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Don't Blame It on My Ovaries: Exploring the Lived Experience of Women with Polycystic Ovarian Syndrome and the Creation of Discourse

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Don't Blame It on My Ovaries:
Exploring the Lived Experience of Women with Polycystic Ovarian Syndrome
and the Creation of Discourse

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts
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Dedication

I dedicate this thesis to my mother, Nancy, who has supported me both emotionally and financially throughout the course of my education. You encouraged me to return to school and finish my bachelor's degree and helped me to remember how much I love learning. You have always been there for me, even when the going got especially rough. You do so much for me, mom, and I could not have gotten this far without you!

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Abstract

Polycystic Ovarian Syndrome (PCOS) is the most common endocrine disorder among females of childbearing age, affecting between 6-8% of the population. It is also the most common cause of infertility. Females with PCOS may have two or more of a constellation of symptoms that can potentially leave them at odds in terms of normative ideals of femininity. This study examines how feminist theory interrogates and analyzes knowledge about the body and PCOS, integrating the lived experiences of women to provide a deeper, more meaningful understanding of what it means to be a woman with PCOS.

Chapter One: Introduction

The advent of modern medicine has been both a blessing and a curse for humanity, particularly women (Reissman 2010); it has provided the means for longer life spans and increased quality of life, but these gains have not been without cost. The influence of conventional medicine has grown exponentially over the last century, and the medical establishment has cemented its position as *the* authority where issues related to health are concerned. This influence has been institutionalized to the point where it is seemingly ubiquitous and rarely questioned. It is, then, relevant for feminist scholars to both interrogate and deconstruct this institution where power is held and wielded mainly by white men¹.

Growing out of the women's rights movement, the women's health movement sought to regain control of women's bodies and their health (Ehrenreich and English 2011; Ruzek and Becker 2000; Turshen 2007). The growing control over knowledge of women's bodies is protected jealously by the medical establishment, with a privileged few holding the keys to what seems to be a well-guarded secret. Today, perhaps, we take for granted the unprecedented access to information that we have at our fingertips, but 40 years ago such information was largely out of reach for many women. As a student in

¹ According to statistics published in 2010 by the American Medical Association, of the more 1.2 million physicians in the United States, 954,224 are male of which 383,704 are white, making them the majority among doctors in this county.

a graduate course on women's health, I recall a story in which a professor recounted her own experience as a woman wanting to know just what her doctor was seeing beneath the white sheet draped over her lap in the 1970s (Personal communication). The doctor's response was indicative to the prevailing attitude at the time: "It is none of your business." Hearing such an utterance incensed me.

Women have been struggling for decades not only to reclaim knowledge and authority over their own bodies, but to have a voice in how that knowledge is constructed, analyzed and disseminated. We have seen activists in the women's health movement challenge the medicalization of pregnancy and menstruation (Greer 1972; Ehrenreich and English 2010; Ehrenreich and English 2011; Martin 1987), yet there remain other conditions that are firmly within the realm of women's health that have yet to be interrogated. Polycystic Ovarian Syndrome (PCOS) is one such example.

Polycystic Ovarian Syndrome is the most commonly reported endocrine disease and the most common cause of infertility among females of childbearing age, yet we hear relatively little about this complex condition. Additionally, Norman, Dewally, Legro and Hickey report that PCOS is the "most frequent cause of hyperandrogenism² and oligo-anovulation³, both of which have substantial psychological, social, and economic consequences" (2007, p. 685). Originally reported by Stein and Leventhal (1935), it is estimated that between six and eight percent of females suffer from PCOS (Carmina and Azziz 2006). While

² An elevated level of testosterone.

³ Infrequent or absent ovulation.

the name of the syndrome is indicative of the presence of ovarian cysts, not all females with PCOS exhibit this particular symptom. In fact, females with PCOS may have two or more of a constellation of symptoms which may include amenorrhea⁴, infertility, hirsutism⁵, acne, weight gain, insulin resistance/type 2 diabetes, high cholesterol, high blood pressure, thinning hair or male pattern baldness, acanthosis nigricans⁶, skin tags, pelvic pain, sleep apnea, anxiety and/or depression generally related to one's appearance or the inability to conceive.

Moreover, PCOS is more than just a disease related to hormones, the ovaries and the endocrine system. Norman et. al (2007) also report that the health consequences of PCOS, including cardiovascular involvement, are of concern throughout the course of a woman's life. The increased risk across multiple body systems has the potential to put women in a rather precarious position. A recent article published in *The New York Times* (Carpenter 2009) highlights a salient point: Individuals with multiple health problems are marginalized within medical settings, both at the clinical and research levels, such that the focus is placed on malfunctioning disparate parts instead of the whole person. This compartmentalization and medicalization of the body has been widely criticized by feminist scholars (Reissman 2010; Weitz 2010) in that it poses a serious threat to the health of an individual. This is particularly concerning for feminist scholars because women's bodies have been subject to

⁴ The absence of a regular menstrual cycle.

⁵ The growth of dark and/or coarse hair in places such as the face, neck, abdomen and chest in females.

⁶ Areas of darkened skin discoloration generally found on the neck, breasts, arms or thighs.

such measures on a greater level than those of men (Reissman 2010). I suggest that this risk is further complicated in the case of women who have been diagnosed with PCOS who may be seeing multiple doctors for the treatment of a handful of symptoms which impact overall health and well-being.

A publication released by the American Association of Clinical Endocrinologists (Cobin et al. 2005) states that, while the exact etiology of PCOS has not yet been determined, three hypotheses have been suggested:

1. Hypothalamic-pituitary abnormalities that result in gonadotropin-releasing hormone and luteinizing hormone dysfunction
2. A primary enzymatic defect in ovarian or combined ovarian and adrenal steroidogenesis
3. A metabolic disorder characterized by insulin resistance in conjunction with compensatory hyperinsulinemia that exerts adverse effects on the hypothalamus, pituitary, ovaries, and, possibly, adrenal glands

It is important to note that two out of these three hypotheses do not associate the cause of PCOS with the ovaries, and the remaining one posits that it may involve the ovaries in addition to the adrenal glands. Consequently, the name polycystic ovarian syndrome might well be a misnomer that potentially adds confusion and frustration to an already difficult disease, placing the “blame,” as it were, on organs that are biologically female when the syndrome may, in fact, result out of a perceived abnormality that female *and* male humans possess.

Moving out of the realm of the medical sciences, there has been relatively little work done on PCOS by those in the social sciences. A 2002 article published in *Social Science and Medicine* entitled “‘The Thief of Womanhood’: Women’s Experience of Polycystic Ovarian Syndrome” by Kitzinger and Willmot is an excellent example of the results research under the auspices of social

sciences can produce. They observe that “Outside medical texts, there has been little public discussion of PCOS, and what rare mentions there are typically serve to reinforce the shame of the conditions as a ‘deviation’ from proper femininity” (Kitzinger & Willmott, 2002, p. 350). They further argue that the experience of PCOS has a negative impact on the way women view themselves in relation to normative ideals of femininity. The research done by Kitzinger and Willmott sheds light on the need to not only hear the stories of women with PCOS, but to empower them to challenge socially constructed notions of what it means to be a woman. I have modeled my research, in some respects, on the work that Kitzinger and Willmott have begun. My intention is to add to the discourse on PCOS by continuing to examine and critically engage with women’s narratives on PCOS.

While the etiology of PCOS remains clouded, it is just one area of inquiry in the larger framework of unanswered questions and unexplored corners. Through my research on PCOS, I will begin to deconstruct just what it means to be a woman with PCOS. The experiences of women living with PCOS have not been examined in any great detail, and I contend that these voices have the unique potential to add to the discourse surrounding PCOS. The vast majority of literature on the subject has been generated by those in the medical domain, and I feel that this one-sided perspective leaves out an essential element – the lived element. By giving voice to the bodily knowledge of women through personal interviews, the opportunity exists to bring feminist research methodology to bear and, through its practice, create additional knowledge that will expand this

particular field of inquiry. While women have traditionally been marginalized when it comes to medical research, I contend that women who are perceived as falling outside the cultural ideals of femininity, specifically women who have such potential PCOS-related characteristics as weight-gain, hirsutism and infertility, are further silenced by preconceived notions which the medical field holds about what a woman should or should not be. I argue that PCOS is a feminist issue in that it challenges notions about the body, sexuality, and femininity. Moreover, PCOS can be used as a platform for resistance and empowerment where women's health is concerned. By encouraging women to become advocates in their own health care, positive health outcomes will be obtained and sustained.

It should also be noted that I count myself among the women living with PCOS. Within the tenets of feminism is the idea made by popular that "the personal is political, and the political is personal." The challenges and frustrations that we face as women are not relegated solely to the individual but to larger structural and institutional factors that influence and exert power over the lives of the individual. It is vital that the relationship between the individual and these larger factors not be discounted or ignored. Over the course of my graduate education as my ideas for my thesis work were taking shape, I have been asked if this issue is simply too close to home for me. In such situations, I think back to this idea of the personal and the political being intertwined because, at least for me, it very much is. My health as an individual is tied up in the larger structures of the healthcare system and its many parts. I may be just one woman with PCOS, but is something I am very passionate about because it was a

catalyst for my interest in the broader topic of women's health. My experience with this syndrome has been a process of both exploration and learning, sometimes fraught with frustration and anger, but overall something that has served to open my eyes and raise my consciousness about just what women experience in the context of their own bodies when it comes to the healthcare system in this country. To get back to this question of the issue being too close, then, I answer that while scientific inquiry has traditionally privileged objectivity, personal experience is indeed valuable and has the capacity to provide insight that simply does not come about through cool, uninvolved study. It is from this point that I begin.

Chapter Two: Feminist Research Methods and PCOS

Feminist research methods have not only the potential to expand the knowledge on PCOS but to begin to remedy past inadequacies where the marked absence of women in the discourse is concerned. This chapter will explore feminist research methods, specifically as such methods are well positioned to both clarify and illuminate aspects of PCOS that are not part of the medical discourse but can help to provide a deeper, more meaningful understanding of this syndrome not only for the women living with it, but for professionals in the field of women's health.

As previously mentioned, there has been a lack of research on PCOS where feminist scholarship is concerned, and feminist perspectives on this condition should be brought to bear to explore and deconstruct its meanings and implications in the lives of women. It is my hope through this research to begin to capitalize on the missed opportunities to explore the experiences of women with this syndrome. Feminist research methodology provides a practical and meaningful guide for considering PCOS; however, it is relevant to examine just what feminist research entails. For this, I turn to Harding (1987) who suggests that feminist researchers may use a variety of traditional methods but the way in which these methods are *used* is what sets them apart. Simply put, feminist research methods place women as “knowers” – capable of creating knowledge – where they have been excluded from this position in the past. Feminist research

methodology seeks to give voice to groups that have historically been excluded from the discourse, and this is particularly true in the arena of health.

