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Stories of the cystorhood: exploring women's experiences with Polycystic Ovarian Syndrome: implications for education, self-perception, and medicalization

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RUNNING HEAD: Stories of the cystorhood

Stories of the cystorhood:

Exploring women's experiences with polycystic ovarian syndrome: Implications for education,
self-perception, and medicalization

by

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Stories of the cystorhood

Abstract

The overarching purpose of this study is to explore the experiences of women with PCOS in more detail to provide further knowledge of the syndrome, to educate others, and reduce stigma – for all women, with or without Polycystic Ovarian Syndrome (PCOS). PCOS occurs in five to 10 percent of women, yet the greater public is generally unaware of it. Biomedicine defines PCOS as an endocrine disorder caused by a hormonal imbalance in women, with symptoms including: irregular or complete lack of menstrual periods; reduced fertility; unwanted facial or body hair; and the potential for weight gain due to insulin resistance. This study explores the experiences of women from the following perspectives: self-perception, education, and medicalization. Using arts-informed inquiry, with the methods of painting, interviews, and life writing, these topics are explored with women with PCOS.

Regarding self-perception, the study found that symptoms of PCOS pose a major challenge to normative femininity, and that the women involved struggle with their femininity and feel “shame” and “embarrassment” about their bodies. A significant number of the women reported feeling depression related to PCOS. They struggled between wanting to “accept” their bodies while at the same time wanting to adhere to normative femininity. Although this was an ongoing issue, several of the women noted that PCOS, perhaps ironically, had also been a source of positive personal transformation. In terms of education the research findings revealed that the conventional patient-practitioner relationship was insufficiently helpful and the women felt inadequately educated about PCOS by their practitioners. In many cases, the women received late diagnosis and felt they knew more about PCOS than their practitioners. Participants felt that there was a lack of support for PCOS and also expressed that they felt “dismissed” by their practitioners. Some women noted that their practitioner focused primarily on their weight without considering other factors of PCOS. They also felt there is a lack of accessible information about PCOS, and that students in the public school system should be informed of the syndrome and its symptoms. In relation to medicalization, the women suggested that they felt their bodies were failing or acting against them, and expressed discomfort at their lack of control. Another issue that surfaced was that biomedicine is limited in its scope and that there are limited treatment options for PCOS. At the same time, not all the women believed alternative medicines are a viable option. Based on the research findings, this study suggests that more information and literature on PCOS written in “lay” terms is needed for women with the syndrome, and that more training should be supplied for medical and mental health practitioners both on the details of PCOS but also on how it affects women’s daily lives. The study also suggests that more research is needed on how alternative lifestyles and medicines may be helpful treatment options for women with PCOS.

Stories of the cystorhood

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¹ I use the term *cystors* as a play on words between "cysts" from polycystic, and "sisters."

Stories of the cystorhood

A Note on Format

This thesis does not follow conventional formatting. During an interview, Zoe, one of the participants, made a comment that spoke to the all too common inaccessibility of academic papers: “I think we need more public ways of accessing [information on PCOS]. People want to access art. They don’t always want to access journal entries.” Zoe’s candid remark was very helpful to me as I thought about the best ways to present my thesis. My overarching intention is that my research be accessible and as reader-friendly a possible.

Arts-integrated inquiry was a methodology used for this study. Sameshima (2007) is one pioneer in the arts-based research field. Her PhD dissertation played with format and structure, and was written in the form of an epistolary novel. I take guidance from the claims made in Sameshima’s (2007) dissertation:

- that the sharing of stories encourages reflexive inquiries in ethical self-consciousness, enlarges paradigms of the "normative," and develops pedagogical practices of liberation and acceptance of diversity;
- that form determines possibilities for content and function thus the use of an alternate format can significantly open new spaces for inquiry;
- and, that transformational learning may be significantly deepened in pedagogical practice through the intentional development of *embodied aesthetic wholeness*. (pp. xi-xii)

In keeping with the tenets of arts-based research, one of which is to bring research into the public realm (Coles & Knowles, 2008), I have chosen to present this thesis single-spaced, and with a slightly different structure than a traditional thesis. As well, since I am using life writing as a way to make the research more personable, I used conversational grammar in the narrative pieces. It is my hope that my voice and the voices of the participants will be that much more alive in the pages on which they are recorded.

