptoms of the syndrome, or there was a great degree of ambiguity between whether they experienced PCOS the syndrome or polycystic ovaries¹⁰, as evidenced by two of my interviewees. Finally, since the term PCOS is a very specific term originating from biomedicine, in all likelihood those who recognized it came across it through some interaction with the medical institution in some way, irrespective of a PCOS diagnosis.

My assumption that people responding to my flyers would have gone through some form of interaction with the institution of contemporary allopathic medicine was substantiated. Every woman I spoke to had had at least one encounter with a medical professional regarding PCOS. One woman had self-identified that she had symptoms of PCOS, learning of it through a morning chat show, but nevertheless went to a doctor for confirmation. Diagnosis is, after all, the medical system's classificatory device and the authority and knowledge needed to confer a diagnosis usually rests with a medical practitioner (Jutel, 2009). According to Blaxter (1978), diagnosis can be both a process and category. As a category, it contains the characteristics needed to identify a medical condition or disease; this can be through description, cause, or prognosis (Blaxter, 1978). As a process, diagnosis brings medical knowledge into practice and underpins the relationship between doctors and patients (Rosenberg, 2002), including interaction, exchange, and authority. Linder (1965) argues that this is not the full extent of the process. After identification, diagnosis also implies another stage that is resultant and corrective action, usually in the form of treatment. In the

¹⁰ the ovarian anatomical morphology without symptoms of hormonal or metabolic imbalance

case of PCOS and its major diagnostic criteria¹¹, diagnosis rests on the presence of multiple symptoms of the condition, mainly polycystic ovaries. The process of identifying these symptoms, confirming the diagnosis, and looking at treatments includes interactions with medical practitioners, medical tests and technologies, and patients' narratives.

In this chapter I unpack what the diagnosis of PCOS meant for the women I spoke to, including the connotations attached to it, the implications of it, and the diagnostic process itself.

The process of PCOS (mis)diagnosis

All the doctors mentioned in this study seemed to be following the Rotterdam diagnostic criteria for PCOS by identifying the presence of at least 2 out of 3 symptoms, mainly polycystic ovaries and hormonal imbalances. However, a uniform diagnostic criterion doesn't guarantee consistency or accuracy in diagnosis when it is translated into practice.

For each of my participants, arriving at the PCOS diagnosis was a different experience. There were two main reasons for this. First, because women were experiencing different symptoms: some sought out a doctor because of amenorrhea, some made appointments after they noticed persistent acne or dark body hair. The second reason for this difference was because the symptoms of PCOS can be very similar to symptoms of certain other health conditions, especially other endocrine and metabolic conditions. Those two reasons combined with the way PCOS symptoms vary between individuals can make the syndrome confusing to identify. In some cases, the diagnosis was quite unexpected, surfacing in the wake of another health condition such as hypothyroidism. For instance, both Kiki and Nandini's doctors initially attributed their symptoms to thyroid dysfunction. Kiki was insulin resistant, and Nandini had suddenly gained weight. In Kiki's case there turned out to be no thyroid issue at all- the symptoms being confused for thyroid problems were of PCOS. Nandini, however, turned out to have hypothyroidism alongside PCOS. Nandini described her diagnosis as an "accident", during a routine check-up with her endocrinologist. "The doctors didn't realize I had it", she told me. In a third case, Fiona was diagnosed and treated for ME (Myalgic Encephalopathy) or Chronic

¹¹ NIH, Rotterdam, and AE-PCOS Society's criteria

Fatigue Syndrome before her PCOS was identified. For all three women, the doctors ran tests to check for PCOS and eventually diagnosed the condition. The occurrence of such co-morbidities parallel to PCOS makes the identification of it complicated.

Symptoms that overlap with other conditions can obstruct the diagnosis of PCOS, and sometimes symptoms that are only one part of the PCOS spectrum can result in a misdiagnosis of PCOS. For instance, it is possible for women to have polycystic ovaries, which is the main identifying characteristic of PCOS, without having the polycystic ovary syndrome. Kate suspects that this is the case with her PCOS. A few years ago, Kate set up an appointment with her doctor because she was concerned about amenorrhea that she had been experiencing for about 5 years. The doctor set up bloodwork to test her hormone levels, and also an abdominal scan to screen for polycystic ovaries. During the scan, as soon as the doctor saw multiple cysts in the ovaries, she told Kate she had PCOS. The diagnosis made Kate imagine how her body might change because of PCOS; for example, she imagined gaining weight and developing acne spots. In the months following her diagnosis, none of these changes occurred. That experience, alongside the all-clear results of her hormonal profile, made Kate suspect that perhaps she didn't have the syndrome after all.

“I think on reflection I'm quite angry that I got this diagnosis almost like off the cuff, when I was lying there having the scan. 'Cause I don't feel like...I don't feel like I do have PCOS. I was angry that I was just diagnosed with it. Having now done the research myself and knowing you need to have cysts on your ovaries, and hormones, and symptoms, I felt like they shouldn't have diagnosed me with that and made me go into this panic that I was going to get diabetes and get acne.”

During her own online research on PCOS, Kate learnt about the difference between cystic ovaries and PCOS, resulting in her challenging a diagnosis she felt did not align with her experience. She also recounted the story of a friend with PCOS, whom she said had been “casually diagnosed with PCOS” after missing just one period.

Kate's experience of a 'casual' diagnosis contrasts with the frustration and confusion that surrounded Nandini, Kiki, and Fiona's diagnoses. Kate's experience would suggest an over-diagnosis of PCOS, whereas the latter cases raise the question of PCOS going unidentified or being underdiagnosed. What can be induced is that the process of diagnosing PCOS can be quite inconsistent because of the varying nature of the syndrome, concurrent co-morbidities and the confusion between cystic ovaries and PCOS.

Methods and Tools of classification: Instinct and Medical Technologies

To make a diagnosis of PCOS, especially according to the Rotterdam criteria, doctors had to screen for the presence of cysts on the ovaries and assess hormonal profiles. Some doctors made pronouncements based on their own experiences and their patient's appearance, as in the case of Smith-Tran (2018). For instance, Nandini's doctor told her, "You've definitely got it, I can see you and tell". However, this was after an abdominal ultrasound showed cysts on Nandini's ovaries. Similarly, Elle's doctor looked at her and said it was "pretty obvious" that she had PCOS. These doctors were using instinct, experience, and observation combined with patient's descriptions to recognize the disorder, which indicates the visibility of symptoms and bodily presence of PCOS. It also points to the possibility of stereotyping PCOS patients by appearance, which can be associated with stigma. PCOS is associated with certain physical traits, notably obesity and acne. While these traits are related to PCOS, they are not fixed characteristics of it; it is possible to have smooth, spotless skin and have always been lean whilst having PCOS. In Elle and Nandini's cases, the visible symptoms their respective doctors had observed were hormonal acne, hirsutism, and bodily appearances, although the doctors did not single out these symptoms. These are the visible characteristics both the girls told me they had when they visited their doctors, so it can be assumed that those were what was observed.

However, the remarks of Nandini and Elle's doctors were not reflected in other women's experiences. What was common across experiences was that doctors were not relying solely on visual recognition of the symptoms and syndrome. To corroborate a diagnosis, doctors ran tests such as blood tests to measure levels of hormones, in particular reproductive hormones like testosterone, oestrogen, follicle-stimulating hormone (FSH) and luteinising hormone (LH). In some

cases, women were also tested for insulin resistance or glucose intolerance, using a blood test or an oral glucose tolerance test. All of the women I spoke to also had ultrasounds to confirm the presence of ovarian cysts, in accordance with the Rotterdam criteria. Kiki, additionally, had an MRI¹² and CT¹³ scan as well as an ultrasound. The technologies that I am referring to in this section are drawn from ideas of how Lock and Nguyen (2010) think of medical technology, such as imaging technologies and medical tests. Amongst imaging technologies, ultrasound scans as they are the most commonly used tool in the diagnosis of PCOS. Ultrasounds, MRIs, and CT scans are all imaging tools that were being used to create representational images of the inside of the body. Another technological tool in PCOS diagnosis are hormonal tests and their resultant reports, including tests of reproductive and sex hormones, insulin, and glucose tolerance. I take these tests to be quantifying tools, which are representations of hormonal levels and ratios inside the body. Medical tests were assigning a quantifying measure like numbers, figures and ratios to symptoms that could not be otherwise quantified, such as internal body changes.

The medical tools used in PCOS diagnosis were extensions of the observational process, reifying PCOS characteristics beyond those that were being felt, seen, and touched. Ultrasound scans of the abdomen and ovaries create visual representations of the inside of the abdominal cavity in the form of an image, that can be viewed on a computer screen or printout. It shows the presence and number of cysts on each ovary and indicates the size of the ovary. Ultrasound scans create an image of the inside of the abdomen that looks like this: a black and white image showing a cluster of black, cavity-like spheres. This image showed a representation of the ovary and the pearl-strand formation of the cysts present on it. This image is characteristic of PCOS, and one of the most powerful visual representations of the condition. Fiona described the ultrasound diagnosis as reassuring, because before it she had always received conflicting opinions from medical practitioners:

¹² Magnetic resonance imaging scans create detailed images of the inside of the body using magnetic and radio waves.

¹³ CT scans are a computerized x-ray used to create image projections of the inside of the body.

“That is why I think getting an ultra-sound really helped me because I could physically see the diagnosis”

Alongside seeing the ultrasound results, women could see reports of their bloodwork and hormonal profiles that represented hormone levels through numeric values and also indicated the normal range of those numeric values. These visual representations were the first material evidence and interaction women had with their PCOS characteristics that they could not otherwise see or tangibly observe but were experiencing indirectly- such as hormonal imbalances and disturbed blood sugar levels. Hence, medical technologies were being used to make visible characteristics of PCOS. Thus, what was (in)visible became visible, known, and experienced through medical technologies and tools that created material representations of that phenomenon. The ultrasound and blood tests proved to be more than just validators for the diagnostic process. These tests also acted as explanatory tools for the doctors, as it enabled them to show the patients what was going on inside their body and explain bodily processes in terms of their material, data representations. Thus, these tools also became an interactional object between doctors and patients during diagnosis.

However, beyond creating representations of what was otherwise ‘invisible’, scans and medical tests were being used to act as proof and as empirical corroboration to validate symptoms that had an experiential presence. These symptoms were being described by patients, such as hair growing in unusual spots, or irregular periods, and were visually observed by the patient, doctor, or both. Such symptoms could obviously be observed by the woman experiencing them, but in order to place them in a diagnostic category, medical practitioners needed more than descriptions provided by the patients. Diagnosis needs to establish the presence of characteristics that cannot be measured through visual observation or description, such as numeric values and ranges assigned to hormone levels to indicate what is ‘normal’ and what is ‘outside the normal range’. Similarly, cysts located inside the body are not observable by vision, touch, or feel- ovarian follicular cysts are not painful, so no sensation indicates their presence and location. The presence of these cysts can be inferred through other symptoms related to them: for instance, cystic ovaries lead to irregular periods. However, cystic ovaries are not the only etiological explanation of an irregular period and there is a range of factors that could be

causing the latter. So, to establish menstrual irregularity because of cystic ovaries, the presence of cystic ovaries must be confirmed. This direction of reasoning is characteristic of biomedicine, where aetiology is as important as the presence of the symptom, especially in the diagnostic process. Aetiology and symptoms are important towards the categorization that diagnosis entails, as the same symptom might be experienced by different people but caused by different underlying factors. Vice versa, the same underlying condition can produce different symptoms, as is the case with PCOS. This is what makes testing for underlying, beyond-visible factors important in the diagnostic process of PCOS, as women with PCOS do experience symptoms very differently, so the diagnosis mostly rests on the aetiology of the condition.

Technology has always been an extension of the human sensory experience. Medical technologies were an essential part of the process of diagnosing PCOS, in the experience of my participants. However, this process reached beyond measuring the 'invisible', and discovering the pathways of symptoms and causes. It also created the medical label of PCOS, and a patient of PCOS. This raises the question of the medical gaze, and of the process of medicalization. Utilizing technological tools to verify symptoms, and to validate women's experiences inevitably traces back to medical authority. These tools, whilst aiding the diagnostic process, are also tools of medicalization, just as the diagnostic process itself is a process of medicalization. Conrad (1992) argues that medicalization is a process that converts problems into medical problems. Here, I take medicalization to be the positioning of an individual as a medical subject. Diagnostic tools reified women's descriptions of their symptoms and experiences, which was reassuring for some women. This same reification exists in a contradictory duality. At the other end of this duality, diagnostic tools were transferring authority from women's own experience to the medical institution; for instance, if these medical tests were to contradict women's accounts of their bodies, how would the medical interaction proceed? Not only medical professionals, but patients would rely on the tests to corroborate their health experience. The diagnostic process in my study was an amalgamation of the doctor-patient interaction and medical tools and produced the same outcome: a woman who was told she had PCOS.

Implications of a PCOS diagnosis

The diagnosis of PCOS produced a PCOS patient. The pronouncement that a woman had PCOS was received in different ways. There were some immediate reactions, manifested in the clinics or consultation rooms where they were told. There were also latently realized implications, which came as the effects and consequences of PCOS unfolded through different interactions and experiences. Temporality was an important factor in experiencing the implications of PCOS. The impressions and implications of PCOS differed in the diagnostic moment and in the diagnostic process, as both occupied different lengths of time. The diagnostic process could span several appointments scattered over days, weeks, or months. In this section, I look at the implications experienced in the diagnostic moment, which I take to be the encounter where women first discovered their diagnosis of PCOS. This diagnostic moment comprises an interaction between women and their doctors. It involved an exchange of information and ideas; it produced reactions that were an amalgamation of this exchange as well as of preconceived notions. Some of the immediately perceived implications were a result of prior knowledge and ideas about PCOS; some resulted after doctors explained what the condition entailed; and some settled in over the course of time. Thus, the perceptions immediately following PCOS diagnosis were a mix that reflected lay knowledge as well as knowledge acquired during the diagnostic interaction.

Emotions

The diagnosis of PCOS resulted in emotional responses, both immediately and over time. Every woman I spoke to told me a variation of the following: that receiving a diagnosis of PCOS created feelings of distress, uncertainty, and fear. In some cases, this was because they had never heard of the condition before, so didn't know what to expect from the diagnosis except for feeling like something was *wrong*, or that something would go wrong. Kiki told me that she felt a fear accompanying her PCOS diagnosis, because she had never heard of the term and the condition before. She found the name and the full form of the acronym PCOS, *polycystic* ovarian disorder, to be alarming and associated it with a severe condition. When she heard "cysts", she thought of something "really serious" that needed to be surgically removed. In other cases, women had heard of the condition beforehand and their perceptions about its severity

and effects created anxiety and fear. For instance, Kate's apprehensions regarding the changes she thought her body would undergo produced an emotional response so strong that she cried. Kate described feeling taken aback by the abruptness of the diagnosis. She told me that in a follow-up conversation with her doctor, she panicked, and she cried.