Central to the work I seek to accomplish through my research is the notion of feminist standpoint epistemology. This concept, originally described by Hartsock (1997) and integrating ideas of Marxist feminism, is grounded in the position that women as an oppressed class possess a perspective unique from that of men. Drawing from Hartsock's work, Jagger suggests that "Standpoint theory emphasizes that marginal social locations offer certain epistemic advantages; it explains that by virtue of having to know how the world looks from more than one perspective, an insider-outsider has available a set of comparisons that make visible the assumptions underpinning dominant worldviews" (2008, p. 207). By incorporating the lived experiences of women with PCOS in my work, it is my intention to shed light on how these experiences can deepen our understanding of this syndrome within the larger framework of women's health.

For the purposes of this research, I draw from Jackson's explanation of lived experience which I feel most closely mirrors my own conception. He suggests that "Lived experience accommodates our shifting sense of ourselves as subjects and as objects, as acting upon and being acted upon the world, of living with and without certainty, of belonging and being estranged" (1989, p. 2). While some might argue that a clinical perspective is adequate and generalizable, such an approach silences the subtle nuances of individual lives

and voices that have the potential to paint a more complete and realistic and reflexive picture of what it means to be an individual with PCOS and to subvert normative ideals of femininity. The embodied experiences of women provide a lens through which we can more fully understand and appreciate their lives and their positions, as well as the potential inroads for resistance against the forces that oppress them (Weitz 2010). These contexts, which frequently remain excluded from the medical discourse, challenge existing notions of what it means to be a woman with PCOS by highlighting the myriad individual embodied experiences of the syndrome, the means by which some women subsequently make sense of themselves and their health in relation to their diagnosis and how their identities challenge the normative discourses of femininity so endemic in Western culture.

Feminist research methodology emphasizes flexibility, innovation, and integration of methods, drawing from various disciplines to provide the researcher with a comprehensive means of investigating the world. In the context of my own research, I will draw from several methods to more accurately and effectively investigate the experiences of women with PCOS. Moreover, as Reinharz (1998) argues, engaging multiple methods adds to the scientific validity of feminist research. This claim flies in the face of traditional research methods which claim that the only valid, reliable knowledge is that which is the product of empirical research. Patriarchal institutions such as the medical establishment privilege this form of epistemology, but feminist research methods challenge

these notions by opening up the possibility of new ways of knowing that differ in the manner of exploration and the fruits of our quest for understanding.

Additionally, feminist research methodology benefits from an interdisciplinary approach by utilizing methods from many areas of study to develop approaches that are well positioned to reveal aspects of inquiry that might be missed by more limited methodologies. As previously mentioned, feminist researchers may engage in traditional research methods such as interviewing, but the feminist researcher carries out their work in such a way that sheds light on those who have been marginalized or left out of previous inquiry. The feminist researcher subverts the master's tools⁷, modifying them to uncover what has been hidden. This willingness to engage open-mindedly makes feminist research methods a well-suited tool for this area of investigation.

Another vital component of feminist research methodology is intersectionality. This perspective, related to identity politics, stresses the importance of considering an individual from multiple angles such as race, gender, and socio-economic status. For example, I am not just a woman. To use that term alone indexes a monolithic sense of just what "woman" is. Am I a woman because I have reproductive organs that mark me as such? Because the gametes which came together at my conception resulted in an XY chromosome combination? Instead, I might state that I am a white female, raised in a non-traditional nuclear, middle-class family in an urban area. I am also a childless

⁷ Reference to Audre Lorde's essay "The Master's Tools Will Never Dismantle the Master's House" (2003).

individual who happens to be living with PCOS with no immediate intentions of addressing my infertility. These different locations shape our experiences and, by extension, who we are. For example, the women whom I interviewed in the course of my research reported much more concern about their infertility, especially in terms of their relationships. Clearly, there are many different facets to the lived experience of PCOS.

By documenting, contemplating, and analyzing the experiences of women, we have the opportunity not only to give voice to a marginalized group, but also to delve into previously unexplored areas of knowledge. As Scott suggests, “Experience is at once always already an interpretation and something that needs to be interpreted” (1991, p. 797). We each see the world through a multiplicity of lenses shaped by who and what we are, and the recounting of those experiences to another, the researcher in this case, adds more lenses still. Consequently, I believe that the narrative segments of interviews provide excellent material for the analysis of commonly recurring themes which will add further support to previous research, such as that done by Kitzinger and Willmott (2002) and Castillo (2008).

Within the realm of feminist research, feminist scholars recognize both the presence of our own subjectivity and the relevance that perspective brings to the larger scope of our “project.” Feminist research creates a space for “I” that traditional social science practices have typically frowned upon in their pursuit of objective knowledge. As an undergraduate student of anthropology studying

ethnographic accounts and conducting my own research, there was no room set aside for the personal perspectives and experiences of the researcher. As a student in my first women's studies class, however, I discovered just how much different feminist research could be from anything I had previously experienced. The course "Feminist Perspectives on Women's Health"⁸ introduced me to autoethnography as a method, and I have continually found it to be a tool of great use in the context of my research. Autoethnographic research melds together the personal experiences of the researcher and the wider social and cultural context of those experiences, such that the lines between the personal and the social become less distinct and rigid (Ellis 2004). Autoethnography is reflective and reflexive, creating a space for the critical analysis of the author's own knowledge. Again, I hearken back to "the personal is political" as I believe that the process of autoethnography is an embodiment of this tenet. Throughout the subsequent chapters of my thesis I will engage with autoethnographic elements, taking the opportunity to situate my own thoughts and experiences against the theoretical approaches and critiques of the literature and narrative accounts addressed herein.

Ethnography, the study of human culture, at its most basic level seeks to help us understand the world through accounts of both social and cultural practices. Devault suggests that, "The promise of feminist ethnography is that we can elicit accounts and produce descriptions of these kinds of practice and

⁸ "Feminist Perspectives on Women's Health" is a graduate level course offered in the Department of Women's and Gender Studies at the University of South Florida and was taught by Dr. Marilyn Myerson.

thought that are part of female consciousness but left out of dominant interpretive frames, shaped around male concerns” (Devault, 1990, p. 100). As previously mentioned, the personal is political. When it comes to women’s health in general and PCOS in particular, I find this statement to be especially accurate. If we remain frightened and ashamed of our bodies, we run the risk of being silenced. Such personal issues as our health, especially when it relates to aspects of ourselves that are perceived inherently “female,” can be difficult at best. It is for these reasons, then, that women must find the strength to overcome our fears and speak clearly and boldly about our experiences. Ethnography offers a vehicle through which we can connect with these stories, but critical ethnography takes this a step further by challenging the researcher to utilize ethnographic accounts in the pursuit of social justice.

Critical ethnography, as Madison contends, “begins with an ethical responsibility to address processes of unfairness or injustice within a particular *lived domain*” (2005, p. 5). Feminist scholars recognize the fact women’s bodies and, by extension, women’s health, have been areas where women have acutely felt the effects of prejudice and discrimination. Realizing that such inequalities can negatively impact the lives and well-being of women, feminist research is tasked with a responsibility to not only raise awareness to these issues but to open up possibilities where change can be made. Madison also argues that critical ethnography challenges us to “resist domestication,” “to penetrate the borders and break through the confines in defense of the voices and experience of subjects whose stories are restrained and out of reach” (2005, p. 5). As I will

discuss at length in the next chapter, women have been conditioned by the medical establishment to trust and accept medical authority without question – to be docile, compliant patients (Ehrenreich and English 2011). The experiences of those who actually live with the day-to-day realities of illness are too often excluded from the conversation in favor of objective clinical “fact.” Moreover, Hyden argues that “One of our most powerful forms for expressing suffering and experiences related to suffering is the narrative. Patients’ narratives give voice to suffering in a way that lies outside the domain of the biomedical voice” (1997, p. 49). By engaging in critical ethnography, by eliciting the stories of women with PCOS - stories of what it means to be a woman with PCOS – feminist scholars have the opportunity to begin to chip away at the bricks of the medical institution, to tunnel under its base and to unsettle that knowledge.

It is through interview that I hope to elicit and explore the stories of women living with PCOS. Interviewing in the traditional sense, however, is not considered a feminist practice. According to Oakley (1981), interviews have been structured in a hierarchical fashion whereby the superior position of the interviewer is a central component to the exchange. Feminist research interrogates and deconstructs this unequal balance of power and seeks to create a more egalitarian relationship between the research and the participant. The result is closer to an exchange of knowledge where a genuine dialogue between researcher and participant is produced, and the voice of the participant is actually privileged for our work would be for naught were it not for the thoughts, feelings, and emotions evoked and shared through the interview process (Devault 1990).

As a woman who is living with PCOS conducting research in conjunction with other women with PCOS, I recognize a degree of reflexivity brought to the exchange in which researcher and participants collaborate in a sense-making effort. To this end, I contend that interactive interviewing (Ellis, Kiesinger, and Tillmann-Healy 1997) has the potential to afford the feminist researcher an even greater level of critical engagement with their research by situating her within the context of the topic and actively contributing to the co-creation of the interview narrative. Interactive interviewing typically involves three or four individuals who enter into the conversation as both research and participant. In traditional interviews we are taught only to look with objective eyes outside of ourselves, but interactive interviewing fosters an environment in which the researcher not only is made aware of her own position in relation to the topic, but can confront it, grapple with it and examine it not only through her own lenses, but through the lenses of the participants joining her on this journey of exploration. This new awareness adds an additional and persuasive element to research, creating the potential for multi-layered meanings within ourselves to be opened up, interrogated and placed in context with the larger frame of inquiry. Ellis et al. (1997) go so far as to argue that that which the researcher brings to the exchange as a participant in the conversation is, in fact, equally as important as the contribution made by the other participants.

I also believe that interactive interviewing can, as Ellis et al. (1997) suggest, promote a sense of vulnerability and self-disclosure between

participants that traditional methodology cannot achieve. When considering the methodology of the interview in a broad sense, one can think of it as a conversation that is “on the record.” What one might disclose in a private conversation might be considerably different from what one is willing to share in the more public context of a formal interview. Such is the case with the interactive interview; however, participants in this process are not simply asked questions without answers first being offered by the researcher. The feminist researcher enters into the conversation with her own identity laid bare for the purview of not only those in which she engages in this dialogue, but for the larger community.

Another significant aspect of interactive interviewing revolves around the way it challenges the primacy of traditional interview techniques through its treatment of the knowledge that is produced through the conversation. Within the context of the interactive interview, analysis is not the sole domain of the researcher, and the three or four participants have the agency to offer their own ideas and perceptions. Knowledge is co-created so that no one voice is privileged over another. In essence, the interview and its resultant conversation becomes a discursive practice where the cultural means of PCOS are created and understood through the lenses of the participants.