Table of Contents

| | |
|--|-----|
| Abstract..... | i |
| Acknowledgements..... | ii |
| A Note on Format..... | iii |
| List of Figures..... | i |
| The Womanless Woman (<i>written from my memory</i>)..... | 1 |
| Chapter One: The Many Faces (and Bodies) of PCOS | 2 |
| Situating Myself..... | 2 |
| Situating Others..... | 4 |
| Zoe..... | 6 |
| Tracy..... | 6 |
| Delia..... | 6 |
| Astrid..... | 6 |
| Fran..... | 7 |
| Judy..... | 7 |
| Chapter Two: What’s the Big Deal? | 8 |
| Putting PCOS in the Spotlight..... | 8 |
| Research Questions..... | 9 |
| Chapter Three: Setting the Context | 10 |
| Introduction..... | 10 |
| PCOS: The “Hidden Epidemic”..... | 10 |
| Biomedicine and Alternatives..... | 13 |
| Medicalization and the Social Construction of Illness..... | 16 |
| Normative Femininity and the Social Construction of the Female Body..... | 21 |
| Concluding Thoughts..... | 24 |
| Chapter Four: Methodology | 25 |
| Introduction..... | 25 |
| Feminist Research..... | 25 |
| Arts-Informed Inquiry and Accessibility..... | 26 |
| Methods..... | 29 |
| Participants..... | 29 |
| Interviews..... | 29 |
| Visual Art..... | 30 |
| Ethics..... | 33 |
| Putting PCOS in the Spotlight..... | 33 |
| Chapter Five: Stories of the Cystorhood | 35 |
| The (PCOS) 28-day Cycle | 35 |
| (Re)Situating Myself..... | 36 |
| Introduction to the Research Findings..... | 38 |
| Education..... | 38 |

Stories of the cystorhood

| | |
|--|-----------|
| Patient-Practitioner Relationship | 39 |
| Knowledge and Accessibility | 43 |
| Self-Perception..... | 47 |
| PCOS as Challenging Normative Femininity..... | 47 |
| Depression as an Unacknowledged Symptom of PCOS | 52 |
| Division/Competition among PCOS Women..... | 53 |
| Internal Struggle: To Shave or Not to Shave? | 55 |
| Personal Transformation..... | 55 |
| Medicalization..... | 56 |
| Illness | 56 |
| Biomedicine as Limited | 58 |
| Biomedicine as Beneficial | 60 |
| Summary..... | 60 |
| Chapter Six: Putting it All Together..... | 63 |
| Appendixes | 85 |
| Appendix A—Interview Guide for PCOS Participants | 85 |
| Appendix B—Initial Introductory E-Mail to PCOS Participants | 86 |
| Appendix C—Cover Letter to PCOS Participants..... | 88 |
| Appendix D—Cover Letter to PCOS Participants Outside Lakehead..... | 90 |
| Appendix E—Consent Form for PCOS Participants | 92 |
| Appendix F—Consent Form for PCOS Participants Outside Lakehead | 94 |
| Appendix G—Consent Form for Facilitator | 96 |
| Appendix H—Follow-Up Consent Form for PCOS Participants..... | 98 |
| Appendix I—Facebook Ad..... | 100 |
| Appendix J—Poster | 101 |

Stories of the cystorhood

List of Figures

| | |
|---|----|
| Figure 1 <i>The naked skinny cystor</i> | 3 |
| Figure 2 <i>Art piece by Judy</i> | 27 |
| Figure 3 <i>Art piece by Astrid</i> | 28 |
| Figure 4 <i>The (PCOS) 28-day cycle</i> | 36 |
| Figure 5 <i>Solidarity</i> | 72 |

The Womanless Woman
(written from my memory)

My first visit to the gynecologist was when I was 13. I was having “girl problems” and the doctors prescribed birth control. I still remember the day. I had been menstruating semi-consistently for six months so my mother took me to the hospital.

“Why didn’t you bring her earlier?” the doctors scolded my mother in disbelief. “This is so unusual!”

I watched my mother gasp and recline in her seat, and feel the shame of the moment. “I, I – I thought . . . I didn’t think it was that that bad . . . I brought her now.”

I felt the guilt of the moment. I hadn’t completely been honest about the situation to my mother. I had hidden details at some times and exaggerated at others, and now she was taking the blame. It was my fault that my body was like this and it was my fault that I had not been fully truthful about it. I sat in the patient’s chair and said nothing.