"I don't know why but [I felt] just very intensely upset and worried that, now [that] I knew about this suddenly, my body would start changing."

These feelings were in response to the bodily changes she immediately thought of and feared: blushes of acne spreading across her face, weight gain, hair growth, and getting diabetes. The abrupt announcement of her diagnosis, the possibility of these changes, and *knowing* the diagnosis induced feeling of panic in Kate. By the time of our conversation, almost a year after the diagnosis, none of these changes had occurred.

Uncertainties

As Kate's story shows, emotional reactions felt after the diagnosis often had more to do with future changes and possibilities instead of the symptoms that were already being experienced. Both Kate and Kiki's diagnoses were unexpected and came as a shock. The immediate shock, however, also included concerns about the future. Kiki described her initial reaction:

"The PCOS, it really struck me. I was like, 'What is this thing? Why do I have it? What does it mean?' I had heard about it from my friend, but it was kind of an abstract, superficial thing that could never happen to me...and it is bad, obviously. It really frightens me that I might not be able to have kids."

The association Kiki instantly made between PCOS and infertility and sterility was also echoed in other women's accounts. Fertility issues are medically linked with PCOS. However, even when women did not already know that, as in Kiki's case, hearing that the condition was a hormonal, ovarian or reproductive disorder sparked an association with infertility. The possibility of being unable to conceive or have children produced powerful feelings. Kiki told me:

"When I was diagnosed with the PCOS I was quite upset because I was like, that's a major thing. And I was really worried that even though I'm really

young obviously, I don't want kids right now, but it could be quite inconvenient years later if I want kids."

I revisit the idea of infertility in a later chapter, as it holds meanings beyond the diagnostic process. It was one of the first concerns that women had in relation to PCOS, the consequences of which were perceived as reaching into the future, creating feelings of distress, fear, and uncertainty. The other possibilities that were related to PCOS were of developing comorbidities. Usually alongside making a diagnosis of PCOS, doctors would talk about risk factors associated with it. Fertility issues were one such factor, but the doctors also alerted women to the possibilities of weight gain, acne, hirsutism, and the risk of developing diabetes type II. Kiki was told that if she didn't manage her symptoms, she would develop diabetes:

"My doctor told me that there was risks for diabetes if I don't follow the diet and everything then I might move on to have diabetes."

Feeling that because of PCOS their future could hold chronic conditions such as diabetes, and other effects that couldn't be predicted was stressful for women, as these effects were overwhelmingly perceived to be disruptive and negative. The diagnosis created uncertainties. There was an uncertainty about the future, in terms of health complications, bodily changes and the effects reaching beyond bodily changes, such as subsequent lifestyle implications.

Acceptance

After the diagnosis was delivered, the next stage in the diagnostic process was to move on to treatment. The treatments that doctors recommended, which I delve into in a later chapter, were largely preventative and aimed at avoiding PCOS-related complications. Treatments were also tailored to whatever symptoms each individual was experiencing. Since some consequences and symptoms of PCOS were not being immediately experienced and were surrounded by the uncertainty that they might never even be experienced, there was nothing that could be done to mitigate them. In lieu of mitigation, doctors suggested preventative action. This preventative action was centred primarily on lifestyle modifications in the form of exercise and diet. The implication was that changes would have to be affected into one's life, and if changes were not made one faced the possibility of health risks. There was thus introduced an

element of individual responsibility towards one's future health. I explore this amongst the themes of treatment and management in following chapters.

PCOS was, as Kate called it, a "dreaded diagnosis". Aside from Kate, the women I spoke to largely accepted their PCOS diagnosis. Kate challenged her diagnosis as she felt that her symptoms did not align with the diagnostic criteria of PCOS. Despite this, it is notable that the women in my study did not ascribe to PCOS as a label, as I call it earlier in this chapter. It did not become a marker of group or personal identity. For instance, none of my participants were part of a PCOS self-help group. Although PCOS did hold implications for the perception of one's health, body, and self, this was assimilated into overall perceptions of the self instead of becoming dominant. The condition and label were perceived as common. The commonness of PCOS was understood in two ways: through personally knowing other women with PCOS, or through medical practitioners citing the condition's prevalence. Kiki, Kate, Elle and Nandini had all spoken to friends and acquaintances with the condition, which played a role in normalizing it. For Kiki, a friend's experience formed the basis of her knowledge of PCOS before her doctor's appointment and diagnosis:

"I had already heard about it from one of my friends who by that time had already been diagnosed with PCOS and insulin resistance and she had also had bulimia. So, I knew quite a bit about it by that time."

Chloe also related feeling the high incidence of PCOS through different encounters with people over time:

"I've realized how common it is. I remember when I called up to get my test results, she (nurse) was like "Possible PCOS. I've got that, too!" And then I spoke to a lady at my church about it and I asked her if she'd heard about it. She was like "Yeah, I've got it. And my friend Tina's got it too!" So yeah, it's really common. So, part of me is like maybe I'll be okay, 'cause I know someone [with PCOS] who just had a baby."

For my participants, knowing that other women, especially women they knew personally, were living with PCOS mitigated the perceived severity of the condition. This contrasts with the perceptions of PCOS having no cure and thus being a condition that one had to live with.

Interactions and Relationships with Doctors

In the narratives of my research, there were usually multiple medical practitioners involved in the process of diagnosing PCOS. In most cases the women I spoke to had seen general practitioners as well as been referred to at least one more specialist medical practitioner such as an endocrinologist, nutritionist, and gynaecologist before receiving a confirmed diagnosis of PCOS. On average, women with PCOS see about two to three, sometimes even up to 5 different doctors before being diagnosed (Gibson-Helm, et al., 2016). All of my participants with an active diagnosis had seen at least two doctors before being diagnosed. After the diagnosis, they had been referred to gynaecologists or nutritionists, as PCOS falls under those domains of medical specialization for treatment options.

My participants and their doctors were from various different countries and thus different medical systems. Some girls were British and accessed healthcare through the UK's public sector health institution, the National Health Service (NHS). Two of the girls had consulted private practitioners in the Middle East. Some had visited private doctors, and some were seeing practitioners in the public sector. The diagnostic methods and tools that doctors from different regions were using were the same. The treatments that were suggested by different doctors were also quite standard, and I explore these in the following chapter. Each woman's subjective encounters with their doctors, however, had certain similarities and certain subtle differences, both of which contributed to the perception of PCOS. Some doctors were resented, and their advice was disregarded, depending on the nature of the interaction. A visit to these doctors usually never recurred. Nandini, for instance, told me she "hated" the specialist she had been referred to as their interaction felt impersonal. Nandini then pursued treatment with the family doctor she had known for years. Her relationship with her current doctor, which I detail later, stands in stark contrast to her opinions regarding the specialist. This is illustrative of the importance of the interactional relationship between doctor and patient. Where this relationship went well, interactions with doctors were sources of information and support in the understanding and management of PCOS

Reassurance, Support, and Involvement

I found that the experience of PCOS, as well as the treatment options explored changed dramatically according to the relationship with one's primary medical practitioner. In every single case, the girls told me that their doctors were extremely reassuring. Doctors explained what PCOS was, sometimes quoting examples of other women with PCOS who had successfully conceived or telling the girls that the condition was very common. Doctors cited the prevalence of the condition to dissipate or downplay the severity of PCOS. Chloe's doctor, for instance, used the prevalence of the condition to reassure her:

"I think she said that one in three women have it or something and that it's really really common, so you don't need to worry about it."

However, the same reassurances of the prevalence of the condition also held connotations of dismissal; if x number of women were dealing with the problem, you would be able to as well. This also relates to the standardized diagnostic measures and treatment recommendations across 'patients', where subjective experience can often be disregarded. This is apparent in Kate's reaction to the following:

"'Its fine' the GP said to me, 'I've got it, and I've got two children. Victoria Beckham has got it, and she's thin!' as if like, don't worry, you can be as thin as Victoria Beckham and still have PCOS."

The GP had shared her own experience with PCOS to dissipate Kate's panic after the diagnosis, without much affect, as it still felt removed from Kate's own experiences and apprehensions. However, some girls had doctors who were very involved, and responded to their assurances differently. For example, Kiki and Nandini met their doctors every few months. Both their doctors ran regular tests every few months to regulate hormone levels and were modifying treatment plans accordingly.

Kiki stressed the importance of finding the right doctor- she told me she had been uncomfortable with a male doctor, for instance. Contrasted with that, she told me how grateful she was to have found her current doctor, after being misdiagnosed and bounced around between 2 other practitioners. Her current doctor has a very hands-on approach to her treatment that includes both

lifestyle changes and medication. She tells Kiki to exercise, has placed her on a specific diet to manage insulin resistance, and has prescribed medicines- all of which Kiki adheres to very particularly. Monitoring the 'progress' of her PCOS, as Kiki calls it, is a process involving both her and the doctor. The doctor checks her hormones and weight at each appointment. Her doctor is a trusted source of comfort and reassurances about future concerns; for example, to alleviate Kiki's worries about being able to conceive, the doctor told Kiki "miracle stories" of women with PCOS who had conceived when "the time was right". She reassured Kiki that her period will become regular as she "settles down", offering alternative explanations for the irregularity apart from PCOS, such as Kiki's frequent travelling. These are reassurances that Kiki has taken to heart, influencing how she perceives her PCOS.

Like Kiki, Nandini also visits her current physician every 3-4 months or whenever she returns home from university. Nandini's doctor is her family physician and has known her for most of her life. He treats Nandini for hypothyroidism, anxiety, and PCOS using homeopathic medicines. At each appointment, the doctor tests her hormone levels and uses the results to adjust her medication. He also regulates his prescriptions according to what is going on in Nandini's life and how she feels:

"I take homeopathic medicines, and my doctor keeps changing my medication depending on how I'm feeling. For example, I'm taking anxiety meds now because I have to work on a stressful project for the next 6 months. I don't know if they actually work, but it's just a psychological thing that I'll be better if I take the medicines."

This is a much more personalized and involved approach that considers Nandini's PCOS, other endocrine conditions, and life events. In turn, Nandini trusts her doctor and takes the medicines he gives her twice a day, in a routine everyday act, even though she told me she is not convinced of their effectiveness. Nandini taking medications whilst also being sceptical of their efficiency is both a conscious mediatory practice and an act of trusting her doctor.

Communication, familiarity, consistency and trust- in essence, the nature of interaction with the doctor- change how the doctor's advice is filtered into

experience, how that advice is incorporated towards managing PCOS, and the perception of PCOS.

Knowledge and Understandings of PCOS

In my study, medical professionals were amongst the primary sources of information about PCOS. While support and reassurances were offered, conversely, uncertainty and a lack of knowledge still persisted. During the interviews, when I asked women what they thought PCOS was, or to explain or describe PCOS to me, women would tell me their perceptions but always express that they were uncertain or unsure whether these were correct. A gap in information given by doctors was recurrent when it came to questions about infertility and sterility. When this surfaced during interviews, I would ask the girls if they had spoken to their doctors about it or asked questions. Most girls had posed questions to the doctors but received vague responses. Elle told me:

“I still feel like I don’t really know much about it, which is surprising. I have no clue about the fertility side. When I saw the doctor last, I wanted him to tell me if I could have kids in the future and he was like: it’s not black and white, you’re not going to know.”

Elle’s statement reflects the uncertainty PCOS can create, and the vagueness of her doctor’s response. She looked to her doctor for reassurance, addressing him with this uncertainty posed as a question. In many other similar accounts, it stood out to me that none of the doctors clarified how anovulatory infertility in PCOS worked and did not tell the girls of the possible fertility treatments and options they could access in the future, if needed. This could be because the girls I spoke to were young students with no plans of having children soon. Nonetheless, this knowledge could have dispelled some of the future concerns these girls were expressing.

I asked my respondents to describe their understanding of PCOS to me. Everyone had a fairly accurate idea of what PCOS was, and this information was attributed to their doctors. Elle knew that she needed to fulfil two of three conditions to be diagnosed with PCOS. Nandini, Kiki, and Kate were very aware of the metabolic underpinnings of the condition. The women who had spent time researching PCOS, mostly through looking up the condition on the internet and speaking to other people, knew the most about it. For instance, Kate knew the

differences between PCOS and polycystic ovaries through researching on PCOS websites and chat forums.

“My understanding of it as a medical phenomenon, from doing my research after my experience with it, is that there are two different things. There’s polycystic ovary syndrome and then there’s polycystic ovaries.”

This knowledge enabled her to challenge her diagnosis.

“I was doing my own research and then talked myself out of the fact like, you don’t have PCOS, you probably just have cysts on your ovaries....I actually went back to my GP and gave this theory to her and she said, “Well it’s a bit of a chicken and egg situation”, which I thought was a weird thing to say.”

Kate felt her doctor’s attitude dismissive towards her knowledge and questions:

“I was really determined to prove them wrong, that I didn’t have PCOS and to get my period.”

As a result of the communication gap between her and her doctor, Kate turned to alternative treatment in order to resist her diagnosis. Echoing a similar reflection in Kitzinger and Wilmott’s piece (2002, p. 352), women in my study also told me that they felt their doctors did not give them enough information about PCOS or take them too seriously. Even in instances where women had a fairly accurate picture of PCOS, they sought this knowledge to validate what they already knew. For instance, Kiki, who knew a lot about the pathophysiology of PCOS through research, repeatedly referred to the condition as ‘mysterious’.

The doctors held medical knowledge that could dispel the girls’ uncertainties and fears: would they be able to have children? Would they be ‘alright’? These questions never received simple or straightforward answers- the very nature of the questions and the unpredictability of PCOS renders answering them almost impossible. However, such questions were nevertheless posed to the doctors, as doctors were seen as sources of health-related knowledge and represented medical authority.

There could be a multitude of factors behind doctors not giving concrete answers and providing detailed knowledge about PCOS. Perhaps they thought an etiological understanding of PCOS was unnecessary for the patients, and

the focus should be on treatment instead. As for vague answers, these were likely because the way PCOS will manifest over time cannot be predicted and is highly individualized. For instance, doctors might have refrained from assuring patients about fertility in order to avoid giving what could turn out to be false hope, so there could be ethical considerations as well. The doctor as a healer and authority on medical knowledge is positioned such that their opinions and reassurances carry weight; after all, that is why the diagnoses they make carry weight too. Kiki's relationship with her doctor, for instance, indicates the importance of the interactional exchange between doctors and patients. Her doctor is an important figure in how she manages PCOS-related uncertainties regarding her future. There is a large element of trust in this relationship that is rooted in interaction: the personal, consistent nature of interaction and the way communication takes place in a mixture of formality and informality. Each doctor's approach to diagnosis, treatments and their relationship with patients is different. The approaches that doctors adapt towards all of these factors influence the way PCOS is perceived and experienced.