Interactive interviewing lends a degree of empathy and solidarity to the work of the feminist researcher. Ellis reflects, “All these thoughts abound as I try to enter their worlds, become their bodies with their concerns. ...it means that I

am willing to consider that they are not so different from the rest of us” (1997, p. 138). Such words are reflective of the ability to foster relationships and understanding that interactive interviewing offers. Taking the many elements and advantages of interactive interviewing into consideration, I have elected to use this method for the interviews I have conducted within the framework of my research project. These interviews will be discussed at length in Chapter 5.

I would be remiss if I failed to give consideration to the ethical concerns generated by interactive interviewing. As Kirsch (2005) argues in her article, “Friendship, Friendliness, and Feminist Fieldwork:”

researchers who strive for the benefits of close, interactive relations with participants must accept the concomitant risks. These risks include the potential for relationships to end abruptly and for participants to feel that they have been misunderstood or betrayed, especially in moments when participants’ and researchers’ priorities diverge, as many times they will. (p. 2163)

In this respect, I believe that it is with a sense of heightened care and caution that the feminist research enters into interactive interviewing. Though we both open up and expose ourselves in the process, the utilization of this method, especially within the context of sensitive subjects, can be risky for those we involve. The potential for harm makes it clear that there is a greater level of ethical responsibility involved in interactive interviewing, yet I believe that when done with care, with active participant involvement where the writing of articles and publications are concerned, this method remains an excellent choice in the field of feminist research – one that can both cultivate our understanding of marginalized women and perhaps even begin to create a space where we can

nurture each other and begin to heal. The qualitative nature of some feminist research methods seeks to look at more than objective facts⁹ about a particular condition, but really to look beyond those bits of data and begin to “see” what it means to be an individual living with PCOS.

Another way we might begin to challenge dominant discourses is through the practice of content analysis. As Leavy argues, feminist content analysis provides a tool that allows us to “[unravel] the texts ... that become an integral component in how women and men are viewed” (2007, p. 234). This is especially true in medical texts that not only define what is “healthy” and “normal,” but in how these same works medicalize the bodies of women, making certain facets of their health seem as if intervention is required. In essence, these documents are not simply the reflection of societal expectations and ideals but actual factors in how these ideals and expectations are shaped (Reinharz 1992). Furthermore, it is vital that we pay careful attention to what is stated in these texts but also what is left out, missing or silenced (Reinharz 1992; Leavy 2007).

I will begin with a content analysis of two medical publications on PCOS: “Revised 2003 consensus on diagnostic criteria and long-term health risks related to polycystic ovary syndrome” published by The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group and the “American Association of Clinical Endocrinologists Position Statement on Metabolic and Cardiovascular Consequences of Polycystic Ovary Syndrome.”

⁹Harding (1987) argues that subjective research is actually *more* objective because it makes visible the reflexive relationship between the research and the subject of the research.

Specifically, I will consider the etiology of PCOS, the language used to describe the syndrome and suggested treatment modalities in each of these publications. I will also evaluate the two most popular books¹⁰ geared towards laypersons with PCOS. Again, I will consider the etiologies offered by the authors, as well as what kind of self-help suggestions they make for their audience.

Through the use of multiple methods and guided by principles of feminist methodology, I feel confident that I will be able to present a well-rounded and comprehensive view of what PCOS means for the women who are living with it. It is my hope that this approach will paint a rich and vivid picture that will help to inform those in the medical profession, as well as my “soul cysters”¹¹ who may find strength and empowerment in these words.

¹⁰ As rated by Amazon.com.

¹¹ This term was coined by Kathryn ‘Kat’ Carney who started the PCOS information web site, <http://www.soulcysters.com>.

Chapter Three: Feminist Theory Applied to Medical Discourse/Knowledge

The bulk of information and research on PCOS has been published by those in the medical field, especially those in the area of endocrinology. Little has been published on PCOS by feminist scholars who have the potential to offer new and valid perspectives on this condition. Feminist scholars have long been questioning why some voices are privileged over others – why some forms of knowledge are deemed important when others are silenced. I question why, when PCOS affects so many women, there is not more extensive literature on this condition from women - the women who actually live with it. Given this gap, it follows that a consideration of the production of knowledge must be undertaken.

Mendelsohn (1977) offers an elegantly simple theory on the social construction of scientific knowledge and, by extension, medical knowledge. He suggests that, because science is the product of human action and interaction, the knowledge developed through its practice is socially constructed knowledge. Human beings are social creatures, and feminist scholars have long stressed ideas of the myriad identities individuals occupy and by which they are influenced. Since doctors and other professionals in the domain of Western medicine are human, they, too, are subject to the influence of social forces. Medical knowledge is not self-created nor does it exist in a vacuum. This notion is a rather sharp deviation from what Mishler calls the “storybook image of

medicine,” which revolves around objectivity and neutrality, carefully walled off from the petty concerns of the subjective social world (1981, p. 16). This concept of medicine as objective science is played out in the practice of biomedicine, or Western medicine.

What makes the biomedical model unique is its conception of disease. Engel contends that biomedicine “assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness” (1977, p. 128). With that said, I believe that it is important to further explore the ways in which medical knowledge is constructed within the biomedical context.

The work of Michel Foucault is germinal to this area of investigation, specifically as it relates to what Foucault refers to as discourse. For Foucault, discourse focuses on the language and practices that provide the means for talking about and creating knowledge about a particular topic. Discourse influences and controls social practices, just as it is shaped and transformed by those same practices. Discourse, then, might be seen to be somewhat circular in nature: discourse organizes and controls the practice of societies, resulting in the further development and transformation of discourse. In *Power/Knowledge*, Foucault (1980) argues that

in a society such as ours, but basically in any society, there are manifold relations of power which permeate, characterise and constitute the social body, and these relations of power cannot themselves be established,

consolidated nor implemented without a certain economy of discourses of truth which operates through and on the basis of this association. We are subjected to the production of truth through power and we cannot exercise power except through the production of truth... Power never ceases its interrogation, its inquisition, its registration of truth: it institutionalises, professionalises and rewards its pursuit. (p. 93)

This leads one to question who, precisely, is endowed with the privilege of creating knowledge and, subsequently, Truth.

To this end, Foucault states, "‘Truth’ is centered on the form of scientific discourse and the institutions which produce it... it is produced and transmitted under the control, dominant if not exclusive, of a few great political and economic apparatuses (university, army, writing, media)... it is the issue of a whole political debate and social confrontation" (1980, pp. 131-132). Medical discourse, or knowledge, is created by an elite class of academician. It is deemed scientific knowledge generated by objective minds, privileging an epistemology grounded in positivism and disregarding the potential Truth stemming from those who fall outside those institutions.

The medical system in the United States has long been understood to be dominated by men and conventional masculine thinking, serving only to reinscribe patriarchy in the health care arena (Pringle 1998). Sherwin argues that those same institutions of dominance and oppression that have existed through history are also prevalent in the context of medical profession, such that race, sex, and socio-economic status are key factors in determining our position in the hierarchy (Sherwin 1992). The power of the medical establishment lies not

only in the production of knowledge, but in its political position (Freidson 1988). In the United States, biomedicine is so deeply entrenched that it permeates myriad aspects of our everyday existence, becoming a ubiquitous presence.

The medical institution exercises the power to influence and decide what is “healthy/unhealthy” and, more importantly, what is “normal.” Historically, disease and illness have been associated with social deviance (Turner and Samson 1995). This leaves women in a precarious situation, what Sherwin calls “multiple double binds,” when it comes to the norms under the domain of health and illness (1992, p. 179). The common experiences of women like menstruation, menopause, and pregnancy are pathologized and subject to medical intervention and management. She further goes on to argue that this predicament situates women’s bodies as especially vulnerable to medicalization because that which is female is inherently unhealthy and in need of supervision by a patriarchal health care system. Moreover, this authority – this appropriation of truth – has become so institutionalized – so seemingly “natural” – that women often fall into the trap of accepting it without question. By remaining uninformed, save for the knowledge imparted to patients by trusted physicians, patients are trained to remain in the role of layperson. As Berger and Luckman point out, “an entire legitimating machinery is at work so that lay[persons] will remain lay[persons], and doctors doctors, and (if at all possible) that both will do so happily” (1967, p. 88). Women are conditioned to be the compliant patient who listens attentively to the advice of our doctors and subsequently follows this advice without question or deviation.

Thus, it is important to look at just what the “experts” on PCOS are saying. Specifically, I am reviewing the “Revised 2003 consensus on diagnostic criteria and long-term health risks related to polycystic ovary syndrome¹²” (R Azziz et al. 2004) and “The Androgen Excess and PCOS Society criteria for the polycystic ovary syndrome: the complete task force report¹³” (R Azziz et al., 2009). Both articles were published in *Fertility and Sterility*¹⁴, which further frames PCOS as a primarily reproductive disorder. Additionally, I have selected two mainstream books geared towards women with PCOS: *PCOS, The Hidden Epidemic* (Thatcher 2000) and *A Patient’s Guide to PCOS* (Futterweit 2006).

In spite of the extensive medical research and technology available today, there seems to be some disagreement within the medical community when it comes to defining just what constitutes PCOS. All of these sources clearly state that a single test to positively diagnose PCOS does not exist. A doctor cannot order a blood test or perform genetic analysis to determine whether or not a woman can be definitively classified as having PCOS. Instead, we are left with speculation as to just what signs and symptoms constitute PCOS. In his book *PCOS: The Hidden Epidemic*, Thatcher goes so far as to quip, “PCOS is like the classic story of a number of blind men, each able to touch just one part, trying to describe what an elephant must look like” (2000, p. 11). Ironically enough, the Androgen Excess and PCOS Society article includes a quote from Sir Thomas

¹² Moving forward, this article will be referred to as the Rotterdam Criteria.

¹³ Moving forward, this article will be referred to as the AEPS Criteria.

¹⁴ According to their web site, <http://www.fertstert.org/>, *Fertility and Sterility* is “an international journal for obstetricians, gynecologists, reproductive endocrinologists, urologists, basic scientists and others who treat and investigate problems of infertility and human reproductive disorders.”

Lewis which suggests, “Diagnosis is a system of more or less guessing” (1944). This is quite the departure from the infallible institution that medicine is sometimes seen as. One would hardly expect the professional to whom one trusts their health to have to rely on something as mundane as guessing, yet it seems that is just the case.

When it comes to positing the underlying cause or etiology of PCOS, the Rotterdam Criteria suggests that “PCOS is a syndrome of ovarian dysfunction” (R Azziz et al., 2004, p. 19). This is yet another example of that which is female being constructed as deviant and abnormal. Of the three hypotheses suggested by American Association of Clinical Endocrinologists (Cobin et al. 2005) and presented in Chapter 1, only one suggests that the underlying cause of the syndrome might be related to ovarian (dys)function. I must question, then, how the Rotterdam Criteria arrives at the conclusion that the ovaries are to blame for this malady. The AEPS Criteria, on the other hand, takes a more neutral stance, suggesting that “PCOS should first be considered a disorder of androgen excess or hyperandrogenism” . Still, there is not a clear emphasis on the fact that there remains a lack of certainty where the cause of PCOS is concerned.