I didn’t understand what was going on, but my body started developing into a woman much faster after the synthetic hormones. I wasn’t happy about the birth control pills because it meant I had to go back to my co-ed swim class. Gym in grade seven was stressful enough, all the hormone-pumped tweens eyeing each other. Each glance at me felt like a violation, a violation of my privacy and assault on my pride. Sometimes I felt ashamed. In gym class some girls held their chins high and giggled in their self-proclaimed confidence, and the eyes of others were often cast downwards, avoiding contact, recognition, admission.

A few years later the doctors said I probably had PCOS, a bunch of letters for a menstrual syndrome. I.N.F.E.R.T.I.L.I.T.Y. were the only letters I heard. They said I might not be able to produce children. As if to be a woman you had to “produce something.” What if you can’t produce? What are you then? If I can’t produce children, am I useless and without value? Can’t I produce other things?

I sat in the patient’s room, my naked body exposed through the back of the robe. The walls were white, and I stared at a bright yellow bin that read ‘Hazardous Waste.’ Some needles were in a tray on the counter and the patient’s bed had loud crackly paper on it that felt unsettling to my skin. The doctor flipped through some sheets of paper. "Now, if you notice any excessive hair growth, I can give you a prescription to fix that. You know, on the legs, on the stomach, wherever."

Fix that. Produce. Fix that.

How does one “fix that?” What is there to fix? These and other questions were buzzing in my head and I couldn’t make sense of it. I imagined myself turning into some kind of monster, a womanless woman.

Chapter One: The Many Faces (and Bodies) of PCOS

Situating Myself

Leggo (2008) argues that self-study and autobiographical work are not merely self-involved activities, but inherently involve the self *in relation to others* (p. 91). He states that the professional is always also the personal—the two are simply inseparable. I want to begin this research by situating myself, as my story is inseparable from the research. I seek transparency and authenticity by naming my story so that it may join the stories of others, always in relation and never alone.

I conducted this research in solidarity with my fellow *cystors*, who have questioned their bodies, their femininity, and their health. And I conducted this research for the women who have wondered whether Polycystic Ovarian Syndrome (PCOS) is even real.

I was unofficially diagnosed with PCOS when I was 13. I say “unofficially” because PCOS is heterogeneous, meaning that it is a collection of signs and symptoms that in various combinations can be seen to form the syndrome. It is therefore very difficult to diagnose, especially during the pubescent years. Although it is considered an endocrine disorder due to a hormonal imbalance, many symptoms of puberty are also symptoms of PCOS, such as irregular menstruation. Nearly 15 years later I was “officially” diagnosed with PCOS by a gynecologist, yet there was still a “most likely” attached to my diagnosis, not a definite “yes.” After 15 years of what I experienced, and now define, as unsuccessful medical treatment, I began seeing a naturopathic doctor who paid less heed to the PCOS label and turned that “most likely” into a “maybe.” Somewhat ironically, since I began this research, I have newly discovered that I may not even have PCOS but a separate menstrual disorder. For these last 15 years, I have self-identified as a person with PCOS, and this has shaped the way I understand myself and my relationship to the world. In this research, therefore, I refer to myself as someone living with and experiencing PCOS.

As a teenager growing up with PCOS, I began to question very early the relevance of PCOS. Was it a sickness, or was it merely a medical classification of the women who did not fit in the 28-day menstrual cycle high school health class taught girls to expect? It is not unusual for a woman with PCOS to menstruate for over two consecutive months, or not at all. I lived in silent fear that my body would grow “manly”—hairy—and that I would be unable to conceive children. I thought the reason I had small breasts was because PCOS women typically have higher levels of testosterone. I couldn’t relate to my friends who got their period exactly every 28 days when I could go a year *without* menstruating. It is only in the past few years that I have developed a more acute understanding of how PCOS has affected not only my identity, but also the identities of many other women.

The preliminary research for this thesis marked the first time I read about PCOS in the academic literature. There are only four articles on PCOS from a feminist perspective that I have located. Reading for the first time the experiences of women with PCOS was, without exaggeration, a monumental experience for me. It became apparent to me that I had never knowingly met another woman with PCOS. Being able to relate to the voices of these women was, quite simply, liberating. I would be extremely excited and honoured if my own research does the same for another woman. The overarching purpose of this research, then, is to explore

the experiences of women with PCOS in more detail to provide further knowledge of the syndrome, to educate others, and reduce stigma—for all women, with or without PCOS.