Chapter Summary

In terms of the weight that a diagnostic label can carry, PCOS produced emotional reactions in women. PCOS as a label was both accepted and resisted. The consequences women associated with PCOS created feelings of uncertainty about their future. In terms of what life with PCOS looked like, treatment and the lifestyle implications brought with them the idea of having to implement change, and the responsibility of one's health status. A large part of the initial perception of PCOS and the diagnosis had to do with the interactions one had to receive the diagnosis. Amongst these interactions, the ones that stood out the most were with doctors. Doctors represented and conveyed ideas of empiricism, standardization, health, and abnormality that underlie biomedical understandings of PCOS. The relationships women had with doctors and their interactions with biomedicine shaped their knowledge of PCOS. When the amount or quality of this knowledge felt insufficient, women turned to alternative understandings of PCOS, which I explore in the following chapter.

Chapter 5

Beyond Biomedicine: Alternative Medicine and Lay Referral Networks

The medical encounter is but one step in a more inclusive sequence.

(Kleinman, et al., 1978)

In the previous chapter, I have looked at understandings of PCOS, including its diagnosis and the doctor-patient relationship. These understandings stem largely from the domain of biomedicine. However, as Kleinman et. al (1978) argue, the experience of illness spans multiple domains. In Kleinman's anthropological approach, sickness involves bodily experience, multiple medical systems, and interpersonal encounters. Perceptions, knowledge, and practices surrounding PCOS reflect more than the biomedical paradigm. They include encounters with other medical systems and cultural perspectives of understanding, treating, managing, and making sense of PCOS.

To map my participants' perceptions and ideas around PCOS, I outline the different medical systems they engaged with. There are various treatment and management approaches to PCOS. The knowledge and availability of these treatments, management methods, and the way they are put into practice stem from several different sources and settings. During the course of my interviews, everyday modes of understanding and mediating with PCOS that my participants engaged in were allopathic biomedicine, alternative and traditional medicine, nutritional science (specifically lay understandings of it), family and friends (and through that, culturally embedded value systems), food practices and choices, and personal mediatory practices (such as cosmetic practices). The focus of this chapter will be on some of the domains outside biomedicine that influence knowledge, ideas, and perceptions surrounding PCOS. In particular, I will look at alternative medical systems and lay referral systems.

All of the women I spoke to had engaged with biomedical and allopathic medicine in some way, even if this engagement was in the form of rejection. Some women had turned to alternative treatment options, sometimes in

opposition of allopathic medicine and sometimes in conjunction with it. Some women engaged only with allopathic biomedicine. Even if women were not explicitly drawing influences from multiple medical models, they still had multiple points of reference for PCOS that were often supplementary to the biomedical model. These included advice from family, friends, and other acquaintances; social and cultural knowledge and perceptions; and information from media sources, especially the internet. Taken together, these knowledges are suggestive of Freidson's (1960) concept of lay referral networks, which I subsequently explore in this chapter.

This chapter traces the perceptions and knowledges that inform the mediation of PCOS through a series of domains, of which biomedicine is only one facet. I begin first with a look at how some traditional and historical medical models viewed conditions similar to PCOS. The rationale in these ancient models underlies the contemporary medical systems that my participants engaged with. I then move on to advice and interactions that were part of mediatory practice but that I have not categorized into a 'medical' system; instead, I use the concept of lay referral systems. Simultaneously, I consider impressions gathered from other sources, like the internet.

In History and Traditional medicine

Before modern medicine, conditions similar to PCOS have been cited in ancient and traditional medical writings. In medical texts by notable European physicians of antiquity like Hippocrates, Maimonides, and Ambroise Pare, there surface occasional descriptions of women with irregular or absent menses whose appearances have been 'transformed' to be more masculine, sometimes 'bearded', sometimes accompanied by sterility (Azziz, et al., 2011, p. 1544) . This group of characteristics is reminiscent of what is now known as PCOS. Similarly, accounts of traditional Persian medicine ranging from medieval times, the 18th and 19th centuries, and contemporary texts contain descriptions of a condition characterized by a lack of menstruation called *Ehtebas-e-tams* or *Habs-e-Tams* (Hosseinkhani, et al., 2018). Multiple medical records from the 18th to 19th centuries described ovarian morphologies of multiple cysts, enlarged size, and differentiated appearance (Szydlarska, et al., 2017).

Traditional Persian medicine is herb-based and like many traditional Asian medical models, derives from the humoral model of disease and illness originating from ancient Greece (Kushner, 2013). The cause of menstrual irregularity was ascribed to an imbalance of humours, specifically phlegm and coldness in the body and congestion or obstruction in the reproductive system. Interestingly, the treatment of *Habs-e-Tams* focused on the underlying metabolic factors instead of external symptoms. For instance, herbal remedies and medicinal plants were prescribed to regulate glucose levels and restore regular menstruation. Treatment was primarily through diet, and it was advised to consume dry and heating foods whilst limiting cold and wet foods to correct humoral imbalance in the body (Tansaz & Bahmani, 2016). The Ayurveda system of medicine, originating in ancient India, utilizes similar ideas. Ayurveda has a system of three *doshas*, which are energies responsible for governing different bodily processes (Hankey, 2005). The pathogenesis of menstrual and ovarian disorders is seen as stemming from blockages and imbalances of *doshas* in the body. Ayurveda does not include direct descriptions of a compound set of PCOS-like symptoms, but it does address menstrual irregularities and metabolic disturbances in conjunction (Patel & Prajapati, 2017). Treatments in Ayurveda are centred on balancing the *doshas* to restore equilibrium. Ayurveda uses herbal medicines, the composite substances of which are attributed properties that replicate or oppose bodily energies (Shama, 2017). Treatments for PCOS are formulated taking into consideration the nature of the imbalance in *doshas* and what substances can correct that. Through the experiences of my participants, I will explore the approaches of different medical systems that are contemporary but utilize similar rationale towards health and the body, especially ideas of balancing bodily compositions.

Medical Systems

Apart from, and sometimes alongside biomedical allopathic medicine, my participants engaged with various other medical systems. This section introduces these different medical modes case by case, exploring how they became part of the PCOS experience. These medical models fall under the umbrella of complementary and alternative medical (CAM) systems. CAM systems are widely understood to be organized bodies of etymology, perspectives, and practices about health, illness, and medicine (Caspi, 2003;

Hardey, 2013). These systems exist outside the domain of biomedicine and usually have different epistemological foundations, etiological explanations, and treatments for illnesses (Ernst, et al., 1995). The most prominent difference is that CAM systems usually take a holistic approach to the body and illness, whereas biomedicine takes a symptomatic approach (Barrett, et al., 2003). Across my participants, three out of the six women had engaged with alternative systems in relation to their PCOS. The different medical and healing modes these women were involved with included Siddha medicine, homeopathy, acupuncture, and a system of natural health practice. All of these systems fall within categories of CAM, especially by way of being holistic and distinct from biomedicine (Kaptchuk & Eisenberg, 2001). Some of my participants took these as supplementary consultations and treatments for PCOS alongside allopathic medicine. Some interactions occurred before the biomedical PCOS diagnosis, whilst seeking explanations for certain symptoms. The reasons for engaging in an alternative medical system, the type of medical system accessed, and stage it was accessed at varied from person to person. The type of alternative medical system my participants engaged in was influenced by social factors, cultural context and background, and family and friends. It was also influenced by, and in turn shaped, perceptions surrounding PCOS and its treatment. These perceptions included ideas- often opposing ideas-about natural and hormonal treatments; invasive and non-invasive treatments; and beliefs about the effectiveness of both allopathic and alternative medicine. I will return to these ideas later, when looking at the management practices surrounding PCOS.

For each woman I spoke to, the interaction with alternative medical systems came about differently, and the role of it in their PCOS experience was different. Out of my participants, Nandini and Kate had actively interacted with alternative medical systems. Fiona had a brief interaction with a natural health practice that she dismissed and discontinued after two visits. To explore how these various interactions came about, I look at parts of each woman's story, beginning with Nandini.

Nandini- Homeopathy and Siddha medicine

Nandini is from a South Indian family. She grew up within a large community of South Indian expatriates and immigrants living in Abu Dhabi. She resides in Exeter, in the UK, and travels back to Abu Dhabi and Chennai alternatively

every few months. She has had no interaction with medical practitioners in the UK regarding her PCOS. Her primary doctor is based in Abu Dhabi and is also of South Indian heritage. He practices both allopathic medicine and homeopathic medicine. In treating Nandini, her doctor combines biomedical methods with homeopathic approaches. For instance, he uses blood tests at each visit to measure hormone levels, as well as asking her about upcoming life events to gauge how these could affect her mood and hormones. He takes this information into account and prescribes homeopathic medication as a holistic treatment to address multiple of Nandini's health concerns: hypothyroidism, PCOS, and anxiety. This holistic perception of the body and illness is characteristic of homeopathy. According to Gale, homeopathic medicine is a substance and herb-based system that considers the body as a whole in balance and sees bodily imbalance and multiple external factors as contributing to illness (Gale, 2011). It is apparent, for instance, when Nandini tells me her body is 'naturally too hot', and attributes that idea to homeopathy. Homeopathy considers a range of factors in treatment, including the body, emotional states, and the environment (Gale, 2011, p. 242). This was also reflected in the methods of Nandini's doctor when he mixed multiple medical tools and asked questions about her life to form a holistic picture of her health and any remedies to be prescribed. Currently, Nandini takes only homeopathic medicines for PCOS.

During one of our conversations, speaking of a 'hot body'- a concept that I return to in discussions of bodily experience- reminded Nandini of Siddha medicine. Siddha is a branch of traditional Ayurveda medicine that is widely practiced in South India. Nandini's visit to a Siddha doctor was prompted by a symptom she later on attributed to PCOS: belching. She and her family visited a homeopath, endocrinologist, gynaecologist, and gastroenterologist. None of these specialists could pinpoint the cause of this belching. An allopathic doctor treated her for an overgrowth of the bacteria *H. Pylori*. However, the belching continued even after she completed the treatment. To find an explanation and treatment for belching, Nandini and her family went to see a Siddha practitioner. According to Nandini's description:

"I think this (Siddha) is some weird South Indian thing, where they give you lots of herbs and medicinal things and you don't know what it is. Siddha is a

discipline, and then the doctor is like a Siddha doctor. Sort of like homeopathy. Homeopathy has got a little more science than Siddha. It's like one of those really rural doctor people who just give you herbs. This was in India, in Chennai.”

The Siddha doctor assessed Nandini’s body and told her she was naturally “hot”, so she had to take food and medication accordingly. The doctor prescribed herbal tablets from the Siddha tradition and supplementary pills that Nandini said were from ‘English medicine’. She also taught Nandini abdominal exercises to help with indigestion and improved circulation.

“We told the Siddha doctor about the PCOS, but she didn't think it was related to the burping and digestion either. She just treated me for indigestion.”

The Siddha doctor did not make a connection between PCOS and burping. She treated Nandini for indigestion. When I asked Nandini to describe how treatment in Siddha works, she simply said: “It doesn’t”. Nandini discontinued taking the medicines after 2 months, as they had no effect, and switched back to homeopathic treatment. Nandini seemed sceptical of the Siddha practitioner’s methods, but she was willing to give it a try in the face of an unexplained recurring symptom.

Approaching the treatment of illness through multiple methods is reflective of the holistic approach often found in CAM method like Ayurveda, which combines exercise and medication for treatment. In the end, Nandini found that belching was related to PCOS from a blog post online. She described the belching as being correlated with stress and metabolic disturbances in PCOS.

On the surface, Nandini’s sole encounter with Siddha seems unfruitful. However, it was later reflected in our conversations in regard to exercise, and the idea of hot and cold properties in bodies and foods.

Kate- Acupuncture

Whilst Nandini turned to Siddha medicine because of a symptom that biomedical practitioners didn’t explain, Kate sought alternatives both for treatment and in refutation of her PCOS diagnosis.

After Kate was diagnosed with PCOS, she started doing research online. Kate read through a range of websites and forums. She found her diagnosis to be vague and began to question it. Kate's research led her to conclude that she did not have some of the characteristic symptoms of PCOS. For instance, her doctor had ambiguously said her cysts "could be within an insignificant range". Kate began to suspect that she might have just polycystic ovaries instead of the syndrome. The main symptom she was concerned about and that her PCOS diagnosis rested on was amenorrhea: Kate hadn't had a period in 5 years. She wanted her period "back", as she put it, for several reasons. Amongst these was that she saw resuming a period cycle as a way of eliminating the biggest PCOS symptom she had. It was also a way to refute the chronic nature of her PCOS diagnosis. Kate told me that she was hesitant to try the hormonal medication her GP suggested and decided to look for alternatives. I asked her how she settled on acupuncture.

"I was just desperate. I knew it was good for hormonal stuff. I think I'd read on some of the forums that someone had tried it. The acupuncturist reassured me that she treated women with amenorrhea and PCOS all the time. She also gave me tips about food. I was quite sceptical about acupuncture and the way it worked. She took my blood and said 'You've got weak blood. You need to eat things with more iron.' I was thinking 'Hmm, sounds a bit hoey to me'."

Despite her apprehensions regarding acupuncture, Kate followed the acupuncture regimen and diet suggestions by the practitioner. After 8 weeks of this regimen, for the first time in nearly 5 years, Kate had a period. It was an emotional moment for Kate, and one she shared with her practitioner:

"When I saw my acupuncturist the next week, I hugged her. She was really excited. I was really excited."

Since then, Kate has had a period almost monthly. She still consults her acupuncturist if she is concerned. For instance, her cycle was late by a few weeks:

"Last month, I didn't get my period. Because I moved houses, and I was really stressed, and I wasn't eating properly. So, I went back to her. She's

like a magician, honestly. I feel like I should have more faith in her. She's like "Oh, you've been stressed, that's why you haven't got your period. I'll just do these few points and you'll get it in the next few days." And I was thinking it's been four weeks late. I doubt it. And she was right, I did! I was amazed!"

Kate's experience with both her allopathic and acupuncture practitioners reflects her shifts in attitudes, from resistance to scepticism to relief. Allopathic medicine gave Kate a diagnosis she wanted to refute, and treatments she was reluctant to try- giving way to a sceptical attitude. Acupuncture unexpectedly resulted in the relief of a long-term symptom, as well as a more involved relationship with her practitioner. Here, her initial scepticism gradually gave way to acceptance.