Futterweit’s book embraces the uncertainty more openly, and he indicates that there may be more than one cause. Both Futterweit and Thatcher propose causes similar to those discussed by American Association of Clinical Endocrinologists (2005), but Futterweit adds the possibility that there may be a genetic link. My major contention with Futterweit’s list of causes comes in his

characterization of testosterone as a “male hormone” (2006, pp. 10-11). Both male and female humans produce the androgen, testosterone, and while males may have testosterone in greater concentrations that are generally found in females, I find its designation as a “male hormone” to be problematic. I wish I could say that this error was an isolated incident, but the most recent edition of the acclaimed feminist work *Our Bodies, Ourselves* (Boston Women’s Health Collective 2005) makes the same mistake. Perhaps it is because Western culture seems to associate testosterone with virility and strength that it is called a male hormone, but telling a female that her body is producing an excess of male hormones is potentially unsettling and incorrect.

As previously mentioned, PCOS is comprised of multiple symptoms which may or may not be presented in a female being considered for a PCOS diagnosis. Each of these articles suggests a specific set of diagnostic criteria that would support a diagnosis of PCOS. The Rotterdam Criteria specifies that two out of three of the following indicates PCOS: “1. Oligo- or anovulation, 2. Clinical and/or biochemical signs of hyperandrogenism, 3. Polycystic ovaries” (R Azziz et al. 2004). At first glance one might believe that this is relatively clear; however, the article goes on to point out that these criteria are problematic. For instance, with regard to clinical hyperandrogenism, the authors note that assessing the signs of hyperandrogenism in clinical presentation (hirsutism) is “relatively subjective” and that “Normative data in large populations are still lacking” (2004, p. 20). The result is that the evaluation for PCOS in a clinical setting is placed in the hands of individual physicians who must make

determinations on criteria that is vague at best. The outlook is similarly murky when it comes to biochemical measurements of androgens obtained through bloodwork. To this end, the authors note that, not only is there a wide range of variability within the general population, but that “Normative ranges have not been well-established using well-characterized control populations” (2004, p. 21).

The AEPS Criteria relies on similar factors. The authors in this case suggest that all of the following must be present for a diagnosis of PCOS: Hyperandrogenism presenting as hirsutism or elevated levels of androgens in blood work; Ovarian dysfunction presenting as oligo- or anovulation and/or the presence of polycystic ovaries; and the exclusion of other androgen disorders (Ricardo Azziz et al. 2009). If there has not been sufficient research with corresponding evidence to suggest just what these “normative ranges” are, the criteria being suggested becomes increasingly challenging, not only for the practitioner in the clinical setting but for the patient who must rely on their practitioner for diagnosis and treatment.

Obesity is another topic prevalent in the medical literature and mentioned in both these articles, specifically as to its correlation with PCOS. The AEPS article suggests that roughly half of the females diagnosed with PCOS are considered to be obese, though obesity is more prevalent in the United States due to what they call “the larger obesity epidemic” (Azziz et al., 2009). One need

only turn on the television to be immersed in the rhetoric that is the “war on fat.”¹⁵ Perhaps it should come as no surprise, then, that Western medicine is intimately involved in this battle. The AEPS article references a large study conducted in the United States where the average body mass index or BMI ranged from 35 to 38. Thatcher takes a similar stance on obesity, referencing the BMI chart again and listing what he perceives are the medical consequences of being obese. According to the Centers for Disease Control, a BMI of 30 and over is considered obese¹⁶. In spite of all the press regarding obesity, there are those who challenge the idea that BMI is a valid indicator of health in and of itself. Burgard points out that “about 9% of the outcome of whether someone has a health problem or not is somehow related to BMI” as opposed to the remaining 91% associated with other factors not related to weight (2009, p. 43). Campos, Saguy, Ernsberger, Olver, and Gaesser (2006) suggest that obesity is less a public health crisis and more an indicator of negative social perceptions and political platform. To Futterweit’s credit, he focuses less on using scare tactics to encourage his readers to lower their BMI and more on developing healthy lifestyles that include eating a balanced diet and incorporating physical activity.

While weight may be a factor in PCOS, it also becomes a hurdle to jump in terms of diagnosis. According to Ratcliff, “A doctor’s power also means that any prejudices he has, whatever lack of empathy he may have for particular kinds of people, may be consequential for his patients” (2002, p. 35). The

¹⁵ Ironically, this “war” started around the same time ads to super-size your next fast food meals became popular (Spurlock 2004).

¹⁶ http://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/index.html

prevalent attitudes about overweight individuals in America seem to blind some doctors who seem more interested in blaming patients for some failing than in making the effort to see beyond their own preconceptions. It is much easier, apparently, to find the cause of excess weight within the (lack of) control of the patient than to attribute it to a chronic health condition. Carrying around extra weight is perceived as slothful or as having some moral failing, as if an overweight woman simply lacks the drive and motivation to improve herself and conform to those unspoken standards (Bordo 2003; R. Puhl and Brownell 2001). Accounts of doctors dismissing women with orders to “just lose some weight” are not at all uncommon when it comes to PCOS and may play a significant role in the delay of diagnosis and treatment. In fact, Cecchine estimates in her documentary, *Scrambled*, that a woman will see 4.5 doctors before being successfully diagnosed with PCOS (2003). Clearly, there is some bias in medicine that calls that vaunted objectivity into question.

This critique calls for consumers of Western medicine in general, and women in particular, to engage a greater level of scrutiny when faced with the information being dispensed by medical providers. While biomedicine is touted as a “pure science” ruled by objective data, one should not dismiss the very real fact that medical practitioners are still human beings, subject to the influences of society, culture, and institutions of which they are a part. One cannot simply compartmentalize off those parts of themselves, even in the name of medicine. Moreover, being human means that we are not infallible, nor is the knowledge we create above questioning and interrogation.

Chapter Four: Feminist Theory Applied to the Bodies of Women with PCOS

If, as previously mentioned, women's bodies are subject to increased levels of discipline, I argue that the bodies affected by PCOS are held to an even higher level of discipline still. As many women with PCOS will testify, the disease has the potential to put a woman at odds not only with her own body, but with a society which values and demands that women conform to standards many of us do not embody. We fight a near constant battle, within and without, to present an outward appearance that is congruent with societal expectations of femininity. In particular, the PCOS-related symptoms of hirsutism, excess weight, and infertility are fertile ground for grounds for analysis and interrogation through the lens of feminist theory.

The Female Body and Social Control

Central to this discussion is the notion of the body as “a *practical*, direct locus of social control” (Bordo, 2003, p. 165). Our bodies are not simply the end result of the reproductive process. Culture and society heavily influence the way we shape and present ourselves to the larger world. The feminine ideal, though not explicitly defined, surrounds women and men alike in mainstream American culture through advertisements, television shows, and movies. Bartky suggests that the current ideal feminine body is “taut, small-breasted, narrow-hipped, and

of a slimness bordering on emaciation” (1990, p. 66). Her face is smooth and Photoshop flawless, free of wrinkles, visible pores, and unsightly hair (Jhally 2010; Newsom and Scully 2011).

The artifice of femininity that many women so carefully construct is not the least bit natural or inherent (Bartky 1990). It is not somehow endemic to the possession of female genitalia or XX chromosomes, rather it is something that must be meticulously constructed, maintained and modified to suit the whims and demands of a culture that is ever-present, even when we are alone. PCOS and its concomitant symptoms make it especially difficult for women to attain acceptable displays of femininity.

Hairy Women

It is generally accepted within the realm of the social sciences that sex and gender are independent of each other. “Sex” (male/female) is a biological category¹⁷, while “gender” (man/woman) is socially constructed (Nicholson 1994). In “Doing Gender,” West and Zimmerman offer a third distinction: sex category. They explain that “placement in a *sex category* is achieved through the application of the sex criteria, but in everyday life, categorization is established and sustained by the socially required identificatory displays that proclaim one’s membership in one or the other category” (West & Zimmerman, 1987, p. 127).

The medical establishment, as well as the larger society, generally are not

¹⁷ Feminist scholars such as Anne Fausto-Sterling (2000), Judith Lorber (2010) and Ruth Bleier (1984) have critiqued this notion of “sex” as biology.

accepting of signifiers outside male/female or man/woman. As a society, we are so tightly bound up in dualistic dichotomies that when faced with an uncertainty, an uncomfortable air settles over us until such time as we can make a clear determination as to which sex category an individual fits into. The symptoms of PCOS, specifically hirsutism, can create a sense of dissonance in the application of sex category.

Elevated levels of testosterone associated with PCOS cause excess hair growth in places that females typically do not have coarse hair: chin, face, neck and abdomen. Bartky argues that “a woman’s skin must be soft, supple, *hairless*, and smooth” (1990, p. 31, my emphasis). Consequently, were an observer to see an individual with a full beard or even a 5 o’clock shadow in the absence of other clear signifiers of gender, it would not be surprising for that individual to be placed into the “male” sex category. Fisanick queers the idea of the PCOS woman by suggesting that women with the condition are “both male (excess testosterone) and female (genitalia)” (2009, p. 107).¹⁸ While such a notion challenges the narrow binary that dominates Western thought, it does very little to relieve the burden that feminine ideals place on a woman with PCOS.

It is, perhaps, this fear of being perceived as not feminine that proves so distressing for women living with PCOS. Even with medication to help “correct” hormonal imbalances, many women with PCOS still suffer the stigma associated with what is considered unsightly facial hair. We pluck, we wax, and those of us

¹⁸ As discussed in Chapter 2, testosterone, an androgen which plays a significant role in secondary sex characteristics such as facial hair, is widely considered to be a male hormone.

who can afford it may resort to the unpleasant and costly option of electrolysis or laser hair removal. I have become both inmate and prison guard (Foucault 1991), constantly aware and watchful of those dark little hairs that sprout from my chin. Sitting in the car at stoplights, I will take advantage of the sunlight and the concealment of tinted windows to examine my face more closely in the mirror. The thought of anyone seeing those little hairs is unnerving to me, no matter how much I tell myself that I am comfortable in my own skin. Being ample in size is something I can handle, but the thought of being perceived as a hairy woman is a possibility I, too, prefer not to face. Drawing from Foucault's discussion of Bentham's Panopticon, Bartky offers, "This 'state of conscious and permanent visibility' is a sign that the tight, disciplinary control of the body has gotten a hold on the mind as well" (1990, p. 65).