In 2014, I created an art piece for a graduate level class on Arts-Integrated Inquiry (see Figure 1). This act of creativity permanently shifted the way I negotiate and understand PCOS—my feelings about PCOS recorded in a visual image what I could not find the words to say. It is this cornerstone that has inspired me to use the arts in my thesis research as a medium for participants to express and represent their own experiences with PCOS.



Figure 1. McKellar, L (2014). *The naked skinny cystor* [Acrylic on canvas, 35 3/8' x 17 1/4']. Thunder Bay: Canada.

Junge (2007) wrote, “The image in art therapy is an illumination of a person’s interior landscape. It illuminates what was, what is, and what might be” (p. 44). The arts can provide a language of expression that is often found lacking in academic literature. In referencing art therapists, Junge argues:

We do not need reminding that expressive communication often does not come in spoken language, that many of our clients need imagery, and that “creative voices” can come in many colors and not in words at all. (p. 45)

I am not suggesting that participants actively engaged in art therapy as part of my thesis; that is well beyond both the professional and academic scope of this thesis research. What I am suggesting is that engaging with our non-textual creativity may be a valuable form of meaning making that can bring new understanding of PCOS to ourselves as individuals and as a collective.

I am aware that my experiences with PCOS shape the way I engaged this research, and I intended to be mindful of this throughout the research process. It is worth noting that I do not have all of the symptoms of PCOS, especially those that may invite stigmatization such as rapid weight gain, acne, and facial hair. In jest, the PCOS community calls women who lack these symptoms “skinny cystors.” It could be said that being a skinny cystor has afforded me “thin

privilege” (see van Amsterdam, 2013; Puhl & Brownell, 2001; Harriger, Calogero, Witherington, & Smith, 2010). In some ways this may have impacted the way in which I related to potential participants and, in turn, how they related to me. I intended to be mindful of this possibility throughout the study and consider a “both/and” or “insider/outsider” approach whereby I consciously and persistently considered multiple standpoints when considering my identity and the identities of others (Trinh, 1991, as cited in Hesse-Biber, 2012). I asked myself, who is the research benefitting? I do not think that my relationship to PCOS subtracted from my ability to listen to and represent the participants’ stories. Rather, I think that my experience enhanced understanding of and sensitivity to the topic and to the participants. Acknowledging that there are always power differentials in research, I aimed to involve the participants as co-researchers as much as possible in order to enhance their control and voice. Still, it is clear that the final research representation is a mosaic of stories woven together by the threads of *my* interpretation, due to my position as primary researcher. I tried to be mindful of this responsibility throughout the study.

I harken back to Leggo (2008) to draw on inspiration for a closing note. On answering why it is so important—and necessary—that each of us shares our stories, he wrote:

Writing autobiographically is like echolocation. By means of echolocation, bats can navigate their nocturnal flights. They send out sound waves which then bounce off distant objects and reflect back to the sender. In a similar way, autobiographers are seeking to locate themselves in a rapidly growing network of contexts including family, neighborhood, community, profession, and school, by sending out resonances from an embodied and personal location to other embodied and personal locations. There is no separating the personal from the professional. (p. 91)

This is part of my story, and the stories of others. By exploring and sharing them, I hope to shed a little more light on PCOS—what it is and how women experience it in their daily lives.

Situating Others

Six women living with PCOS were interviewed for this study. The participants were recruited by email, postering, and Facebook. Participants came from Thunder Bay, except one who lives in Southern Ontario. Ages of the participants ranged from 18-41.

I endeavored to involve these participants in the research by conducting semi-structured interviews that allowed room for the conversation to flow organically and for topics to emerge from the participant. I also sent the final transcripts to the participants for them to review in an attempt to maintain transparency and ensure the authenticity of their voices. Participants also reviewed their profile to ensure accuracy. All of the participants have their own unique experiences with PCOS. I have chosen to present a brief profile of each of the participants at the outset of this thesis because I view them as primary collaborators in this study. While our stories are all varied and different, they also have many common threads that bind them together and present a collective voice. Though my voice is the dominant one in this study, many of my concerns and experiences were reflected in the words and stories of the other women. In cases where participants’ experiences were different than mine, this added richness to the research and illustrated how there are many “faces” of PCOS.