Fiona- Homeopathy and Natural Practice

Kate and Nandini both engaged with alternative systems after their PCOS diagnosis. Fiona, however, consulted a natural health practice before her PCOS diagnosis. Fiona's mother prefers natural treatments to allopathic medicines and has taken Fiona to see homeopaths since childhood. Three years ago, Fiona went to a clinic located in Winchester, in the UK, that was called The Natural Health Practice. She went there at the recommendation of a friend and at the insistence of her mother. Both Fiona and I were unsure as to how to categorize the practice she consulted in terms of a wider health system; it seemed like a mix of holistic systems. Fiona's concern behind the consultation was persistently feeling fatigue and exhaustion, and infrequent periods. Before visiting the natural health practice, a homeopathic doctor had diagnosed Fiona with Chronic Fatigue Syndrome/ME¹⁴. She now attributes both the fatigue and irregular menstruation to PCOS. However, at the time she was still in the process of finding an explanation. Fiona saw two successive doctors at the natural health practice. Both were working through measuring bodily blockages and hormone levels. Fiona described the method of the first doctor as:

"His tests were like running little electrical currents through my body. I had to hold a current, these two little electrodes in each hand, and he put something in the machine. Depending on the reading he'd get back it was a blockage of my body. It was really strange."

¹⁴ Myalgic encephalomyelitis

This doctor diagnosed Fiona with a Candida (bacterial) overgrowth in her gut and put her on an anti-Candida diet. This produced no effects, and Fiona continued to experience the same symptoms as before. Her first doctor retired, and she continued seeing another doctor at the same practice. His diagnostic methods were different as he took blood tests:

“From the blood tests he tried to heal me through whatever was low in my body, like B5 or B12, so he would give me supplements to try and bring those levels back up. Then my hormones as well, because I had really low progesterone. He took me off the pill and gave me progesterone to increase the level (of it).”

The second doctor prescribed supplements, vitamins, and hormonal medications and discontinued Fiona’s use of the contraceptive pill. This treatment worked through balancing substances like minerals, vitamins, and hormones in the body to eliminate deficiencies or ‘blockages’ and achieve a balance. This contrasts with biomedicine, where treatment is often dependent on isolating the cause of the issue. As Fiona put it:

“It wasn’t trying to find a root cause to anything, it was just trying to heal my levels and bring them back to what they were.”

Fiona returned to the practice a few months after following the new treatments. She described feeling a bit healthier, but otherwise no different. She still had the symptoms, especially a debilitating fatigue, that was making her university life very difficult. Fiona summed up her experience with different medical systems as such:

“The hardest part is that every doctor or person I go to tells me something completely different and because of that I’ve become sceptical of everything now. That is why I think getting an ultra-sound really helped me because I could physically see the diagnosis.”

Fiona is now consulting an endocrinologist who diagnosed her with PCOS using an ultrasound and blood tests. She contrasts her experience with alternative systems and allopathic biomedicine, favouring the tangible evidence involved in the biomedical diagnostic process as it helped her overcome confusion.

Section Summary

Nandini, Kate, and Fiona had varied experiences with alternative medical systems. All the girls consulted multiple medical practitioners for explanations they would find acceptable. Nandini found Siddha treatment ineffective but kept incorporating some practices and knowledge from it afterwards. Kate found acupuncture to be surprisingly effective and relies on it as mediation for her PCOS. Fiona's experience reflected engaging with multiple medical systems to find a plausible explanation for her symptoms, and ultimately settling on the evidence-based one. What is common between these medical systems is their holistic view of illness and healing as being situated within bodily, environmental, social, and cultural contexts (Barrett, et al., 2003; Hardey, 2013). The holistic approach in CAM systems is two-fold. First, they treat the body as a whole, including the idea of healing one bodily process through harnessing another process. Second, this inclusive nature allows space for variation in treatments and the assimilation of different practices, including biomedicine. The CAM systems in this study shared an emphasis on balance- balancing the body through substances, movement, and mental and emotional states. Health was not considered a system of additions and subtractions, as it often is in biomedicine. Instead, health was more of a scale, that needed to hang in balance. Symptoms were seen as the consequence of an imbalance and not seen as something that needed to be eliminated or subtracted; their rectification lay in correcting imbalances. The other commonality amongst my participants' experiences with CAM systems was the emphasis on metabolism and diet. The role of food and the digestive system was given a lot of importance across CAM approaches, both in terms of understanding the problem and treating it. Eating, digestion, and metabolism was the primary pathway of ingesting substances needed to rectify imbalances. Food substances were attributed different properties; bodies were attributed properties, too. In my research, these properties were seen most obviously in Siddha medicine, where the concept of hot and cold was important in imbalance. The digestive system was the site of assimilating the properties of food and medicine, and thus the site of restoring balance. Engaging with alternative medical systems led to my participants incorporating complementary and alternative medical treatments into mediatory practices for PCOS. These

medical systems acted as sources of knowledge that shaped the perception of PCOS as an illness, what that entailed, as well as the way it was managed in daily life.

Lay Networks

Freidson's (1960) work introduced the concept of lay referral systems into medical sociology. In lay referral systems knowledge is filtered through cultural and contextual influences and social networks that include family, friends, and acquaintances (Freidson, 1960). This network is a means of recognizing illness, seeking advice, and deciding to see a medical professional. Lay networks are distinct from medical systems of knowledge but may work in conjunction with the latter. I adapt Freidson's concept in my analysis and expand upon it to look at how ideas and advice about illness, health, and healing from various sources are incorporated into the management of PCOS. My main focus will be on the impressions and attitude towards health stemming from the family, especially mothers, and friends and acquaintances. I look at how these impressions manifested at different stages: sometimes the lay networks played a role before and during the diagnostic process, and sometimes the knowledge from lay networks manifested in the mediatory practices following PCOS diagnosis. In this section I focus on the role of networks before and during diagnosis, and I discuss mediation in a later chapter.

Mothers

For five out of my six participants, within their family, their mothers were most closely involved in their health-related attitudes and decision-making. The girls told me that they went to most their doctor's appointments with family members, especially mothers. I continue with Fiona's story to show her mother's role in her interactions with medical systems. Fiona went to an allopathic doctor only after exhausting multiple alternative practices for an explanation of her symptoms. This was largely due to her mother's influence:

“My mum really believes natural and alternative healing. If I was ill as a child, she would make these little concoctions for us which consisted of depending on what your illness was.”

Fiona's mother accompanied her on visits to the natural practice. Her mother prefers homeopathy, and Fiona told me that was why she didn't go to a

'mainstream' doctor for a long time. Her mother also cooks low-carbohydrate foods, which Fiona cites as shaping a large part of her current diet. This diet is now part of Fiona's PCOS management:

"Usually what I cook for myself is what I would have back in my family home as my mum is really healthy."

Elle similarly told me that her mother is also particular about eating healthy, as she is a trainee nutritionist. Elle's mother actually recognized that she had PCOS before Elle got her diagnosis, observing that Elle had hirsutism and acne. She did not tell her daughter as she did not want to upset her. "I confronted her about it and I was a bit shocked that she didn't tell me", Elle laughed to me. She subsequently went to a doctor to get tested for PCOS. Chloe was similarly prompted by her mother to go to the doctor's appointment that resulted in her PCOS diagnosis. Chloe's mother recommended she get tested after Chloe told her that she was bothered by excessive hair growth. After her diagnosis, Chloe's mother would assure her by saying that the condition was really common. Nandini's mother accompanied her to every single visit to the doctor and was very involved in her PCOS-related food and cosmetic practices. Nandini also told me she suspected that her mother had had PCOS when she was younger; she and her mother discussed having infrequent periods at the same age.

Kiki first consulted a public sector doctor while looking for an explanation for amenorrhea. She was diagnosed with insulin resistance, but the doctor didn't connect it to PCOS. She describes that experience as rushed:

"He never did anything with the PCOS, he never sent me for CT or MRI. Especially because it was a public hospital, I felt like they didn't really care. It was always a long queue, it always took more time. I felt that I was just one tiny little person that needed to be treated."

After this experience, Kiki's mother encouraged her to see a private doctor instead of a doctor from the public sector. Kiki is from Hungary, and she told me the quality of service, attention, and care provided between the private and public health sectors differs dramatically.

“My mum always said that that’s the one thing that’s worth the money, no matter how much, that health is really important.”

Kiki’s PCOS was diagnosed through visiting a private sector doctor, who she now consults regularly and who plays an active role in her PCOS management. One of Kiki’s mother’s experiences also influenced the way Kiki saw her own body. A few years before Kiki’s diagnosis, her mother had undergone surgery for the removal of an abdominal cyst. When Kiki heard that she had cystic ovaries, her immediate reaction included fearing that she might also need surgery. She associated cysts with surgery because of her mother’s experience. However, Kiki’s ovarian cysts were different from her mother’s abdominal cyst and did not require surgery.

While her mother suggested switching to private practice, it was a friend who suggested the particular doctor Kiki sees now.

This brings me to the next thread of lay networks: friends, and other women with PCOS.

Friendships and Shared Experience

During interviews, my participants frequently referenced or mentioned their friends in various contexts. Friends were sources of advice, sharing, and emotional support. All the friendships mentioned were between females, pointing to PCOS, periods, reproductive health, and sexuality being situated in networks and ideas of shared womanhood. Sometimes friends were a direct source of advice and information about PCOS; for instance, Kiki being referred to a doctor treating her friend. This friend of Kiki’s was diagnosed with PCOS before Kiki. While describing her diagnosis Kiki began by telling me:

“I had already heard about insulin resistance from one of my friends who had been diagnosed with PCOS and insulin resistance and she had also had bulimia. So, I knew quite a bit about it.”

Kiki’s friend became someone she regularly spoke to about dealing with insulin resistance and PCOS after her diagnosis. Knowing of other women who shared the condition of PCOS was reassuring towards the prevalence of the condition. Chloe spoke to women at her church, one of whom was a midwife, who assured her they had the condition too and spoke of fertility treatments. Chloe also had

conversations about PCOS with her housemates, who were curious as to why she took contraceptives since she wasn't sexually active. Chloe told me that 'none of them had ever heard about it'. She then explained that the medication was for PCOS. Fiona had similar discussions with her housemates. Out of her 8 female housemates, two had cystic ovaries, and that was 'quite normal and common, but not a lot of people know about it'. Chloe and Fiona echoed that not many people knew of the condition despite its prevalence. Nandini pointed out an interesting observation:

"After I got diagnosed, I feel like suddenly everyone around me started getting diagnosed with PCOS, like all the girls in my class"

Kiki echoed this statement:

"When I got diagnosed, I felt that everybody around me started to get diagnosed either with PCOS or PCOS and insulin resistance"

To me these statements indicate an increase in the conversations and discussions surrounding PCOS rather than an actual increase in PCOS cases. Women with PCOS weren't just absorbing knowledge and information about the condition, they were also disseminating it within their social networks, especially female networks. The shared experience of PCOS was two-way and highly interactional. As I indicated in a reflective section in my methodology, I felt this exchange during my data collection for this project. Knowledge, impressions, and ideas about PCOS were exchanged freely between me and my participants during the interview process. The flow of knowledge in lay networks was not unidirectional; it was an exchange, and an assimilative process.

However, this sharing and interaction could also create conflict where experiences were dissimilar. Kate had a close friend who she spoke to after her PCOS diagnosis:

"I was really worried for some reason. Anyway, I spoke to a friend and she said, "Oh yeah, I've got PCOS apparently". And I was asking her loads of questions and getting really frustrated, because she couldn't really remember much."

Kate's diagnosis was very distressing for her. She reached out to her friend for support and reassurance, but instead found that her experience was actually not similar at all. Her friend had been diagnosed with PCOS only because she missed a few periods. Unlike Kate, her friend actually resumed her period. This made Kate question the PCOS diagnosis altogether:

"I asked her if she got her periods now and she said yeah. So, I felt like she'd been sort of really casually diagnosed with PCOS. Pretty soon afterwards I was doing my own research and then talked myself out of the fact like oh no you don't have it (PCOS)."

Kate's subsequent research to disprove her diagnosis is indicative of the role of the media and online resources in lay knowledge about PCOS.

Amalgamated Knowing

Kate told me she combed through online forums and chat rooms dedicated to PCOS. Nandini had read blog posts on certain symptoms and treatments. Chloe described searching for PCOS on Google after her diagnosis to learn more about the condition. Kiki told me that after she received her test results and before her diagnosis, she went on Google to find out what her symptoms and results meant. Elle first suspected she had PCOS after she saw a woman with the condition talk about it on a television morning show. She realized the symptoms the woman was describing were the same as hers, and subsequently looked up her condition on, of course, Google. The media and internet hold a huge repertoire of health-related knowledge, rendering it instantly accessible. Whilst the scope of my piece is not vast enough to cover the online presence of PCOS, it surfaced enough times in my interviews to warrant mentioning. Kiki told me:

"I follow quite a lot of Instagram accounts or read blogs from people that have PCOS or insulin resistance. Those really affect me because they show me that progress is possible, and I'm not the only one out there. Now especially, that I met you. That really helps."

For me, this is a summary of how various ways of knowing that the PCOS experience was shared one was meaningful. This is where the comfort of shared experience lay; in knowing that there were other people out there,

whether family members or friends or strangers online, whose stories reflected fragments of one's own. In knowing that their PCOS experience, whilst their own and subjective and individual, was still not a singular one.

Chapter Summary

Attempting to unravel and delineate ways of knowing PCOS has led me to the conclusion that whilst influential sources of knowledge can be identified, separating them is difficult. Even if it is possible, for the outlook I adapt, it is unnecessary. For my participants, different strands of knowing health and illness were woven together in their perception of PCOS. Their ideas and understanding of PCOS were a result of knowledge amalgamated from biomedicine, alternative medical systems, and lay knowledge networks, amongst others. The relationship networks around PCOS comprised primarily of females: women with PCOS, their mothers, and their friends. Amalgamated knowledge from various lay sources reflects how women developed their own understandings of PCOS. So far, I have looked at influences from overarching and organized systems of knowledge, and interactions with other people. I now move on to a different location of knowledge and perception: the PCOS body.

Chapter 6: The Body in PCOS

The body is an instrument of perception. According to Merleau-Ponty, it is the primary and fundamental instrument of perception, the very channel rendering perception possible (Merleau-Ponty, 1962). The body is a perceptive device, constantly being used to make sense of the world. However, this process is not a one-way transcription; the body interacts with the world and with dimensions of temporality, space, and materiality. The body blooms, drips, ingests, secretes, throbs. It is governed by a constant state of dynamism, of change, a thrum of activity, pulses, and breaths. Perhaps the most distinctive element between a living body and a non-living entity is static; a body is never static.