Returning to Foucauldian notions of discourse, women with PCOS subject their bodies to the practices which dictate "proper" displays of femininity – displays which clearly do not include visible facial hair. In essence, the bodies of women are subject to a higher level of discipline and conformity (Bartky 1990; Crawley, Foley, and Shehan 2008). The influence of patriarchal power, then, is insidious and subtle. Even when we find ourselves in solitude, shielded from the ever watchful gaze, we conduct ourselves as if we are constantly on display, dutifully carrying out a carefully scripted performance. The work required is seemingly endless, and the effect is what Foucault (1991) refers to as the docile body – bodies whose energies have been harnessed towards the amelioration of that which is external as subject to public scrutiny (Bordo 2003).

Large Bodies

As discussed in the previous chapter, women with PCOS may face issues in their relationships with health professionals when it comes to their weight. The notion that large-bodied females are socially unacceptable goes beyond the level of the medical institution, however. An integral part of mainstream American culture's feminine ideal revolves around a body that is slender and small, taking up as little space as possible. Surplus flesh is considered undesirable, and the obese are acceptable targets for discrimination (R. Puhl and Brownell 2001).¹⁹ While not all women with PCOS experience challenges with their weight, it is a fairly common experience with roughly 50-80% of PCOS women considered obese (Thatcher 2000).

The ample body is seen as a lack of control (Bartky 1990; Bordo 2003), but sometimes even an iron will is not enough to allow a woman with PCOS to overcome her struggle with weight. While some may assume that simply consuming fewer calories and exercising regularly are adequate to produce effective weight loss, the same is not true for women with PCOS. The cause for obesity in women with PCOS is not clear, but it is believed that there is a correlation between obesity and insulin resistance (Thatcher 2000). The result is that many women with PCOS find that weight goes on very easily but is difficult to lose. A lifestyle that consists of a reasonable caloric intake and moderate

¹⁹ In March 2012, Disney came under fire for their "Habit Heroes" exhibit at Epcot. The exhibit portrayed large-bodied villains such as "Lead Bottom" and "Snacker," kept in check by heroes "Will Power" and "Callie Stentics" (Ryan 2012).

exercise may not necessarily positively impact the weight of a woman with PCOS, even though such a regimen may benefit her overall health.

The focus, then, is less on whether such a physical state is “healthy” or not, but on the notion that this body falls outside what is deemed acceptable in terms of normative ideals of femininity. Brown argues that “a fat woman by her presence violates primal norms of misogynist society that deny nurturance, space, power, and visibility to woman” (1985, p. 65). The consequence of this deviance is that many women with PCOS are made to somehow feel less because they are “more.” The ample-bodied are relegated to invisibility and ultimately devalued. They frequently suffer from poor body image and depression (Himelein and Thatcher 2006; Sigrid Elsenbruch et al. 2006).

Such rules that demean and devalue seem to make little sense until one questions who benefits from devaluing women. Again, we are back to the subtle but ever-present notion of patriarchy. In holding women to often unattainable ideals of what they should be, women are denied power, visibility, and voice.

Scrambled Eggs

Another issue for many women with PCOS pertains to fertility or the lack thereof. Notions of femininity and what defines us as women are frequently bound up in conceptions of motherhood. From a biological perspective, a woman fulfills her physiological potential in motherhood (De Beauvoir 1964).

Each semester when I query my students²⁰ about the qualities they associate with the “ideal woman” they often respond with “mother,” and “nurturer.” In fact, it is as if we define woman by these traits – it is both a role and an expectation. Failure to assume this mantle is deemed behavior unbecoming for a woman and is met with scrutiny and derision (Morell 1994). The inability to conceive or to become a mother, then, is a considerable concern for women with PCOS who may find themselves in this situation because of their condition.

Some years ago I was under the care of an OB/GYN who would remind me at my annual visit that the clock was ticking for me, then follow that sage bit of advice with a query as to whether I had any “good irons in the fire.” Each time, I would respond, “Not yet.” I simply had no desire to have a child at the time and indicated as such. In all honesty, fertility has not been something that worried me or caused me any considerable amount of distress, but then I realize that I am not every woman. You cannot simply lump every female with PCOS into a singular group because we are, in reality, quite disparate.

While I was only too happy to use my PCOS as a “get out of jail free card” every time I was asked why I did not wish to have children, I have read too many accounts and listened to the stories of women who agonized over the possibility that they would never become pregnant and bear their own child. For those who feel the desire or the compulsion to have children, infertility treatments offer some hope, but also a greater degree of medicalization and intervention. Moreover,

²⁰ I am a graduate teaching associate and instructor of record for WST 2600: Human Sexual Behavior.

reproductive technologies themselves are fraught with challenges and complications (Fathalla 2002). These therapies can serve as further reminder that a PCOS woman is somehow less than a “real woman” who does not require medical technology to attain the much-desired state of motherhood.

Each of these issues, I believe, is a matter of continuing to deconstruct and broaden our definition of what it means to be a woman. Feminist scholars and laypeople alike must be able to pull apart, to interrogate, to expose and reveal how much of what we believe to be so concrete is no more than arbitrary constructs that have value and meaning only because we participate in a society that creates the conditions for them.

Like most women in mainstream Western culture, women with PCOS are held accountable (West and Zimmerman 1987) to these unrealistic standards of femininity, and for the failure to adequately meet the appraising expectations of the critical eyes around us, we are scorned or relegated to a status of invisibility. Unfortunately, for a woman living with PCOS, all the effort and control in the world is sometimes not enough to transform her body into something acceptable in terms of the prevailing discourse.

While such examples provide clear evidence of the discursive control exerted over the bodies of women, one cannot help but question the logic behind such narrow conceptions of “woman.” In the essay “Believing is Seeing: Biology as Ideology,” Lorber argues that the experiences of *some* women, such as menstruation, pregnancy, etc., do not create a clear demarcation between males

and females in terms of sex and gender because these experiences are not constant. Females are not always menstruating or always pregnant, nor do all women possess uteruses, ovaries and breasts. The article “How Sexually Dimorphic Are We?” (Hull and Fausto-Sterling 2000) delves further into this line of thinking and calls into question just how rigid the lines between “female” and “male” really are. The authors suggest that strict sexual dimorphism is overly narrow and rigid, proposing instead that we instead consider the extensive variation in populations of females and males.

Considering this wide potential for variation, it seems to make little logical sense that mainstream Western society expects individuals willingly to conform or strive to conform to unrealistic ideals. Nonetheless, these ideals are surprisingly concrete where their potential to interfere with our ability to receive proper medical attention is concerned. Indeed, one must ask if there is such a thing as “woman²¹.” Wittig suggests that “not only is there no natural group ‘women’, but as individuals as well we question ‘woman’” (1997, p. 266). While Wittig is referring to lesbians when she uses the pronoun “we,” I suggest that those of us with PCOS find ourselves similarly questioning this monolithic concept of woman.

²¹ Or man, for that matter.

Chapter 5: The Lived Experiences of Women with PCOS

As I have discussed in prior chapters, the voices of women living with PCOS have been largely excluded from the discourse surrounding this condition. Because one of the goals of feminist research focuses on creating a space for voices that have been traditionally silenced, I believe that it is vital to include not only my own story but that of other women who are also living with PCOS.

The process of working with the university's institutional review board (IRB) proved to be an interesting experience, specifically as it relates to my critique of the way that the medical institution defines who or what is "healthy." Part of the IRB application requires the researcher to describe the population from which they will be recruiting. The options range from "normal health adult subjects," to children, prisoners, "socially disadvantaged persons," and finally "other adult subjects." Those of us in the social sciences tend to be aware of labels, especially when they pertain to our areas of research. Consequently, the selection of a single description became something of a task in and of itself. My initial thought was to select "other adult subjects" as my research does involve a condition that is medicalized. At the same rate, being a woman with PCOS I resented the notion of being categorized as another but a normal healthy adult.

In the end, I selected normal healthy adults and found a measure of satisfaction when my study was approved with that descriptor.

After I was approved to begin collecting data for my research. I made posts to three online communities²² focused on PCOS and run by women with PCOS. In each case, I contacted the moderator/owner of the community and requested permission to post the wording that had been approved by the IRB. Considering the level of activity on each of these communities and the large number of members, I felt positive that I would not encounter a large amount of difficulty in finding at least four to six women who would be interested in contributing their own stories to my research. I was further bolstered in my hopes of finding other women with PCOS when, after only a few hours, I had my first contact. I immediately replied to her e-mail with more information about my research and what I hoped to achieve, providing her a copy of the informed consent agreement and the interview guide. She replied the next day indicating that she had read over the information and was still interested in participating.

Unfortunately, another two weeks would pass without further contact from additional participants. I made a second post to each of the communities, identical to the first. This time, other members of the online communities responded to my post indicating their desire to help, but they were not local to Tampa Bay. I felt it vital to have at least a few stories included in my research, so

²² The communities were: <https://www.facebook.com/groups/PCOSers/>, <https://www.facebook.com/groups/55155893970/>, and <http://pcos.livejournal.com/>.

I went back to the IRB and filed an amendment to allow me to conduct interviews through the online service Skype, in addition to ones done face-to-face.

Once that amendment was approved, I contacted the women who had expressed interest, again hopeful that I would be able to garner the number of participants that I had anticipated. Again, I provided additional information about the research, as well as the informed consent agreement and the interview guide. I explained that, if these individuals were still interested in contributing to my research, that I could arrange to speak with them over Skype. Of the four women that I contacted, three responded. Only one, however, actually participated in my research, as they were not familiar with Skype or did not have the necessary computer hardware that would enable them to do so.

I did receive one additional contact from another local woman in response to my second post, and, after sending her the necessary information, I was finally able to schedule the interactive interview that I had planned for.

Based on the availability of my three participants, I conducted the online interview via Skype first. I was able to find a piece of software that would enable me to record our conversation as was originally planned in the study. Despite a few scheduling issues, I was finally able to speak with Nicole²³, a 27 year-old white married female.

While this was the first time Nicole and I verbally communicated with each other, there seemed to be little hesitation about opening up and talking about our

²³ Actual names have been replaced with pseudonyms to protect the privacy of the participants.

experiences with PCOS. After going over the informed consent process with her, Nicole described to me that, around age 16, her periods began to be more infrequent but lasting up to a month when she finally did have one. Her OB/GYN suggested that this was simply a result of her age and that, as an active and healthy young woman, her periods would become more regular as time went on. Two years later, she was placed on oral contraceptives to help regulate her period. In retrospect, she felt as if her doctor did not take her concerns seriously. Nicole's story is actually quite similar to my own, and I shared my experiences with her.

As mentioned, menstruation is one aspect of female experience that has come under the scrutiny of the medical profession. According to Worcester and Whatley, "The normal physiological process of menstruation has been defined and redefined by male 'experts' throughout history. It has been labeled a disability or illness, as a barrier to higher education for women, as a weakness that justified keeping middle-class women from working outside the home" (2004, 193). Contemporary medical ideologies heavily influenced by positivistic notions have seemingly come to terms with menstruation, tacitly accepting it as the biological process it is.