As mentioned above, I have chosen to present the six participants in a brief profile that outlines their historical experience of PCOS. Since there are many symptoms and sub-symptoms of PCOS, depending on which and how many symptoms a woman has, experience can vary greatly amongst cystors. Briefly exploring each participant's profile illustrates these differences and brings richness to the data. I argue that it is also beneficial to share the participants' diagnostic history and symptoms as a reference for other women with PCOS. Four of the participants requested to be anonymous in the research. Of these four, three chose their own pseudonym. I created the pseudonym "Delia". Tracy and Judy chose to have their identity revealed and so their real names are used.

Zoe is 27 and self-identifies as White with Ukrainian heritage. She has experienced irregular menstruation and unwanted body hair growth. She was diagnosed with PCOS by a gynecologist around the age of 23, after going to the emergency room prompted by intense pain around her ovaries. She also has endometriosis. Zoe had experienced what doctors called a “hormonal imbalance” as a teenager, with symptoms of irregular menstruation and hair growth. She does not have symptoms of weight gain. She went on birth control when she was 13 and has been on it ever since with the exception of two years intermittently during phases where she decided she didn’t want to be on it. During one of those phases Zoe sought out a naturopath to try to regulate her menstruation. She did not achieve the results she desired and instead went without a period for nine months, at which time she induced a period with progesterone pills. Zoe currently takes the birth control pill, and spironolactone to mitigate hair growth. She is considering going off her medication and seeing a naturopath again to achieve regular ovulation in preparation for conception.

Tracy is 37 and self-identifies as White with Métis heritage. She was diagnosed with PCOS when she was in her early 30s, by a general practitioner. She did not experience her first period until she was 18, at which point it was induced by birth control. At this time she was also prescribed spironolactone to reduce her testosterone levels. Tracy has experienced body and facial hair growth, oily skin, weight gain, and difficulty losing weight. She later went off birth control for several years, until she began speaking to friends and learned about PCOS. Thinking PCOS was a “case-study” of her life, she presented PCOS to her doctor and was later diagnosed with it. Tracy has since been on metformin and spironolactone. She has been trying to conceive for several years now and cannot take spironolactone during this time. Tracy is currently trying various fertility treatments to become pregnant.

Delia is 18 and self-identifies as being of Finnish heritage. She has experienced irregular periods. She was first diagnosed with PCOS by a gynecologist when she was 16. She is currently on the birth control pill to regulate her periods. Delia also has a hyperactive thyroid and had difficulty gaining weight in her early teens. She has no other major symptoms. Her last ultrasound revealed she has polycystic ovaries. Delia has experienced acne but is unsure whether or not it was related to puberty or PCOS.

Astrid is 34 and self-identifies as White. She was diagnosed with PCOS at 34 by a nurse practitioner. Astrid has experienced irregular menstruation since she was a teenager, including having her period six months at a time. She experiences very heavy periods, often losing two ounces of blood in a single day. She has experienced painful ovulation, sometimes accompanied by heavy cramping. She has been anemic in the past. She does not have excess androgens and has no other major symptoms. Astrid was on birth control sporadically from between around the ages 15 to 23, but has since made a conscious choice to go off it as she dislikes the synthetic hormones. She is also preparing for the possibility of conceiving in the near future and already has one child.

Fran is 30 and self-identifies as being of European heritage. She was diagnosed with PCOS by a gynecologist when she was around 14. She experienced irregular menstruation, very bad cramping, diarrhea, acne, and spontaneous lactation. She also had a pituitary adenoma² that has since disappeared or shrunk. It is unknown to what degree it affected these symptoms. Fran has also experienced depression and anxiety, but is unsure to what degree this is related to PCOS. She went on the birth control pill as a young teenager to regulate these symptoms. She attempted going off the pill in her adult life but resumed the irregular periods, so began taking the pill again. She is now off the birth control and has regular periods, which she believes may be linked to her recent lifestyle changes, specifically engaging in weightlifting.

Judy is 41 and self-identifies as being of Polish heritage. Judy was diagnosed with PCOS when she was about 39 by a gynecologist, but had never heard of PCOS until the woman who does her laser hair removal treatment suggested she may have it. Judy started noticing really thick hairs growing on her chin, sideburn areas, and jawline when she was around 28, after having noticed a mustache in her early teens. Fat builds in her middle area and she has difficulty losing weight. She experienced irregular periods and fainting spells when she was around 13 and went on the birth control pill to treat this until she was 25. She has since gone off the pill and now has regular periods. Judy has two children. She is currently receiving laser hair removal treatment on her face.