If the body is a perceptive and semiotic tool between the person and the world- where such distinctions are assumed- it is also a result chiselled from the interaction of the external and the internal. For thinkers like Csordas (1990), the internal-external divide dissipates rather than manifests on the site of the body. The body is both ongoing process and a simultaneous, ever-evolving consequence. What, then, if there is a snag in this circular process and consequence? What of an ill body, a non-conforming body, a body that has persistent patterns of non-conformity and illness? In short, a chronically ill body. The notion of PCOS as a chronic illness can be debated. In terms of temporality and as an 'incurable' condition I take it PCOS to be chronic. Bury calls chronic illness a "disruption", an interference that is felt in everyday life, manifesting in interpersonal relationships as well (Bury, 1982). In PCOS, to me the moment of diagnosis is a moment of disruption. Diagnosis defined and ascribed the label of PCOS, implies chronicity, and places the bodily experience of PCOS into a taxonomy consisting of symptoms.

Is there a PCOS body? For the purposes of this study, there very much is a PCOS body. There is a PCOS body as defined and designated by medical literature, and there is a living, experiential PCOS body. This bodily way of being need not be dichotomous. The PCOS body is rather a synthesis, where influences from medical systems, lay networks, cultures, and epistemologies coalesce. However, this site of coalescence in PCOS merits an exploration of

its own, before delving into its intersections. I am interested in the material PCOS body: its growths, textures, flows (or lack thereof), and sensations.

In this chapter, I chronicle what constituted as the bodily experience of PCOS for my participants, mainly through symptoms of the condition. I then move to the way these symptoms were perceived. These include interactional influences, such as interpersonal relationships and with medical practitioners. I also look at what is expected and wanted of a body, particularly a female body, and how PCOS challenges that in terms of femininity and fertility.

What is the PCOS Body?

Diagnosis aside, there are bodily experiences that the persons living them classify as unusual, painful, or abnormal. For the purposes of this study, I look at such bodily experiences as 'symptoms', alongside symptoms in biomedicine that are pathological states considered indications of disease. The PCOS body need not be restricted to symptoms; however, it is a useful foundation to build upon, and any analysis would be incomplete without considering what was happening to the bodies of women with PCOS.

Amongst the women I interviewed, the most commonly experienced symptom was menstrual problems, in particular amenorrhea, which is the absence of periods for three months or longer. Every woman also had multiple cysts on both ovaries. Other PCOS symptoms that women spoke about were acne, mostly around the face and jawline; weight gain or difficulty losing weight; hirsutism on the face, neck, thighs or stomach; hair thinning; fatigue or dizziness, in relation to insulin resistance; and painful periods and abdominal pain. My participants experienced PCOS symptoms differently. None of my interviewees had the same combination of symptoms, each experiencing a different set. The significance each woman placed on their symptoms was different as well. Kate and Kiki's PCOS experience was characterized by a persistent amenorrhea. By the time we spoke, Kate had resumed her period while Kiki had not, and this difference reflected in their management of PCOS. Both these women felt the effects of PCOS in terms of womanhood, due to associations between menstruation and femininity. The symptoms Nandini experienced were hirsutism, amenorrhea, and weight gain. Her main concern with PCOS was still irregular periods, but there was an element of her

appearance being affected too. Some symptoms were visually observable, appearing on the exterior of the body- such as acne bumps, or patches of hair. Symptoms were also temporally distinguished; some were felt in stages, and some repeatedly after certain intervals- such as disrupted cycles of menstruation. Nonetheless, as is characteristic of PCOS and chronic illness in general, there were patterns and recurrence of one symptom or another ever since the onset of the condition.

It is worth noting that many of my participants had ideas and impressions of what PCOS symptoms were, but alongside categorizing their own experiences as symptoms they were also drawing distinctions where they did not have conditions associated with PCOS. Chloe, for instance, told me of her doctor remarking that despite having PCOS she was not overweight. Kate told me of not experiencing symptoms she associated with PCOS:

“I didn’t have acne or hair (growth), but I didn’t get my periods. And I had cysts on my ovaries which, obviously, I didn’t feel anything, it was only when I had the scan. So, I didn’t actually have any symptoms, at all.”

Kate draws attention to another aspect of PCOS symptoms: visibility, and invisibility; the solely felt nature of some symptoms as compared to the visual and tactile nature of others. This is not to say that visible, touched symptoms were not also felt- however, some symptoms were not seen or observed, but sensorially differentiated in the way they were bodily experienced.

Seeing and Knowing

My participants told me of a mix of such visible and sensed symptoms that they associated with PCOS. The bodily presence of PCOS was made known in different ways: observable bodily manifestations, ‘invisibly’ felt symptoms, the interactional and cultural nature of the body, and intersections with biomedical ways of knowing and rendering visible the body.

Kiki brought up the term ‘visible’ and expressed a telling relief over not having observable symptoms of PCOS: “As for the visible symptoms, I feel like I’m quite lucky to not have them”. What are these visible symptoms, and what implications did they hold? Amongst my participants, the most apparent observable symptoms of PCOS were hirsutism and acne. At a bodily and personal level, they are experienced as unusual or unwanted, especially when

the body begins to change in appearance. Hirsutism is especially illustrative of this. Fiona, for instance, told me that she began noticing hair growth between her thighs and on the sides of her face that was darker than any other hair on her body. Chloe said that her hair progressively got thicker over the course of a few years and would regrow so quickly that traditional methods of hair removal were not working for her, so she went to see a doctor.

Bodily experience and self-observation, however, are not isolated; they infer meaning from social and cultural ideas of what is normal, healthy, and feminine. With observable symptoms, it also appears that bodily materiality and visibility is not restricted to oneself; others can see and touch the body too. Physically observable symptoms, then, have the potential to enter interactional and interpersonal spaces. Nandini told me she had hirsute hair on her face, neck, stomach, and arms. She described this hair as dark, thick, and hard. She told me that back home her family and friends, especially her mother, frequently notice this hair and point it out. The women at her local parlour in India do the same.

“The parlour ladies are horrible! They make you notice the hair. They make me cry every single time, without meaning too. It’s really annoying, because every single time the ladies there make comments like, ‘Oh my God she’s so hairy! This is sad, you need to go for treatment, you need to get laser done’”

In this one statement, Nandini reflects how others see her symptoms as unusual and warranting treatment, and how distressing that feels for her. Other people’s perceptions of the body can produce distress and embarrassment. However, Nandini also made an interesting cultural comparison between the UK and India. She told me that even if people noticed hirsutism in the UK, they never pointed it out. People in India were likelier to comment on it. However, she felt more uncomfortable with her hirsutism in the UK as compared to when she is in India.

“It’s just when you go abroad or to the parlour that you can stand out. In India nobody cares. They do point it out to you, but it’s like whatever”

Elle talked about her hirsutism in terms of tactility rather than visibility. She has blonde, hirsute hair on her jawline, the sides of her face, and below her belly button. To her, the interactional aspect of hirsutism comes into play with touch:

“It is just when you touch it, or when people touch my face- like boyfriends and stuff, it’s more about that. It’s just the touching. But I think the visibility is not an issue, because all my friends and people never notice it unless you point it out or you get them to touch it.”

I did not see the hirsute hair on either Nandini or Elle-they both removed it regularly- so I cannot speculate on whether differences in their experience were due to varying severities of hirsutism. Even if this were the case, the differences in visibility and tactility of hirsutism for Nandini and Elle still represent the multiple interactional grounds the same symptom can occupy; from interpersonal relationships to cultural attitudes towards bodily appearances.

Visible and invisible symptoms are not always categorically delineated. Symptoms frequently slip from the invisible realm into the visible one, and when they are no longer experienced, they recede from attention. How did the invisible symptoms and characteristics of PCOS become known? Certain PCOS symptoms that were not observed externally were experienced instead through the bodily processes they resulted in: for instance, one of the manifestations of hormonal imbalances is acne; and insulin resistance is experienced as ‘brain fog’ or fatigue, and appetite fluctuations. Menstrual irregularity is notable here, as it becomes known through absences rather than a presence. However, this still doesn’t explain knowing the foremost ‘symptom’ that defines PCOS: polycystic ovaries. All of my participants told me they had polycystic ovaries, a condition that cannot be seen but manifests through menstruation.

The absence, infrequency, or long gaps between period cycles are the first indicators of cystic ovaries. However, this indication is medical rather than lay or common knowledge. For the women I was interviewing, absent or infrequent menses were simply the indication of something not being right and often became the first reason for consulting a medical practitioner. Cystic ovaries in conjunction with irregular periods became known through the medical encounter and specifically through diagnostic tools employed during it. Medical transcription, thus, had a transformative effect on how women knew their body. The instrument used to render the ovaries visible was the ultrasound, a concept I have already visited. Kiki told me of a particularly interesting effect the

ultrasound had on changing how she visualized and felt about the cysts in her ovaries.

When Kiki first heard of her diagnosis and was told she had cystic ovaries, she visualized the cysts inside her as worms, moving within her ovaries, as something 'gross', even though she knew that she didn't have actual worms inside her. Kiki is Hungarian, and she told me that there was a phonetic similarity between the Hungarian words for cyst and worm. She explained that the translation for cyst in Hungarian is 'ciszta', and the translation for worm is 'giliszta'- the two words have the same suffix. I asked her if she knew now what the cysts actually were and what they were made of. She told me she wasn't sure, but she thought of them as little rocks inside her ovaries- an image that made me, in turn, think of my own cysts as rocks nestled in flesh and flinch. We continued discussing how Kiki visualized the cysts over time. "The last scan was like little spots, like cysts", she told me. Kiki had scheduled another ultrasound scan with her doctor back home, and she was hoping for an improved result.

"I sort of know that I will have cysts, but I sort of hope that I won't have. I don't think that's possible. I don't know if they can disappear"

The visual representation of PCOS through the ultrasound shows how medical technologies are a way of knowing one's body. For Kiki, it transformed the picture she had of the inside of her body, it was a monitor of progress, and just as it showed her that she had cysts, it could potentially show that she no longer had them. Cysts became indicators of illness or wellness. It held the potential to show Kiki the changes in her body she hoped for; but Kiki's statement also shows the vulnerability attached to a bodily condition that one can neither observe, nor predict.

Abnormality

For my participants what constituted as a normative bodily experience and what was classified as a symptom of PCOS was mostly influenced by biomedical knowledge. The PCOS diagnosis challenged ideas of what experiences, especially bodily experiences, were normal, and which experiences were considered symptoms. PCOS also reframed certain experiences women had before their diagnosis as symptoms. These symptoms played a part in women

seeking a doctor's opinion in the first place, as they were experienced as out of the ordinary, distressing, or something that needed to be addressed and rectified. "Once we found out it was PCOS, it was easier to relate the symptoms to it", Nandini expressed, indicating the cyclical nature of a condition being felt and then defined as a symptom. Sometimes bodily conditions were understood as symptoms retrospectively. Elle, for instance, told me she "always had a lot of hair" and called herself a "naturally hairy person". At 17, she developed hormonal acne and hair growth on her face and chin. She was concerned about the acne, but she was initially dismissive of the hair growth: "This is probably me just being a hairy person and I'll carry on just as normal." However, what she thought of before as hairiness became "hirsutism" after she received a diagnosis of PCOS. During our conversation, she forgot the exact term hirsutism, but still paused to recall it in order to complete the description for me. This re-categorization of an experience from something unusual to a symptom is indicative of medicalization. It is also indicative of how normal and abnormal are understood differently outside and within medical contexts. One of Nandini's statements directly shows how biomedical categorization led to the idea of abnormality:

"You don't really realize that you've got hair on your face or something, unless someone points it out to you. So, once we went to the doctor and they said yeah that's abnormal, *that's* when you start thinking about it. Till then I was like okay, whatever. Then when they said this is a symptom, this is *abnormal*, then it started bothering me, like oh my god, this is something weird about me."

When a condition is medically abnormal, it takes on a new layer of meaning. Now it is no longer just unusual, or bothersome; now it is the signifier of disease, of an internal disruption or malfunction in health, of abnormality. This can be seen through an increased awareness of one's own body and its processes, in a sort of self-tracking and self-policing. Kate told me that following her diagnosis, she feared visible signs of PCOS, almost as though those would ratify the presence of a condition she had already been diagnosed with.

“I became more hyper-aware of my body. Every time I’d get a spot I would think okay this is it, the acne’s starting. (*Laughs*). Or just regular hair that we all get (*gestures to her jaw and neck*) and I was like this is it now.”

This heightened monitoring of one’s body was reflected in menstrual patterns as well. Disturbed menstrual patterns brought with them a host of uncertainties, one of them simply being not knowing when the period would begin. Kate told me she was very aware of when she was ovulating as she used a mobile application to know what stage of her cycle she was at, and when to expect her period. Fiona was also using a mobile app to track her period cycle. Nandini and Kiki both relied on regular visits to their doctors where their hormone levels were checked to track their progress. This self-tracking was another way of knowing and re-knowing one’s body; it also reflects greater meanings, in terms of how the body should function, specifically as a feminine body.

The Feminine body

PCOS is, predominantly, known as an ovarian and female reproductive disorder. The last three words, taken apart, reflect the consequences of this way of knowing the condition: it is a *dysfunction* in the reproduction or maintenance of *female-ness*, or femininity. PCOS carries with it the idea that one’s ovaries are not as they should be, thus resulting in menstrual irregularities. Ovaries and periods carry with them connotations of fertility and sterility, and womanhood. This was a recurring, and emotionally-laden concern for my participants when speaking of PCOS and their bodies. One conversation with Kiki took an emotional foray into the topic of womanhood, and she told me:

“The thing was that there was something wrong with my ovaries. If there had been something wrong with my...I don’t know, *anything* else, that would be not that bad.”

Speaking about her diagnosis, Kate also mentioned ovaries, fertility, and womanhood together:

“I really did feel not feel like a proper woman. Not a fertile, feminine woman. Like my ovaries were deforming...I’m somehow deficient and broken in some way.”

These concepts were inextricably linked and are once again represented as dysfunction through the words 'broken' and 'deficient'. This is tied to how PCOS was perceived. When I asked Nandini to describe PCOS she told me:

“(It is) something that happens to a lot of people, but no-one really talks about it that much. I suppose it is because it’s in the ovaries that people are just like *aagh*. (*She does a slow jazz-hands motion*). It is literally just having cysts in the ovaries...it affects your metabolism, it then affects abilities of having kids...”

This statement reflects Nandini’s idea of PCOS involving both metabolism and ovaries, but the emphasis is invariably on the ovarian aspect of it. Both Kiki and Nandini’s statements also reflect stigma and associations surrounding ovaries. Whilst in different cultural contexts this stigma can hold different meanings, the root of it seems to be in the idea of privacy. The ovaries are private, evocative of insides and wombs and bodily cavities, surrounded by intimacy.