This acceptance, however, comes at a price, though, for those of us who fail to conform in one way or another to the "normal" menstrual cycle. Amenorrhea is the medical term for the lack of a "regular" menstrual cycle. For many women with PCOS, myself included, the lack of a period is what initially

prompts us to seek out medical advice. The first indication that something “wasn’t right” with my body came when I was in high school. My mother noticed that I was not getting periods as I was not asking for tampons or the like. In 1991, I was 15 years old and a student at an all-girls Catholic school in Chicago. Sex education in the form of health classes had made me aware that a “normal” woman got her period each month. It is difficult to recall my exact thoughts on my deviation from that expected pattern, but I don’t remember being particularly disturbed or worried about it. I was, I think, thankful not to have to go through experience of cramps and the accompanying messiness that I associated with having a regular period. Moreover, I was not heterosexually active and had no immediate plans of becoming so. As such, the lack of a period was not cause for me to worry about pregnancy.

It was not at all unusual for me to go anywhere between six and nine months without a period. When my periods did come, they were painful and filled with cramps. They tended to last more than seven days, during which I bled heavily. Consequently, I was quite content that they not come at all. My mother, on the other hand, did not agree. She made an appointment for me to see a gynecologist for my first pelvic examination. I imagine that I was not unlike many young women who were nervous about such an examination and the resulting vulnerability in one’s body being so exposed, and I was not looking forward to the regular return of my period. Based on the exam, the doctor assured my mother and me that there were no anatomical abnormalities. She prescribed Provera, a synthetic drug which mimics the hormone progesterone, to jump start my

menstrual cycle, then oral contraceptives to force them back into what she believed was a regular, predictable pattern. There was no blood work done, and the gynecologist did not express an indication as to what she believed was causing the amenorrhea. We simply followed the instructions as given, trusting that the doctor knew what was best for me. My periods returned as expected, and I, like many other women in similar positions, believed that everything was as it should be for no other reason than my doctor told me so. I did not delve further into the issue. At the time, I do not think the thought occurred to me to do so. High school health classes, even in an all-girls Catholic high school simply did not give me the tools that I needed to be an advocate for my own health. It seemed that, at the time, the goal was simply to simulate a “normal” period and be done with it.

In the fall of 1992, I began college in Florida and moved away from my home in Chicago. I continued taking the pill, relying on the health center on campus for my medical needs. For the most part, my periods remained regular, save for a few occurrences where it would disappear for a month, only to return again the following month. By that time, I had become heterosexually active, and suddenly missed periods became much more of a concern. I saw my original gynecologist back in Chicago on my first holiday break from college, and I remember how incredibly nervous I was about having missed my period for fear of being pregnant. A home test had come back neither positive nor negative, and I think that only raised my level of anxiety. The test performed at the gynecologist’s office confirmed that I was not pregnant, and the doctor assured

me that it was not abnormal to skip periods during times of stress. I was relieved, counted myself lucky and let the matter drop.

From time to time, I would still skip periods even while taking the pill, only instead of missing it for only a month at a time, I was now missing between two and three months in a row. As I was living with my male partner at the time and going to school, the possibility of pregnancy was still cause for anxiety. The prevailing discourse regarding “regularly occurring” menstruation creates a fear that a deviation from this schedule could well mean that one might indeed be pregnant. I saw the doctor at the university’s health center, confirmed once again that I was not pregnant and was told that I should begin getting the Depo-Provera shot to avoid pregnancy. I was not provided with any detailed information about this form of contraception, save that it was administered by a health professional every three months. Possible side effects were never discussed, and I trusted that it was safe and went ahead with the shot, deciding that it was worth it not to have to keep worrying. Again, the recommendation by the physician at the health center was not made in conjunction with any diagnostic tests that might explain the more frequent missing periods. In retrospect, I imagine that the medical staff at the student health clinic just grouped me along with the thousands of other young women at the university who were afraid of becoming pregnant, deciding to prescribe a solution that would, at least in their eyes, assure that I was not skipping pills or show up with another scare. It seemed very much as if their aim was to find the quickest and

easiest method of dealing with my issues, without being concerned with the whole picture.

I came to regret taking the Depo-Provera shots. Even though I felt less anxious about becoming pregnant, I was gaining more weight and began to lose all interest in sex. I did not consciously associate the onset of these symptoms with the shots for some months after the fact. By then, we had moved back to Tampa, and I was without health insurance. I had been given a dose of Depo-Provera to take with me by the university's health center, but I would need a doctor's office to administer it for me. My aunt lived in Tampa, so I took her recommendation and went to see her gynecologist. I detailed my history for him, as I had done with each previous doctor, noting the absence of my periods and my lifelong struggle with my weight. Perhaps it was a result of the gains I experienced as a result of the Depo-Provera, but I had become more and more self-conscious about my weight. My cousin, who also was struggling with her weight, had mentioned to me that her doctor gave her a prescription for the popular drug combination Fen-Phen. I mentioned this to the doctor, but he quickly dismissed me, suggesting that what I needed was diet and exercise. I was given my last injection of Depo-Provera and sent on my way without any further information or guidance. I was frustrated and disappointed, but I felt relatively powerless to do anything about it.

Without health insurance through my mother or access to a school health center, I was unable to afford more shots or oral contraceptives, and so I fell back

into the cycle of irregular periods. It was approximately one year before I had insurance again through my employer. This time I got another recommendation from a co-worker about a gynecologist, certain that I was not going back to my aunt's after having been treated with so little respect. I requested my records from the first doctor whom I had seen more than a year ago, and in doing so, became familiar with the term polycystic ovarian syndrome for the first time. Despite the fact that it was clearly written in the doctor's notes, he never once mentioned it to me. I distinctly recall being very upset that this information had been withheld from me and frightened because I did not know what it was that I was dealing with. I had put my trust in this doctor with the expectation that I would be made aware of information regarding my health, so the fact that the impressions about the cause of my irregular periods were kept from me felt like a serious betrayal. This was, after all, my body that we were talking about. Did I not have the right to know things pertaining to my body? Did this gynecologist feel that I was not competent enough to understand the diagnosis? Would this diagnosis mean that something was horribly wrong with me or prevent me from having children in the future if I so desired? There were too many unanswered questions, and that, perhaps was most disconcerting of all.

It is said that anger can be useful. It was in my case. I did not feel there was much I could do in regard to the doctor's failure to be forthcoming about my health with more than a year having passed. I was, however, determined that such a thing not happen to me again. In making that decision to become more aggressive about information pertaining to my health, I feel that I gained some

sense of control over my own body. For the first time, I had a name that I could assign to what I was going through, and like Nicole, that brought a sense of relief. It is somehow easier to face a challenge when you can call it something. We may not understand the full extent of that thing, but we at least have the opportunity to begin to work through it, to explore it and eventually come to a point in which we can deal with it comfortably. In becoming familiar with the challenges I faced, I felt that I could move past the fear that was the unknown.

As my discussion with Nicole continued, she explained that being on oral contraceptives masked some of the symptoms associated with PCOS. When she and her husband decided that they wanted to try to conceive, she ceased taking contraceptives and the symptoms of PCOS, including weight gain, hirsutism, skin tags and, most concerning, anovulation, began to appear. Her frustration with her OB/GYN and general practitioner led Nicole to begin doing research on her own and felt convinced that, based on the symptoms she was experiencing, she had PCOS. She finally managed to persuade her OB/GYN to screen her for PCOS through bloodwork and a pelvic ultrasound. Her feeling that she had PCOS turned out to be correct, and she was referred to a reproductive endocrinologist for follow-up and additional testing. Nicole describes her reaction to the diagnosis as one of relief as she had suspected she had PCOS for some time and was anxious to find a cause for her ovulatory issues. While she describes feeling more weary of doctors for not taking her concerns more seriously, she continued treatment with the hopes of conceiving. Frustration with

medical professions, however, does appear to be yet another common theme in the experiences of women with PCOS.

At this point, I want to segue into my second interview, though I will return to Nicole as I move through this discussion. As I mentioned in Chapter 2, interactive interviewing was one research method that appealed to me as a feminist researcher specifically because it was a more conversational way of eliciting information about women's lived experiences of PCOS. With two local women willing to speak to me and each other about their experiences with PCOS, I was fortunate enough to be able to make use of this particular method.

My interview with Eliza and Eve²⁴ took place in a library meeting room which afforded us the opportunity to talk privately and without distraction. After setting up the necessary recording equipment, I went over the informed consent process with Eliza and Eve and delved into our discussion. Eliza is a 38-year-old white married female, and Eve is a 26-year-old white female with a long-term partner. While they come from different backgrounds, a common concern about rapid, unexplained weight gain was one of the major factors that caused them to seek out medical attention, though Eve was in her teens when she did, and Eliza had only done so in the last couple years. Eliza characterized her motivation for seeking out medical attention as a need to find out "what is wrong with my body." The topic of weight, both excess and the fight to lose it, emerged as one of the major themes of our conversation.

²⁴ Again, pseudonyms are used to protect the privacy of the participants.

There is an overwhelming stigma in mainstream Western culture associated with being “fat” or “overweight,” such that eating disorders, diet fads and “get-slim-quick” schemes run rampant, unchecked and unquestioned by mainstream American culture (R. Puhl and Brownell 2001; Brown 1985). The ample body is perceived as distasteful (Bartky 1990), slothful, and showing a distinct lack of control (Walden 1985). Those of us who fail to meet those standards are the objects of ridicule or, worse, reduced to invisibility. As outrageous as it seems to hurl insults to people we encounter, it is socially acceptable to cast such dispersions on those who are deemed fat (R. M. Puhl and Brownell 2006). Both Eve and Eliza shared accounts of how they have been ridiculed about their weight by strangers who knew nothing about them, why their bodies were more ample or what impact unsolicited comments might have. For Eve, who relies primarily on public transportation, being out and about means opening herself up to the ridicule of passers-by who make animal noises or other unsolicited rude remarks. For Eliza who is an active woman who has competed in events, she has found herself the object of criticism from thinner individuals who tout “people like her” as the reason why they exercise.

It was a trend of rapid weight gain that eventually drove Eliza to seek out the attention of her doctor approximately 3 years ago. Though she had been gaining weight around her middle section and had periods only once or twice a year, she related that she “kind of ignored it all. Then I got married and thought about having children.” Her weight was something she felt that she was “too heavy to have children.” It was at that point she was diagnosed with PCOS.

Eliza's experience is an excellent example of just how intense the struggle is for a woman with PCOS. Prior to her diagnosis, she took part in a study examining the relationship between exercise and obesity. As part of the study, participants had to agree to work out at least four times per month. Eliza worked out six days a *week* and managed to reduce her weight by only twenty pounds over the course of eight months, all the while eating a well-balanced diet. "It was so frustrating..." she relates.