The ovaries are also connected to the idea of fertility, and childbearing, as Nandini said. Kate told me that the diagnosis of PCOS made her feel shamed and stigmatized, and she unpacked the idea for me:

“I think it would be a common reaction to feel shame with PCOS- I think why it is so specifically shaming and stigmatizing for women is because it’s like non-womanhood. Anti-womanhood. Like, fertility, and male characteristics like the hair growth and acne and weight gain. It is almost like the antithesis of how you’re supposed to be a woman in the world.”

Kate groups together a host of associations, but to me most notable is her use of the word antithesis. This harkens to Kitzinger and Wilmott’s (2002) ideas of PCOS creating friction within the ideal of womanhood.

Fertility

PCOS introduces contradictions in the many commonly-held facets of womanhood, especially motherhood. Motherhood is both a social role and the result of a transformative, reproductive bodily process. The many dimensions of womanhood, including motherhood, intersect with life stages; for instance, all the girls I interviewed were young women studying at university. None of them were in serious relationships, or starting families, or thinking about motherhood.

So PCOS implications about fertility and concerns around sterility manifested mainly as concerns and uncertainties about the future. Elle told me:

“I have no clue about the fertility side. When I saw the doctor last, I wanted him to tell me if I could have kids in the future, and he was like it’s not black and white, you’re not going to know.”

However, Chloe told me how this concern wasn’t just relegated to the future.

“It’s just always going to be a bit of an underlying worry until I’m in a position where I want to start having kids and it might be at that point when I’m like, 30, when it’s like “Oh, you can’t!”. So, it just feels like a bit of a waiting game, which is a shame.”

Elle told me how wanting children in the future could have enormous impact on her present-day decisions:

“I’m so career-driven. I’ve always said that if I ever got pregnant at a young age, I would have an abortion. But then, as soon as I got diagnosed with PCOS, I thought: Oh no, if I got pregnant at a young age, I should keep it ‘cause I might not be able to have a baby in the future.”

She later said that she would probably still prefer an abortion if an unplanned pregnancy occurred. Kiki also spoke of how uncertainty around being able to have children affected the course of life she had imagined:

“For me, all my whole life having kids was a basic thing. It’s like the traditional, natural way: high school, university, some years of career, then husband, kids, everything. The fact that this was threatened by PCOS just felt like shaking up my whole world. I know there are ways, I know, like adoption. But I wouldn’t be able to have my own kids that’s like...that’s the end of the world”

Here, I recall the intimacy of what childbearing means for a woman. As I quote Kiki, I remember handing her a tissue to wipe her eyes, and then pulling one out for myself. Her feelings around being able to conceive children mirrored mine when I was diagnosed with PCOS. A non-conforming body, on an emotional front, can be painful. As Kiki’s statement shows, and many other participants said to me, they questioned traditional ideas of womanhood and understood

there were many ways of being a woman. Kate called herself a 'bad feminist' for the associations she held about PCOS. However, alongside this acknowledgement was the fact that these ideas of womanhood were nonetheless internalized, even as they were realized.

I asked Kiki what ovaries made her think of.

“(Of) being a woman, and children. I also associate it with hormones and then hormones with being a woman in the sense that you look like the way you do”

Kiki made the connection between hormonal functions and feminine appearance, another theme that is recurrent in PCOS literature. However, she was not experiencing any androgenic manifestations of PCOS in her appearance, the most common of which is hirsutism. Elle, however, had hirsutism on her face and body, and she told me:

“I feel like on the face it’s more associated with like...male hair. It’s like hair that boys or men would have. But it doesn’t really bother me anywhere else, just my face. I don’t know, it does make me feel like less feminine, a 100%.”

While Elle had hirsute hair on her body too, she distinguished only her facial hair as manly. Nandini also has dark facial hair, and she told me that she felt compelled to either remove or hide it, even though she didn’t think anyone else noticed.

“There’s this self-consciousness about it...PCOS also links in with your self-confidence and what you think about yourself, because it affects the way you look and for women, that’s a big thing.”

The way a body should look had always held cultural and social meanings. The way a female body should look has, especially in contemporary times, taken on a multiplicity of meanings and notions, as well as resistances to those notions. Elle attributed these notions to “social media and stereotypes”. Nandini acknowledged such notions, but she also dismissed them by saying that she had accepted the way her body was.

Menstruation was also an important aspect of womanhood. Irregular periods, in fact, were the biggest worry amongst my participants. As both Fiona and

Nandini both told me, they didn't miss having periods as they had very painful cycles. Yet both girls had the desire to have a regular period, even though this meant undergoing pain. Periods were the signifier of the ovulation cycle, the most evident aspect of it, and the sign of the cycle functioning as expected. For all my participants periods were linked to feeling feminine or unfeminine, and feeling like a healthy woman. This was especially apparent in Kiki and Kate's cases, as both girls had had prolonged instances of amenorrhea. Kate had resumed her period, but Kiki still hadn't had a period. Kiki's doctor had told her that she was not ovulating, which exacerbated her fertility concerns.

Kiki and Kate were coming from a history of self-policing their bodies. Both girls had overcome anorexia nervosa before their PCOS diagnosis. In fact, for both anorexia had triggered the onset of amenorrhea. Menstruation then became significant on two fronts: it represented their full recovery from anorexia through the resumption of a bodily process they had 'lost' during it. Periods also represented feminine function.

The PCOS body was experienced through many layers of womanhood that intersected and overlapped. This including ideas of how the body should look, feel, and function if it was to be womanly and feminine. My participants wove in and out of these ideas, taking affect from dominant narratives of womanhood whilst also negotiating how to, quite simply, feel okay.

Chapter Conclusion

The PCOS body experiences a range of symptoms at different stages and times, fluctuating in both occurrence and severity. The PCOS body is defined by these fluctuations and ensuing unpredictability and uncertainty. This is shown in future concerns regarding the body, as effects and co-morbidities of the condition are understood to manifest across time.

In my participants' experience, the body became re-known and re-interpreted in various ways as it underwent physical changes. Various perspectives were enmeshed in knowing one's own body. The PCOS body was a site for generating this knowledge as well, materially manifesting changes and processes characteristic of PCOS. However, alongside being a source of knowing, it also became the site of amalgamated knowledge taken from various contexts, perspectives, and paradigms.

Chapter 7: Mediatory Practices

In the previous sections, I have traced several dimensions that PCOS was being perceived and experienced through. Impressions and interactions from medical systems, lay knowledge networks and embodied experience were woven together to inform the perception of PCOS. Radiating from these modes of knowing were ways of doing PCOS and ways of negotiating or mediating with PCOS in the course of everyday life. In this chapter, I look at mediatory practices surrounding PCOS. Mediatory practice is a term that I have borrowed from Guell's (2012) concept of mediatory tactics. Guell uses the concept of mediation to describe how people with diabetes choose between and the incorporate advice from the health sector and everyday life in managing their health (Guell, 2012). I adapt this concept to examine the lived experience of PCOS through everyday practices. I take mediatory practices as an overarching term that means practices employed to manage and live with PCOS. I see the experience of PCOS being situated in everyday life in the form of actions, and patterns of practices. My focus here will be on those practices and actions that women employed to negotiate with their PCOS, with the intention of looking at how people live with PCOS. The practices of PCOS reflect multiple perspectives assimilated into the PCOS experience; they were subjective, tailored to each woman's experiences and needs. These practices also reflected values, biases, conformity or nonconformity; in essence, the practices embody PCOS in daily life.

Why do women mediate PCOS? PCOS, as of yet, has no cure. It is a condition that one has to adjust to living with, and that places it in the category of chronic conditions. An illness is defined as 'chronic' in terms of temporality; if it stretches over a swathe of time, persistently or recurrently, illness becomes less of an event and more of something that one has to negotiate with as a part of life (Bury & Monaghan, 2013). By this definition, PCOS is a chronic condition. Although it must be noted that some women with PCOS refer to the condition as something they used to have, as though it has been cured or is in remission. Even though research frames PCOS as a lifelong condition, not all my participants ascribed to this idea. Kiki in particular told me that she was aiming to cure her PCOS through her lifestyle and the medication she was on. For her

being cured meant having a 'natural' period cycle. The idea of PCOS becoming cured persists because, at an experiential and bodily level, the condition registers when it creates symptoms or consequences. When these symptoms are not actively experienced, discontinued, or are resolved the active feeling of the condition recedes into the background. However, whatever symptoms a woman may have due to PCOS, she has to reconcile with the knowledge that she has an incurable condition. The 'incurability' of PCOS can be resisted and challenged- nonetheless, medically, PCOS is a chronic, incurable condition.

Every single one of the women I spoke to was engaged in some kind of treatment for PCOS. This indicates a need for reconciling with and making sense of a chronic condition, regardless of a cure as an end result.

Reconciliation is done through various means, or mediatory tactics. This negotiation helps the experience of PCOS in everyday life by managing and attempting to alleviate current symptoms. Alongside symptom relief, mediatory practices are also aimed at preventing future complications and risks associated with PCOS. This is likely in response to the uncertainties that PCOS entails, and a present means of dealing with future concerns. Mediation is also shaped by bodily experience, especially symptoms.

In general, the repertoire of PCOS treatments includes hormone therapy, infertility treatments, surgical interventions, and lifestyle changes, including exercise and dietary modifications. My focus on treatment and mediatory practice is body-centric. The severity and perception of PCOS symptoms in terms of pain or discomfort, and cultural attitudes towards what bodily experiences are normal or accepted all play a role in wanting to change or modify appearances, sensations, and functions of the body. Bodily interactions and encounters with other people, too, inform mediation. The main mediatory practices my participants engaged in were medication and lifestyle practices. These lifestyle practices included food choices, exercise, and bodily maintenance through cosmetic practices. Mediatory practice was an act of maintaining, producing, correcting, and modifying one's body. Within these practices, subjectivities constantly emerged. I will begin by looking at biomedical treatments of PCOS, where various values and perspectives overlap.

Medicine

Biomedical treatments for PCOS are contingent on the symptom that the intervention aims to address. For PCOS, doctors usually combine medications with lifestyle advice. The medication treatment options available for PCOS are usually ingestible medicines in the forms of pills and tablets. Occasionally, topical creams are prescribed for hirsutism. Surgical interventions are rare. Ingestible pills and tablets usually work by way of a regimen, so flow into everyday life, and target specific symptoms. For instance, to address hormonal imbalances in PCOS, treatments include insulin-regulating drugs; androgen-blocking agents such as spironolactone; and the humble contraceptive pill, such as Diane 35 (Goodman, et al., 2015). These drugs can be taken in combination with one another or separately. In my study, nobody was taking spironolactone, which is a strong anti-androgen. This was because none of my participants were experiencing androgen levels high enough to cause virilisation¹⁵ that normally merits a spironolactone prescription. Then there are drugs that improve insulin sensitivity. These drugs are meant to target the metabolic disturbances thought to be at the root of the disorder, to encourage weight loss, and to prevent the future risk of developing cardiovascular diseases or diabetes (Sharma & Nestler, 2006). Metformin is a commonly used oral medicine for insulin resistance, and it has been shown to improve ovulation (Moggetti, et al., 2000). In my study, one girl was taking metformin, as insulin resistance was a major part of her diagnosis. Whether or not a doctor prescribed metformin seemed dependent on the importance they assigned to insulin resistance in the pathophysiology of PCOS, as well as on their patient's experience of it. The most common and widely-used medication for PCOS is the contraceptive pill. Amongst my participants, I found the use of contraceptives to be laden with cultural connotations, meanings and stigma. I will use the attitudes towards contraceptives to illustrate how a biomedical treatment became, or was rejected as, part of one's personal mediatory practices for PCOS.

Contraceptives

Oral contraceptives are a standardized and hormone-based treatment prescribed to regularize the menstrual cycle by mimicking the body's natural

¹⁵ A condition in which extremely high testosterone levels can drastically affect the voice, appearances and libido in women.

hormone levels and inducing a monthly period. Contraceptives are also the first recommended treatment aimed at reducing the visible symptoms of free-circulating androgens, such as acne and hirsutism, so they serve a cosmetic purpose as well. Attitudes towards contraceptives and the incorporation of them into everyday practice is strongly influenced by cultural ideas and values. I saw this most clearly in Nandini's account of meeting with a gynaecologist after her PCOS diagnosis. The specialist prescribed contraceptive pills and gave Nandini a pack to take home. Nandini recounted this to me with mirth and dismissal: "We threw them away when we got home". Nandini explained her strong reaction to the idea of a hormonal pill in terms of her family's attitude, which was shaped by their South Indian heritage:

"I didn't feel comfortable taking contraceptives. Maybe it was because of the stigma attached to it, especially in Asian families. For my family specifically, drugs that help you put off your periods have traditionally been associated with health problems. They think its hormones. By that reasoning, contraceptives are also hormones and so they're bad for you."

Nandini's statement reflects the idea of the contraceptive pill as a hormonal treatment- which it is. Attitudes surrounding hormonal treatments can be quite pronounced and loaded with cultural meanings. Continuing the discussions with Nandini reaffirmed this notion.

"It's just a thing in society that you're not meant to take hormones, it's not ladylike...taking contraceptives is just for avoiding pregnancy, so you need to be sexually active to take contraceptives."

To me this association between contraceptives and sexual activity was at the root of the stigma and mistrust Nandini attached to hormonal treatments and the main cause behind her reluctance to take contraceptives.

"... (With contraceptives) they feel like they are exposing women to something. I was just 17 when I was prescribed contraceptives and they said she's way too young for this, you can't inject hormones in her or contraceptives. It brings sexually active a little too close to home, and they just don't like that."

Nandini's age, her marital status, the assumption of her sexual inactivity, and desire to maintain this status all intertwined to inform her family's attitude, and in turn hers, to the contraceptive pill. Since contraceptives were off the table, Nandini was taking homeopathic medicine instead of contraceptives. She told me that she thought homeopathic medicines helped regularize her period, although she was uncertain of this:

"A few of my friends who have PCOS are also taking homeopathy. I think it's just an Asian mentality, where people don't trust- especially things like this (contraceptives) where hormones are involved- so people won't go for it. Nobody knows if homeopathy actually does anything but people still take it."

For Nandini, homeopathic medicines held no stigma, and were instead thought of as neutral in the sense that even if they did not produce noticeable affects, they also didn't produce any side-effects. Homeopathy was associated with a more natural, non-invasive treatment approach. Despite being sceptical of their effectiveness, Nandini continued to take homeopathic medicines whilst rejecting hormones. Whilst Nandini's reasoning was rooted in familiar and cultural values, similar ideas persisted in some other women I spoke to, even though they had different cultural backgrounds.