I, too, have been stung by the comments of people who feel compelled to judge me based on how they perceive my body. I told Eve and Eliza how, two semesters ago, two separate students in two different sections of the class I teach as a graduate teaching associate made comments about my size: "... her necks scare me the way they engulf her necklaces," remarks one student. Another says, "I can't find her neck." My partners in conversation seemed to understand too well how painful an experience it can be to find yourself under the scrutiny of a stranger. I shared with them a quote that I had read from a body-positive blogger whose work I admire. Ragen Chastain wrote, "My fat body is not a message to you that I am somehow incapable of taking care of myself. The only thing that you can tell from looking at my body is what size I am, and what your prejudices and stereotypes about my size are." I have found some solace in her words and even a degree of empowerment, but while we can learn to love, respect and value our own bodies, the society to which we are deeply embedded continues to preach a message that no matter how intelligent, accomplished, talented or gifted we are, we are still *inherently less*.

At least among the women I had the privilege of speaking with, we can and do take care of ourselves. We are vigilant in seeking out health care, and mindful of the way we nourish and treat our bodies. It seems, however, that doing so simply is not enough. Each of us talked about the struggles we have had with our body weight, the measures we have taken to exert some control over the size of our bodies, and the inevitable feeling of frustration when no amount of exercise or careful calorie monitoring makes a considerable difference in the numbers that stare accusingly back at you from the scale. Even our physicians, some of them who are knowledgeable about PCOS, continue to press the issue of weight loss. Those who are less informed about the difficulties women with PCOS have with weight loss have difficulties seeing past a body mass index (BMI) that categorizes us as “obese” or even “morbidly obese.” Consequently, each of the women I spoke with, as well as myself, has been told that her condition would improve if only she could control herself enough to lose weight. Eliza mentioned one doctor she had seen who said, “Well, I really just don’t understand what it is like to be fat.”²⁵ Even though we all had occasions when we were teaching our own doctors about PCOS, we are still subject to their judgment and plans of treatment. We try repeatedly, but what happens when PCOS is not about just losing weight?

This leads to another issue that Eve, Eliza, Nicole and I have all experienced: the lack of knowledge about PCOS on the part of the physicians to

²⁵ Eliza said she responded by telling the doctor, “You’re fired.” She went on to tell Eve and I that she has what she characterizes as “habit of firing doctors” who have not given her the level of care and respect that she expects.

whom we entrust our health care. Eve mentioned, “My perception of doctors has changed a lot over the last few years because I realized so many of them don’t know what they’re talking about.” Similarly, Nicole had to beg and plead with her doctors to screen her for PCOS after her own research led her to believe she had the condition. Eliza added, “The doctors I have the hardest time with are the ones that are nonchalant about it... who say, ‘Well, you have PCOS. Lose some weight.’ and that’s about it because I am so much more proactive.” In my own experience, I have frequently had to explain to my doctors what PCOS is and why I am taking medication for diabetes when I am not a diabetic. It seems as if it is imperative for a woman with PCOS to become as conversant about her condition as she is humanly able just to make sure that she is receiving the appropriate level of care and treatment.

It is also important to consider the psychological impact of PCOS. Depression is one of the symptoms included among the constellation that make up PCOS, but I had not given it any considerable thought until I participated in the interview process. In all honesty, it should not be at all surprising that depression became a common theme in my conversations. When one considers the stigma associated with being large-bodied in American culture, it only follows suit that the negative connotations of fatness become a source of oppression and depression (R. M. Puhl and Brownell 2006). Much as there are many different symptoms associated with PCOS, issues of depression and anxiety related are expressed in a variety of ways.

For Eliza, her dissatisfaction with her body has caused her to withdraw for periods of time or decline invitations to social events. She reported feeling as if she were being scrutinized by those who saw her. Eve, already living with a disability²⁶, finds herself increasingly isolated, sharing that she spends much of her time at home, sequestered away. Eve's account of her life now vividly portrays her anguish:

I don't feel like myself anymore. I used to be artistic. I used to feel like I was smart. I used to read and go out with friends. Now I sit at home all day in the dark, in front of the computer, because I don't want to go outside. I don't want someone to look at me like the fat bearded lady who just escaped from the zoo. I am not myself anymore.

In addition to her weight, Eve fights a daily battle with hirsutism, resorting to shaving her face to remove the facial hair that PCOS has brought about. Eve started seeing the appearance of facial hair when she was only 15 years old. Her mother, finding this unusual, took her to see an endocrinologist. I thought back to my own teenage years, how much pressure there was to look a certain way, and what a struggle it would be to live in a body I felt so much at odds with.

The emotional and psychological strain of dealing with this symptom, which seems an affront to normative ideals of femininity, should not be dismissed or underestimated (Ekback, Wijma, and Benzein 2009). Although Eve has tried medication to help alleviate the depression and anxiety she feels, she expressed dissatisfaction with the way the medications worked or failed to work in treating depression which had, in the past, escalated to cutting. Thinking back to the time

²⁶ Her specific disability was not disclosed in the process of the interview.

after she was first diagnosed, Eve shares, “I had the excess hair, the weight gain, anxiety depression... And you can see my scars. I hated myself.” The inability to conform to that feminine ideal seems to create a deep sense of self-loathing for one’s own body.

Aside from the infertility, Eliza expressed considerable frustration and dissatisfaction with her weight. “I just feel defeated with it all. I feel like a creature... like I don’t look like I’m a person... Just a non-entity that nobody can see me... that all that anybody can see is the weight. They can’t see that I am an intelligent, beautiful woman, which I think I am...” Eliza’s words seem to bring to light the internal struggle that I, too, have experienced. In your own mind, you know that you are good, worthwhile and beautiful, but you are so much at odds with what is narrowly defined as beauty that you lose yourself in it.

Nicole also expressed a sense of depression relating to her PCOS. When I asked Nicole how PCOS has affected her life and the way she views herself, she replied, “I feel depressed because I don’t feel like a woman. I feel this way because I lack a cycle on my own, losing my once lovely, thick hair, shave my face/neck/chest/belly everyday and am infertile.” Clearly, PCOS has a destructive effect on a woman’s self-esteem.

While there have been studies discussing depression as it relates to quality of life in women with PCOS (Barth et al. 1993; S. Elsenbruch 2003; Sigrid Elsenbruch et al. 2006), there is relatively little literature that brings to light the individual experiences of depression exhibited by women with PCOS. The

existing body of work fails to bring in narrative accounts that clearly depict just what it means to live with depression as a woman with PCOS. This is one area where I think the work in which I am engaged is relevant to this discussion.

An additional theme that emerged in the course of my research is tangential to the issue of depression. In talking about PCOS, it is vital that we remember that, among all the symptoms associated with this condition, infertility is often one of those most difficult to make sense of. Though I have not given much thought to having children, I cannot dismiss the distinct significance that motherhood holds for many women. Two years ago when I sought out the advice of a reproductive endocrinologist, I had a brief taste of what women with PCOS who wanted to have children felt. During a transvaginal ultrasound, I saw the image on the screen that appeared like a large black hole on my ovary. The nurse performing the procedure recorded the images but could not explain to me what we were seeing on the screen. When the nurse left me alone in the room, I had a few moments of terror. For years, I had felt that PCOS was my “get out of jail free” card when it came to the obligation to have children, but that prospect no longer seemed quite as attractive as it had once been. I know that PCOS can cause infertility, but somehow I thought that there would always be sufficient treatment that would allow me to conceive, if I elected to do so. Suddenly, seeing that image on the screen, I thought that I would soon be told that I was unable to have children – that I was without a choice. Perhaps for the first time, I had an inkling of what it might be like to have the unfulfilled desire of motherhood.

While my doctor soon appeared and allayed my fears, the women I spoke with were not as fortunate. When Eliza was initially diagnosed as having PCOS, she also was given the news that she had complex hyperplasia with atypia, a condition involving cell abnormalities within the endometrium with the potential of malignancy. While uterine cancer is not frequently seen with PCOS, Eliza refers to herself as “a special case.” Treatments for this condition include hysterectomy - the complete removal of the uterus. Eliza made the decision that she would not go through with the hysterectomy after going through biopsies, surgeries, and a multitude of other tests that she characterized as “violations of her body.” She decided she had had enough and took a break from the chaos that medicine brought with it. She said she simply needed time to process everything that had happened to her. Even though she does not presently show signs of cancerous growth, the possibility of malignancy remains with her. As to where she finds herself now, she shared that she is “grieving for the loss of me.” She characterizes her infertility as “the single most shattering thing in [her] life.” For a woman who had always imagined herself becoming a mother one day, she is having a difficult time coming to terms with the fact that she may never be able to fulfill that dream. Seeing friends and family have children has been especially difficult for her, as it serves as painful reminder of what she has been denied.

For Nicole, it was her desire to become a mother that led to her eventual diagnosis with PCOS. Under the treatment of her OB/GYN and reproductive endocrinologist, Nicole is hoping to conceive in the near future. After a few months of being on the prescription drug metformin without achieving pregnancy,

her doctors switched her to Clomid and Menopur injections as well as encouraging an adjusted diet and exercise to improve her chances of conception.

Though Eve has considered having children and expressed a desire to become a mother, her experience with infertility is somewhat different. Her long-time partner has been talking about children for a number of years and is having trouble understanding why they have not moved forward with plans to do so. She also mentioned that her family has peppered her with questions as to why she has not had children. With her current weight and health, Eve has been told that conceiving will be difficult, and she has done her best to explain to her partner that it is not a lack of her desire to conceive that has prevented them from having children, but the complications of being a woman with PCOS.

In considering the three individual experiences of these women in conjunction with my own, I find it almost impossible to detach the themes that emerged from each other. They cannot be considered in a vacuum, neatly separated from each other. If one thing has become exceptionally evident to me, it is that so much of the discussion about PCOS is complex and fraught with overlapping issues that cannot be simply brushed off with a firm admonishment to “just lose weight.”

Chapter Six: Conclusions

Qualitative feminist research helps to promote a greater understanding of the particular experiences of women living with PCOS, a perspective that has been largely absent from the body of literature on this topic. In recent decades, narrative medicine has shown the value of patient stories in contributing to the pool of knowledge (Charon 2001). Though physicians remain a major source of health information, the experiences and stories of their patients have the power to both challenge and influence the medical model in positive directions. In the realm of Western medicine, the stories of females patients who have historically been silenced by the medical institution are especially significant. In this respect, such narratives can serve as tools to aid in our critique of these institutions (Stone-Mediatore 2003). Such work is vital to feminist research.

Hopefully contributing to the growing body of feminist research which confronts, and interacts with the institution of medicine, my thesis adds to both critical analysis and the important realm of patient experience. In embarking upon this project, I sought to justify PCOS as a relevant issue for feminist analysis. Perhaps now more than any other time in recent decades, PCOS has come to the forefront with its role in the ongoing birth control controversy. PCOS is well-situated in the ongoing battle for women's health, serving as a case in point as to why oral contraceptives should be included under preventative care

(Fluke 2012). Again, we are reminded that the personal is political, and the political is personal.