Kiki was not experiencing an ovulatory cycle. She wanted to experience a period, especially because of the associations it held with fertility. Kiki was taking a range of supplements and pills to minimize her cysts and regulate her insulin levels, so she was quite comfortable with biomedical treatments. However, she still rejected the contraceptive pill. Part of this was due to a doctor's recommendation against it, and part of this was due to connotations of artificiality. Hormonal treatment would have induced a period for her- but that is exactly what made the difference. Kiki told me she wanted a 'natural' period rather than a hormonally-induced one, which she called 'artificial'. Similarly, Kate had wanted a period for a very long time, but did not consider hormonal treatment an option:

"Speaking with my GP, she said we can give you this synthetic hormone pill that can bring back your period and that didn't appeal to me."

Instead, Kate opted for acupuncture as treatment. She chose this despite being initially sceptical of acupuncture and knowing that hormonal treatment would guarantee the outcome she wanted. Ideas of hormones being an invasive, synthetic, or artificial intervention contrast with the notion of herbal and alternative treatments being natural, gentle, and non-invasive. Hormonal treatment through the contraceptive pill was seen as temporary symptom relief. It was understood that whilst hormones imitated and (re)produced a bodily process, they did not signal that the bodily function or process had resumed as desired. This is also apparent in some cases where women actually were taking the contraceptive pill. For instance, Elle had been on the pill for almost 2 years when we spoke. Once during this time, she ran out of pills. Elle waited a few months before resuming medication because she was curious to see if she would get a 'natural' period. She made a distinction between a 'natural' period and the 'medical' period she would get when she was on the pill. Apart from a short break, Elle remained on the pill. This is because the symptom she was most concerned with was not her period. It was acne. The pill had helped clear Elle's acne and kept her skin clear, which was important for Elle. So, taking the pill daily was an important part of her PCOS mediation. Chloe went on the pill to deal with hirsutism and found that it also cleared up her acne.

"They put me on the pill and that's kind of dealt with all my side-effects and stuff. She said it's a hormonal one that lowers your testosterone levels because she said that's what was causing body hair. I've been taking the pill for about a year. It has definitely improved my body hair."

Elle and Chloe found symptom relief through the contraceptive pill. Depending on the symptomatic concern in question, and the outcome desired from taking the pill, attitudes towards it shifted. Biomedical attitudes posited the pill as a standard treatment for PCOS. However, whether or not the contraceptive pill became part of a woman's mediatory practice was filtered through a subjective system of meanings. These meanings reflected cultural attitudes and prejudices, especially mistrust towards hormonal treatments.

Food

Food, eating practices, and diets have long occupied the rhetoric surrounding PCOS management, from biomedicine to the internet to traditional knowledge.

In the experiences of my participants, PCOS and food were related in a number of ways. For Kate and Kiki, eating disorders seemed to be precursors to PCOS, and eating practices were deeply correlated to PCOS treatment. The perception of food in terms of PCOS and its mediation was very personal, and quite literally tailored to individual tastes. Not all girls modified food and diets for PCOS mediation, but all drew parallels between food and health, or food and the body. Food was conceptualized through its properties and the substances constituting it, for instance in terms of nutrients, weight, or hormones.

Hormones

Perceptions of the presence of hormones, and their effect on the body, were not just restricted to oral contraceptives. The idea of hormones also crept into perceptions and practices surrounding food. Nandini mentioned milk and dairy being laden with artificial hormones fed to livestock. Similarly, Elle said she had heard that meat products contained hormones. Both girls couldn't place the exact source of this idea but told me that they felt they should avoid food containing hormones. Elle avoided meat, but Nandini said she could not omit milk and yogurt as they were staples of her South Indian diet. In contrast to omitting food containing hormones, there was also an idea of taking foods that balanced hormones. Fiona said she drank matcha green tea as she had heard it was good for balancing hormones. The idea of hormones in food and the effects of these hormones on the body stemmed from lay narratives. Hormones, like micronutrients, were thought of as a substance contained and transferred through the medium of food. This becomes especially relevant in a condition characterized by hormonal imbalances. Similar to medical hormonal treatments, hormonal attributes of food were considered through the question of how they would impact a body already in imbalance.

Lay narratives of PCOS and lifestyle modifications take food practices as management devices for PCOS, using metabolic pathways of the syndrome as an explanation. When I asked my participants if PCOS influenced how they ate, most of them did pick out changes and practices they had incorporated as a consequence of the condition. Kiki connected the role of food in PCOS management to the condition's metabolic aspects:

“As far as I know, insulin resistance and PCOS almost always goes hand in hand. That might be why there’s such a strong narrative about food around it.”

Kiki was the only one of my participants who was following a specific diet for PCOS and insulin resistance. Other girls had modified eating practices. Even where the actual changes and practices around food were minimal, there persisted perceptions that one should eat a certain way for PCOS, and how to do so. These perceptions and practices were usually a mix of doctors’ advice (where offered), interactions with nutritionists, lay nutritional ideas, information online, cultural ways of eating, and familial ways of eating. Foremost, however, are the way perceptions of the body itself informed ways of eating. The body was perceived in different ways in relation to food. Sometimes the body was seen in numbers: in terms of weight, of calories, of measurements. The body could be seen as a system of additions and subtractions. Sometimes the body was attributed properties, such as ‘hot’ or ‘cold’. This view of the body stems from ancient Greek humoral theory (Kushner, 2013) and has trickled down into various other medical and lay knowledge systems over time. It sees the body in terms of substances and balancing those substances. When it came to PCOS-related food choices the women I spoke to were condensing knowledge and impressions from a diverse range of sources. This manifested in a curiously personal way, as food usually does. Eating is an activity where decision-making and mediation takes place between a host of factors, one of which is PCOS.

Diets

During our second conversation, Kiki told me that she had recently been out with a friend. Her friend also has PCOS. They were at an event where there was free ice cream. Kiki’s friend was, understandably, enthusiastic to have some. Kiki tells me she was taken aback- she had assumed people with PCOS never ate sugar, as her own PCOS diet restricted sugar.

Kiki has been on a diet for PCOS for one and a half year. A major reason behind this diet is that Kiki has insulin resistance, and her doctor regularly reminds her that she is at risk for developing diabetes if she strays from the diet. Kiki began the diet after consultations with her doctor and a nutritionist, who tailored it to her individual needs. The diet is called the 180-gram diet, and Kiki

showed me a booklet in Hungarian that detailed the plan. The diet is based on carb-counting. 180 grams of carbohydrates need to be consumed every day, spread across five mealtimes. A number any lower puts her at risk for low blood sugar, and a higher amount could mean high blood sugar levels. A higher count is allowed if she exercises. The diet consists of whole foods, vegetables, and avoiding sugar completely. Kiki showed me the kitchen scales she uses to measure out meal portions. In recounting consultations with her nutritionist, she told me:

“I was always really interested to see how my body consisted of fat and muscles and stuff. It was also like a specific number and we could actually say that this number needs to increase or decrease. So, it was visible, you know, the progress would be visible.”

Kiki had a history with anorexia, where she said she had been ‘obsessed with the scale’. Numbers ascribed to weight played a huge part in her perceptions of her body at that time in her life, and she brought some these perceptions to how she saw her body in PCOS as well. However, with PCOS she continued to resist thinking of her body in terms of weight. For instance, she told me that she felt relieved that measuring her weight and the recommended amounts of her food was now relegated to her nutritionist. Although Kiki no longer thought of her body in terms of weight, and was focusing on health instead, she still relied on quantifying food. Another interesting aspect of this is the quantification of food not just by weight, but through micronutrients. Information from her nutritionist played a role in these classifications. Most of my participants had similar categorizations of food through micronutrients. Fiona followed a diet called the ketogenic diet based around micronutrient control. Her diet restricted carbohydrates and was based around consuming mainly protein and fats. Fiona adhered to this diet “about 80% of the time”, usually compromising only when she went out to eat. Even though her diet is centred around micronutrients, Fiona told me she didn’t think of her food only in amounts of macronutrients:

“I never tally out the carbs or levels of nutrition in my meal. I tried carb counting but it was just too stressful.”

The diet plan Fiona followed was for her PCOS. It did not dictate the way she thought either of food or her body, but the nutritionist principles of the diet

became assimilated into how she constructed a meal: mostly vegetables, a piece of meat, and almost no carbohydrate-dense foods like rice or bread.

Kate also followed a specific diet for a few months when she began acupuncture. Her acupuncturist told her she was anaemic and had 'weak blood', so she had to eat a lot of iron-rich foods such as red meat as part of her treatment. Kate is vegetarian, so eating meat was not an option. She began eating spinach and taking iron supplements. She also began drinking bone broth, as a compromise between iron-rich meat and vegetarianism. Kate was also advised to eat high-fat dairy products, which she did. She ate bone broth until she resumed her period and stopped afterwards. Since then she has followed a vegetarian diet.

Nandini's mediation of PCOS through food was different from the rest of my participants, once again because of cultural contexts. Nandini does not follow a particular diet for PCOS. She is vegetarian for religious reasons. However, she eats a certain way in response to certain PCOS symptoms. Nandini's periods are irregular, and she describes feeling moody, bloated and 'heavy' every time it is late. In order to induce a period, she does two things. The first is light exercise, mainly by taking long walks and sometimes using the exercises learnt from a Siddha doctor. Secondly:

"I eat hot food, because that's supposed to help. But when I actually get my period then I don't eat hot food, then I actually eat cold food."

This concept of heat and cold in the body is found in Southeast Asian health systems such as Ayurveda and Siddha (Hankey, 2005). It also influences lay understandings of health; Nandini gets this idea primarily from her mother. In Indian tradition, hot and cold properties of food relate to bodily energies and processes rather than temperatures. Heat is associated with flow, pain, eruptions, inflammation and release: expansion. Cold is associated with soothing, congestion, blockages, and relief: constriction. Heat can exacerbate and induce bodily processes, whereas cold calms or slows them down. Nandini's use of hot and cold foods reflected these concepts. She assimilated these ideas from her mother and her encounter with Siddha medicine. The fundamental idea was of balance. If a period is late, eating hot food will create heat in the body, counter any coldness or congestion, and induce menstruation.

So, when Nandini's period is late, she increases her intake of hot foods like sesame, garlic, ginger, and spices. Nandini said the idea is that:

“Heat is supposed to induce periods. But then after actually getting the period, for some reason it (heat) incites the pain, I don't know why...I think my body naturally gets heated up during that time so putting more heat into it just makes it go crazy.”

Too much hot food during the period could cause a painful imbalance. There, Nandini used cooling foods such as cucumber and yogurt to counteract an imbalance of heat.

Modifications in diets and food practices depended on what bodily experiences people had, and what outcome they wished to see. Whilst medications were associated with temporary symptom relief, food was associated with long-term action and seen as an investment in one's overall health. There was a great emphasis on using food as mediation for bodily processes, largely to regularize menstrual cycles. My participants' food choices were somewhat influenced by bodily appearances, usually the desire to lose or maintain weight. Aside from food's role towards bodily appearances, there were some PCOS practices that were specifically directed at altering appearances.

Cosmetic Practices

Cosmetic practices were material, tangible interactions with the one's own body to modify appearances. Sometimes these practices were personal, carried out on the body by oneself. Sometimes other people were involved in these practices. However, even if the process was solitary, it was still relational. Cosmetic practices were always in response to the visible symptoms of PCOS. The visibility of these symptoms is relational and holds implications for personal identity. In some cases, they affected women more when they were visible to other people, and sometimes they prompted mediation irrespective of other people's observation. There, appearance took on significance for personal identity, and how one- quite literally- felt comfortable in their own skin.

Amongst my participants, the most visible symptoms were acne and hirsutism. The mediatory tactics for acne were medication and healthy eating, usually with correlations being made between 'bad eating habits' and 'bad skin'. My focus

here will be on hirsutism, as it was mentioned more frequently and with greater emphasis by my participants.

Hair Removal

The appearance of hair was laden with cultural meanings. Three of my participants using the terms 'like a dude', 'male characteristics', 'manly', and 'unfeminine' in relation to their body and facial hair. Facial hair held these associations the most- it was the most visible because of its bodily location, and women described it as embarrassing and annoying. My participants' perceptions of hirsute hair are reminiscent of studies by Kitzinger and Wilmott (2002) and Pfister & Rømer (2017), where women similarly used masculine adjectives to describe their body hair.

Four of my six participants had hirsute hair on some part of their body. Nandini and Elle spoke of facial hirsutism. The girls were shaving, waxing, and threading- regularly engaging in processes to remove their body hair. The frequency of hair removal depended on how quickly it grew back, and how it became visible in other ways. For instance, other people pointing it out, or the possibility of someone else touching their skin and hair. Nandini told me:

"I can feel it. And people point it out to me. Once you know it's there you keep getting paranoid...I think I get quite self-conscious"

Practical factors, such as the accessibility of sources and their financial cost also played a role in what practices were adapted; and that is where mediatory decisions came in. Nandini told me that the best possible solution for her would be laser hair removal, which produces longer-lasting results. However, laser treatment is very expensive, making it less accessible than cheaper alternatives. Nandini continued:

"I remove my hirsute hair. I get waxing or threading done. It's too expensive over here (England). Back home I'd get it done at a parlour, never by myself. I tried it by myself, didn't really work, so now I need to go to the parlour at some point."

Nandini's experiences at beauty parlours, however, were upsetting. She told me that the ladies who worked there would point out the thickness of her hair and complain about how difficult it was to thread. Nandini went there anyway, as it

was the most practical method of hair removal available to her. She was only removing hair from parts of her skin that were visible.

“I’ve never done waxing or threading anywhere except my face. I do have hair growth on the body. It’s kind of dark and thick. I’ve never removed it...I would take the hair off if I were showing those parts of the body.”

Nandini usually dresses in a way that covers her skin. When she had to wear the traditional *sari*, which reveals the navel, she felt awkward. Elle also told me about feeling hirsute; for her the feel of her hair was a bigger factor than the visibility. Elle also waxed and shaved her hair, preferring waxing. She felt her hair grew back quicker than that of most people and waxed it about once every two weeks. She mentioned how it felt inconvenient:

“It’s one of the banes of my life, de-hairing my body. But it doesn’t really bother me anywhere else, just my face.”

Elle was conscious about boyfriends touching her hair. However, she told me she regularly removed her hair even when she was at home and knew she wouldn’t be meeting anyone apart from her family. She explained why she still maintained this so particularly:

“It makes me feel better, to not have hair. It’s such a thing for me, with social media and stereotypes and women having super smooth skin. It’s not even like I do it for other people, I do it for myself. ‘Cause of what I think makes me feel better.”

Keeping this regime helped Elle feel feminine and comfortable, and it was a response to her hair making her feel unfeminine. Elle was also taking contraceptives to control hirsutism. She told me she was prescribed a topical cream to reduce hair growth. The cream irritated her skin and resulted in a rash, so Elle stopped using it and just waxed instead. Waxing became a weekly or bi-weekly routine for Elle, but she told me she found the routine manageable.

With cosmetic mediatory practices, women were negotiating between practical factors and wanting to look and feel a certain way. Participants felt that the changes that PCOS induced in appearances, especially through hair, felt unwomanly. This was a result of hair and appearance being interpreted through cultural body standards and ideals of womanhood and femininity. As Elle

pointed out, symptoms of PCOS could make women feel less feminine, stretching into implications for identity and self-image. Mediatory practices came in response to this, utilized to eliminate symptoms that were placing the body outside the category of normal, generic womanhood. The body was a site for of conflict, and negotiation through mediation was a means to reduce and control internal conflict.

Chapter Conclusion

I found one of Elle's statements in relation to PCOS management particularly striking.

“Even though it annoys me, I'm okay with it at the moment. Even though I'm not. But you know what I mean. *(laughs)* It could be better.”

To me this statement reflects the frustration that can accompany mediatory practices, including medication, food, and cosmetic practices. Mediation needs to be repeated and adjusted into everyday life. It consumes time, money and effort. Mediatory practices can be acts of symptom relief, but also acts of conformity. Where they are acts of conformity, they hold values, attitudes, and meanings imbibed from various perspectives. Experiencing this multiplicity through PCOS, and mediating with it, can be exhausting. When producing certain bodily outcomes, these mediatory tactics are also a reminder of why those outcomes are desired in the first place: because of a defiant body, a body chronically and persistently producing undesirable consequences. PCOS can make the body a ground for the conflict that requires negotiation and mediation in the first place.

Mediatory practices are an exercise in sense-making, where meanings from various modes of perception and experiences collide. This why, at certain times, women chose one medical system is chosen over another. Or why two medical systems are used simultaneously for treatment. This is why different people choose to treat- or not treat- the same symptom through many different ways. Mediation is not just an arbitration between PCOS as a health condition and everyday life. Mediation is also the how the methods of this arbitration and negotiation are combined, conflicted, or reconciled with one another.

Findings and Conclusion

Findings

The aim of this thesis has been to develop subjective descriptions of women's experiences of the polycystic ovary syndrome. All of the women I spoke to for this project had a different experiential landscape of PCOS; from their cultural and family attitudes, the medical systems they consulted, and the effect of PCOS on their body. So, over the course of this project, representing this experience through individual voice became increasingly important to me. Especially when these voices were juxtaposed with the outlook that institutional biomedicine has towards PCOS, which offers little room for individual expression amidst standardized understandings of health.

In the experiences of my participants, PCOS was understood through multiple frameworks of health and illness. Foremost amongst these was biomedicine, where the definitions and categorization of PCOS originated. However, biomedical explanations for the cause behind PCOS are still murky. Where biomedical explanations for and of PCOS do exist, and if they are communicated by medical professionals, they remain cased in medical terminologies and specialist understandings, restricting the access and understanding of many women experiencing the condition. My participants found medical perspectives on PCOS questionable, especially due to the assumptions it imposed regarding what a healthy and feminine body should be. Women's interactions with biomedicine occurred through encounters with medical practitioners. In my study, women had both positive and reassuring experiences and negative or distressing experiences with doctors. However, they all shared impressions that the biomedical information communicated to them about PCOS is vague, leaving some of their questions and concerns unaddressed. I found that the specialized health approaches that make biomedicine efficient took on a deconstructive nature in PCOS. The condition itself and bodily experience was separated into symptoms, and consequently, treatment was also deconstructed. Treatment was symptom-specific and standardized across individuals. A lack of individualized treatment resulted in inefficiency when these treatments were rejected on personal grounds, for instance in the case of contraceptives.

Another, and contrastingly holistic, framework of understanding PCOS came from the alternative modes of medicine that women consulted such as homeopathy, siddha medicine, and acupuncture. These medical systems are rooted in cultural and natural understandings of health and illness. They are commonly modelled on a holistic approach to health, illness, and medicine that considers the entire body and the environment surrounding it as the site and pathway of both pathology and treatment. The idea of disease as an imbalance and healing through balance is important and recurrent in these medical models. Balance was a central tenet in the personal approaches of women towards PCOS.

Lay networks of relationships including family members and friends were an important sphere connecting interpersonal and institutional interactions around PCOS. These relationships became spaces containing referrals towards doctors or medical systems; discussions of personal PCOS experiences; and perceptions of the consequences, prevalence, and severity of PCOS. As these relationships were primarily between women, they offer an alternative narrative of PCOS to male-dominated biomedicine. As I traced the biomedical history of PCOS, the most influential names in the discovery, research, and classification of the condition were all overwhelmingly male. Hence, networks of womanhood offer a counter-narrative for a condition that affects biological females. Women were engaging in their own research to fill in the gaps of information left by biomedicine and learn about PCOS. Self-research was also a tool of empowerment, as it helped women develop an individual understanding of PCOS, contributing to a personalized narrative of the condition. I noted that the interactions I had with my participants also played a role within knowledge networks. Our conversations became places where they could freely express, create, and exchange subjective narratives and the knowledge these contained. That interaction was characterized by my position as a woman with PCOS, and also as someone researching it. I frequently answered questions about my experience and knowledge of PCOS. My participants found such conversations to be shared spaces, as did I. I left these conversations with different impressions and information that later influenced how I engaged with my own PCOS. I find this strengthening towards the significance of interactional

knowledge in health contexts, as well as pointing to the importance of positionality in research.

Womanhood and femininity were deeply interlinked with the embodied experience of PCOS. Women's accounts of their bodily experience reflected a range of symptoms being felt at different stages and times, fluctuating in both occurrence and severity. The PCOS body was characterized by these fluctuations and an ensuing unpredictability and uncertainty. Women expressed bodily experience through sensorial, tangible symptoms as well as future concerns regarding their body, as effects and co-morbidities of the condition were understood to manifest across time. In my participants' experience, the body became known and re-known, interpreted and re-interpreted in various ways as it underwent physical changes. Various perspectives were enmeshed in knowing one's own body. The PCOS body was a site for generating knowledge as well, as it felt or tangibly manifested the changes and processes characteristic of PCOS. Similar to Csordas' understandings (2015), the body was a medium for perception whilst simultaneously being a location of perception. Alongside being a source of knowing, the body in PCOS became the site of amalgamated knowledge taken from various contexts, perspectives, and paradigms.

Each of my participants had subjective understandings of PCOS based on multiple knowledge networks. This is especially illustrative through the different forms of mediation that women employed for PCOS. The mediatory practices looked at in this study were: how women used medication, how women ate, and how women managed appearances all in relation to their PCOS. PCOS experiences vary across women, resulting in different attitudes and experiences, and ultimately influencing mediatory practices. My participants' everyday management of PCOS was consistently tailored to their experience of its symptoms. Women filtered mediatory choices through considerations of individual symptoms, biomedical attitudes, personal values, assimilated knowledge, cultural attitudes, interactions, desired outcomes, identity and womanhood. Whilst mediatory practice reflected all these knowledge modes of perception, it was deeply influenced by how the body felt and was aimed at managing the body, suggesting the importance of embodiment within the experience of chronic illness.

Final Conclusion

A collective habitus of PCOS, shared between women, formed from and in turn informed, perception and personal experience. The experience of PCOS was multi-layered, embedded with meanings, knowledge and information. For the women in my study, these were amalgamated into an individual habitus of PCOS that derived from a multi-faceted knowledge network of PCOS. Medical systems, lay networks of family and friends, cultural values and attitudes, and one's own body were all threads within this knowledge network, becoming both sources that generated and links that interconnected an individual's knowledge. Knowledge, perception and experience were not static. They were evolving and symbiotic, constantly co-producing the habitus of PCOS experience. Within such a multiplicity of perspectives and choices, and within such variations between individual experiences there emerges a niche for agency. I think of this as an individual habitus of PCOS, where a person constantly assimilates knowledge, where perception occurs in a dynamic process, and where agency is exercised through everyday practices. The individual habitus is personal practice and perception regarding PCOS filtered through the collective, social, and medical contexts of PCOS.

An individual habitus could be seen in action through mediatory practices for PCOS, where women chose and modified their everyday practices surrounding health, food, and appearances for managing PCOS. This selection reflects the intersection of acquired and integrated ways of knowing PCOS together with how women live with it in everyday life. Women managed PCOS depending on the bodily symptoms they experienced intermingling with knowledge, impressions, and attitudes assimilated from various health contexts. Women's PCOS experiences and the subsequent methods through which they mediated PCOS held some parallels but ultimately varied between each individual.

Variation between women's PCOS experiences suggests two things: first, that PCOS is highly individualized and this renders standardized biomedical approaches questionable. Second, variation also is indicative of individual approaches towards PCOS, and agency. The differences in women's mediatory approaches to PCOS show that they were adapting and modifying knowledge from different sources to suit themselves, in accordance to their personal

narrative and perception of PCOS. Personal narratives are important, as they contain ideas of womanhood and multiple ideas of bodily being that challenge and destabilize biomedicine's fragmenting approach to the body.

In contrast to impressions from previous literature (Kitzinger & Willmott, 2002), for the women I spoke to PCOS is not simply a negation of womanhood. A body that disrupts or subverts medical standards of health and femininity produces alternative modes of being; these modes of being can be messy, causing distress for the person experiencing them and entangling with subjective life experiences. However, when they diffuse into everyday life, these 'other' modes of being a woman are reified through practice, once again creating counter-narratives of womanhood and health. For instance, PCOS was felt when its symptoms were experienced- when the symptoms dissipated, the experience diminished. Hence, the biomedical labelling of PCOS as incurable was resisted. PCOS' effects on womanhood were similarly impermanent; if a missing period was the symptom creating feelings of differentiation from 'normal' womanhood, when a woman resumed her period and the symptom was gone, she felt feminine again.

My participants' personal narratives of PCOS were a medium where multiple perspectives collided, initially creating conflict. For instance, women first reacted to their PCOS with dismay and uncertainty, especially when it was understood as a chronic, ovarian, and hormonal condition. This distress, however, was later met with acceptance and resilience, as is evident in the way each woman approached, treated, or resisted the condition. Women understood PCOS through different contexts, selecting specific aspects of these contexts and synthesizing them into an individual habitus. For my participants, the identity implications of PCOS fluctuated with the occurrence and severity of symptoms, so while the condition did have an influence on self-perception, this effect was also fluctuating and did not determine self-perception. Perhaps women's greatest resistance towards rigid biomedical, cultural or social understandings of PCOS was too see PCOS as something to live *with*, rather than live against.

Limitations and future research

Previous literature has touched upon the "reframing" of PCOS through positivity in narratives (Williams, et al., 2016). In my study, this is more an act of

reclaiming, as how women negotiate PCOS is represented through practice. Women were re-creating perceptions of themselves by forming personalized mediatory practices and narratives of PCOS. Personalized and subjective narratives of PCOS such as the ones in this study rarely appear in PCOS literature, which turns concerning in the light of the prevalence of the condition. Considering that at least 10% of the female population experience PCOS, it is a phenomenon ripe for more social science research.

This thesis has looked at ideas of womanhood, but the gender perspective is limited. As some other existing literature has done (Ellerman, 2012; Kitzinger & Willmott, 2002), future research could look into PCOS through femininity and masculinity together and strengthen a gender-based perspective on PCOS experience. Aside from interview-based studies, ethnographic research over a longer period of time would sit well with the temporally chronic nature of the syndrome and study PCOS over time.

In my study, I touch upon various facets of PCOS experience that could each be studied in depth; for instance, stigma and shame, medication, and self-research. My study looked at experience and contextualized it through bodily experience. However, future research could address the large gap in qualitative and experiential studies on PCOS by grounding it in a specific cultural context. The bodily experience itself reveals numerous avenues of interest such as sensorial experience, identity implications, sexuality, and interpersonal relationships. My study is limited by the participants being in the same stage of life: all of them were young women, students, and not looking to start families or have children. All of them were worried about a future where might have fertility issues. Future studies could look at women with PCOS at other stages of life such as women trying to get pregnant, women with children, women around the age of menopause, and women who have PCOS alongside other co-morbidities. In terms of lifestyle, research can focus on how women exercise for PCOS mediation. In my research, food behaviours were consistently mentioned in lay narratives of PCOS. The intersection of food and health behaviours is an area that PCOS research has hardly touched, holding great potential for further work. The correlation of eating disorders and the onset of PCOS could be explored both qualitatively and quantitatively, offering insight into environmental

triggers of PCOS. Food and eating in PCOS management could offer an interesting structural and contextual perspective on PCOS.

Within the knowledge networks I have looked at, the one that holds enormous scope for further research is how individuals create personal knowledge through mediums like the internet, self-help books, and self-help groups for PCOS. The women in my study were not deeply involved in these methods but did mention them, indicating room for online content- and forum-based research.

In this thesis I argue that biomedicine presents itself as scientific fact, and bases its generalizations on that, but even so it is not objective. Even the most rigorous and concrete scientific knowledge that modern medicine is based on is interpreted through medical practitioners, who are not impartial vessels and dispensers of medical knowledge. Previous research has similarly criticized such disconnected and isolated biomedical approaches to PCOS (Ellerman, 2012; Lock & Nguyen, 2010). Scientific fact interacts with medical practice on multiple fronts. Future research on PCOS could expand on this by qualitatively looking at medical practitioners' perceptions and experiences of this condition. This could explain approaches to medication, doctor-patient interactions and how the different diagnostic criteria are applied.

Ideas of health and womanhood reside in a variety of contexts. Through this thesis, I undertook a subjective exploration of some of the health contexts of PCOS. Previous literature has looked at PCOS through one context at a time, whether it was biomedicine, feminism, quality of life, or mental health. This study acknowledges and emphasizes the multiplicity and intersectionality of health contexts that PCOS exists in. PCOS in the body is a condition characterized by various symptoms occurring together; PCOS contextually is characterized by being present in various perspectives and epistemologies. It is therefore vital to study as much of the health contexts surrounding PCOS as practically possible, with an emphasis on under-studied subjective narratives, and to look at the interrelations between health contexts in order to comprehensively understand and ultimately address the condition.

This text is a work built upon subjectivity, arguing for the increased representation of subjectivity and individual voice in health contexts. However, it acknowledges that subjectivity itself is not isolated or separable from context.

Subjectivity develops from assimilation, from interactions between the body, the person, and the world they inhabit. That is not to say that subjectivity is merely a product. Instead, subjectivity is an ongoing process where the world and individual agency collide. Subjectivity is a rare space where individual agency can thrive, making studies of subjectivity crucial towards understanding human health experiences.

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