Moreover, feminist theory is a tool well-suited to interrogating and deconstructing institutional and social bodies that impact the health of woman, especially those with PCOS. For three of us in this study²⁷, we share a common experience in our refusal to be objects acted upon by the medical institution. Instead of tacitly following recommendations made by physicians or settling for diagnoses that do not make sense to us, we have claimed the right to ask questions and participate in active resistance that we believe will ultimately lead to better health outcomes.

When I consider my vision for change concerning PCOS, the women it affects and the health professionals to whom we entrust our care, I am confronted by the reality that there is still a great deal of work to be done on a number of levels. Starting with at a macro level, I will address some strategies for change, keeping women at the center of my thoughts.

As social scientists, we recognize the role that society and culture plays in the development of norms and mores. Socio-cultural factors shapes individuals and groups with a subtle power that is too often taken for granted. The current paradigm that negatively views large bodies is detrimental to the mental health and well being of many women with PCOS. To begin to change the current paradigm that describes fatness in such damaging manner, a shift would have to

²⁷ Eve did not express a similar experience.

occur that would influence the minds and hearts of a society's members. One good step in that direction may be the Health at Every Size (HAES) movement.

The HAES movement is a relatively recent development that emerged only in the last decade. In a culture that almost constantly emphasizes the need to be thin and informs its members that dieting and weight loss regimes are practically a requirement²⁸, the HAES movement challenges these ideas of weight-loss and provides an approach that views good health as the result of a balanced diet and physical activity. While this perspective might not sound much different from traditional weight-loss programs, the HAES is unique in that good health is not a status or label reserved exclusively for the thin but is something that is attainable for individuals at every size. Burgard sums it up well, stating, "The HAES model tries to untangle the effects of weight stereotyping. It asks us all to focus on the day-to-day self-nurturing behaviors that result in physical and mental health improvements, and to challenge the pursuit of weight loss so that our bodies can settle at the weight they do when we are living in a healthy way" (2009, p. 48). Pending additional and more varied research, HAES has the potential to transform public health policy in a positive way. Moreover, this development could lead to wider acceptance of body types that would help to counter the negative stigma associated with fatness in mainstream American culture.

Simply put, the stigmatization that accompanies obesity in this country is damaging to people in terms of body image, self-esteem and overall mental

²⁸ Beyond the scope of the present work but important to look at, "supersize" trend.

health²⁹ (Schwartz et al.; Wang, K. D. Brownell, and Wadden; Hassan et al.). This “fatophobia” is not only external, but internalized into a sense of self-loathing (Wang, K. D. Brownell, and Wadden). Even so, we do not see wide-spread campaigns advocating for an end to discrimination. For all the celebrities who have boasted about their amazing weight loss on prime-time television, there is a distinct absence in those who might champion the cause for greater acceptance of larger body size. No government officials speak of the cost of such intolerance, and it is a complex matter to quantify the emotional toll that living in a fat body has in a society that scorns the shape that seems to define one’s personhood. Nearly 10 years have passed since the war on obesity began (Wright 2003), and yet in spite of all the social pressure, people are still obese and the numbers keep climbing. The causes of obesity are varied, and my focus here is on PCOS. Furthermore, in light of the fact that women with PCOS may experience depression in relation to their body image, the HAES movement could go a long way towards changing life for the better.

Taking into consideration the fact that paradigm shifts generally occur over an extended period, I would also like to offer a immediate solution to the notion of the deviant body of the PCOS woman. As a feminist scholar I look for sites of resistance whereby the dominant notions of the ideal body might be subverted and challenged. If this ideal body is a docile body, shaped by the culture in which it is immersed, then perhaps the PCOS body is an anarchic body (Oksala 2004) which resists normative ideals.

²⁹ Not only damaging to those who are “fat,” but to those who are susceptible to eating disorders.

Oksala suggests that “Power inscribes the limits of normal bodily experiences, but it is exactly the existence of these limits that makes their transgression possible” (2004, p. 108). Perhaps then, by embracing the PCOS body, by refusing to conform to the narrow conceptions prescribed by mainstream Western culture, the experience of PCOS body is itself a locus of resistance and transgression that allows women to reclaim their own power.

The medical institution is another area that could benefit from change. Meanwhile, laypeople are increasingly encouraged to become advocates for their own health. Mainstream news outlets like CNN.com feature health news as part as their regular offerings and include an ongoing special feature called “The Empowered Patient.”³⁰ As I have previously discussed, Americans in general, and women in particular are socialized to endow doctors with our implicit trust and faith, relying on medical professionals for “facts” (Ratcliff 2002) – or, as Foucault might say, Truth. When we feel that our bodies are not functioning as we are taught to expect, it is typical for us to seek out the advice of a medical professional who provides us with information and guidance as to what can or should be done to bring our bodies back into a state of “normalcy.” It is, Radcliff (2002) suggests, this information that is the primary resource or commodity in the doctor-patient interaction. The decision as to what and how much information is to be given to a patient is within the hands of that doctor who controls the flow of information. In my case, the failure of a doctor to disclose the details of my diagnosis was a major turning point for me. I was simply not content to be a

³⁰ <http://www.cnn.com/SPECIALS/empowered.patient/>

docile patient any longer. Ruzek and Becker note that “More than three decades ago, when access to medical information was restricted almost exclusively to physicians (who were mostly men), laywomen’s insistence on access to medical research was truly revolutionary” (2000, p. 47). By taking doctors as a class down off the pedestal on which they have been placed, by demanding access to information and seeking alternative epistemologies, we challenge and subvert the existing power structures.

Another way in which women can (re)claim power in the medical interaction is through embodied knowledge. As the inhabitants of our corporeal forms, human beings have access to a unique awareness of self. Learning first to trust our bodies to tell us when something does not feel right is an important step towards becoming an active agent in our own health care. And while doctors undoubtedly have years of specialized training, the knowledge that the patient can provide through the medical interaction is no less valid or important than that gained through extensive schooling. The interaction of these two epistemologies provide a more detailed, meaningful picture of health and wellness.

Following in the footsteps of radical feminists, channeling righteous anger and indignation can be a useful, if somewhat painful, process. In *Feminist Politics and Human Nature*, Jagger suggests that “radical feminist actions are conceived as a type of consciousness raising – making visible the destructive power of patriarchy, a destructiveness that is invisible because it is so familiar as

to appear natural... Radical feminist actions are supposed to disrupt the spectacle and to show it for what it is" (1983, p. 286). Women have the ability to equip themselves with information that will give them the ability to question and expose the potential fallibilities of the medical authority. In the essay, "How to Tell Your Doctor a Thing or Two," Hunt argues that patients who take on passive roles in the doctor/patient relationship are less likely than to achieve good health outcomes than "bad patients" who insist on questioning their doctors and actively claim a role in their own health (2009, p. 23). Espousing a willingness to question medical professionals and explore different avenues of knowledge are essential first steps along the road to being a successful "bad" patient.

The Information Age has made consciousness-raising efforts more effective and accessible (Vogt 2001). The advent of the Internet has provided an incredibly useful medium for women to locate, exchange, and publicize information³¹. While there are issues of class, race, and economic status inherent in the use of and access to the Internet that cannot and should not be ignored, the Internet does offer the ability for even those with minimal computer skills to take part in the creation of discourse. For those with the means to surf the World Wide Web, information is more readily available than ever. Groups of individuals with common interests have the opportunity to join together in mutually beneficial forums.

³¹ It is important to note, however, that there is a need to winnow out non-credible sources since the Internet is, in many ways, an open forum.

For the last few years, I have been a member of two communities on the blogging site “LiveJournal” that deal specifically with PCOS, one of which I participate in as a moderator. The groups offer interested parties the chance to share their personal experiences with PCOS, to ask for and offer advice and generally find a common ground. Each participant is allowed to occupy the place of “expert” where her own body is concerned, and there is a sense of equality among members of the groups. Different modalities of treatment can be explored and examined with the potential that new options might be presented and applied to one’s own dealing with PCOS. Members do not have to face the judgment of doctors and can feel secure that, in the sharing of intimate details, kindred spirits not only listen but understand and empathize. In reading through individual accounts, the community members can supplement and build upon their own knowledge of PCOS.

In my experience, the participants of these online groups are frequent women over the age of 21, many of whom are concerned with weight-loss strategies or are trying to conceive. While these are certainly valid issues, there are other issues that are generally not addressed in these forums. I am specifically referring to adolescents who have been diagnosed with PCOS. Considering the amount of pressure young women feel, especially during their high school years, a condition that drives them further outside of what is “normal” can be a particularly stressful experience. Making available resources that are targeted towards these young women and their individual experiences of PCOS could help to alleviate some of the strain in those formative years.

This exchange of information and support need not be restricted to the virtual world, however. In the course of talking to women with PCOS, I realize that, while the Internet can be a useful tool for bringing together people with common interest and concerns, it also lacks the very human element that companionship brings. Both Eliza and Eve expressed their wish for a local support group where women with PCOS could actually get together, whether it be just to talk over coffee or to shop for clothes together³² or be active together simply because doing so feels *good*. Within a week of our discussion, Eliza set up an online group through the site Meetup.com to organize women with PCOS in the Tampa Bay area. I would like to think that talking about her experiences with PCOS as a result of my research inspired her to take that next step.

The company of those who have an intimate understanding of just what it is like to be a woman with PCOS might be an invaluable resource in helping to combat the isolation and depression that can accompany PCOS. Local support groups might also help to mitigate the isolation experienced by women with PCOS by giving them the opportunity to meet face-to-face with other women with similar experiences, providing an environment that offers safety in numbers. Additionally, one cannot assume that all women with PCOS have easy access to the Internet. In this respect, a local support group has the potential to give those women the benefit of having other SoulCysters to share their experiences and challenges with.

³² Eliza, Eve and I shared the sentiment that there is not the selection of clothes for women of ample size that exists for smaller women. This was also a shared point of frustration.

Though my time talking with Nicole, Eliza, and Eve was brief, I have found an immense amount of admiration and respect for these women for their bravery. Their stories bring to light the reality of what it means to be a woman living with PCOS in this time and in this culture. Their accounts are a stark contrast to the clinical literature on PCOS, and what they have shared is just as meaningful. The lifeworlds of patients, specifically those with PCOS, have so very much to tell the medical institution, if only women like us are given the opportunity to speak about them.

If the statistics are correct and 6-8% of women of childbearing age are living with PCOS, further attention must be given to this issue. Women with PCOS must be given the space and time to speak about their experiences, sharing valuable knowledge that has the potential to make great contributions towards a better understanding of this condition. Instead of being isolated and shunned by a society that devalues bodies that fail to meet normative ideals, women with PCOS must come together and make their voices heard.

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