² A pituitary adenoma is a common benign tumor of the pituitary gland.

Chapter Two: What's the Big Deal?

Putting PCOS in the Spotlight

Fisanick (2009/2005) argues that PCOS needs to be put in the spotlight, and Kitzinger and Wilmott (2002) argue that more research on the experiences of women with PCOS is “desperately needed” (p. 359). Specifically, research that: helps destigmatize and give voice to women with PCOS; expand the way women with PCOS understand themselves; aids medical practitioners in understanding how it can affect women; and possibly offers insight into how medical practitioners can explain and understand health concerns to their patients in a manner that is aware of and sensitive to normative views. Answering their calls and wanting to contribute to public education on PCOS is the focal motivation behind this research. Without visibility, the general public, as well as medical practitioners, remain either unaware of PCOS or uninformed as to what personal degree it can affect women. Furthermore, there is a significant amount of stigma attached to the symptoms of PCOS, which make public acceptance of it more difficult. In fact, it is not uncommon for women with PCOS to keep silent, withholding their experiences with PCOS even from their spouses (Kitzinger & Wilmott, 2002).

PCOS remains an “invisible” syndrome despite its visible symptoms, some of which can include “excess” body and facial hair growth, acne, and weight gain. Feminist researchers have done extensive research on the effects of body hair, and to a lesser extent, facial hair on women (see Toerien & Wilkinson, 2003; Tiggerman & Lewis, 2004; Lipton et al., 2006). In a related vein, fat studies is a growing field, and there has been much writing on the implications of being “fat” and female (see Rothblum & Solovay’s 2009 *The Fat Studies Reader*, and Fisanick, 2007 as examples). The studies on both facial hair and fat reveal that these symptoms of PCOS are stigmatized. Along with other less visible symptoms such as irregular menstruation and reduced fertility, they disrupt normative femininity, and in doing so, can pose challenges for the self-perception of women who experience PCOS. The Western medical community is still shifting in its understanding of PCOS and has not established an exact definition and diagnosis of the syndrome. This confusion has a tendency to transfer over to patients, who are often unclear about what they have or how (or if) to treat it (Kitzinger & Wilmott, 2002).

Due to the stigma attached to symptoms of PCOS, it is exceedingly important that discussion of the syndrome occurs not only in the public realm, but is unfiltered and unapologetic. For example, Fisanick (2009/2005) argues that the hiring of a plus-sized fashion model as a spokeswoman by the Internet-based support group Polycystic Ovarian Syndrome Association (PCOSA) actually worked to undermine public acceptance of PCOS because she conformed to many standards of normative femininity (shiny hair, no facial hair, and clear skin, for example) and, therefore, many women with PCOS could not identify with her body. Furthermore, since her body was meant to be representative of PCOS, it continued to conceal what some might deem a more “accurate” representation of the PCOS body.³ On top of this, the spokeswoman had lost nearly 100 pounds prior to being hired and claimed to have successfully “overcome” PCOS. This implicitly placed pressure on women with PCOS to do the same.

³ As noted earlier, PCOS is heterogeneous with many possible combinations of symptoms. Therefore, there is no singular “PCOS body”—it can come in many varieties.

The conventional understanding of PCOS in biomedical literature is that PCOS is a common “syndrome.” Between five-10 percent of women have PCOS (Verity, 2008), although given debates about diagnostic criteria, these percentages could be as high as 26 percent (March et al., 2010). It remains somewhat surprising then, stigma notwithstanding, that it is seldom referenced in public. Why the silence? As Kitzinger and Wilmott (2002) note:

In particular, despite a far-reaching concern with women’s health issues in general, feminist awareness of, or activism in relation to, PCOS is very limited: the classic *Our Bodies, Ourselves* (Phillips & Rakusen, 1996) fails to mention it at all. Worse still, in Germaine Greer’s *The Whole Woman* (1999), PCOS is mentioned only in the context of women seeking sex-change treatment. (p. 350)

The consequences of this silence and stigma are not trivial. Results from a study by Kitzinger and Wilmott (2002) on 30 women with PCOS revealed that the “word ‘freak’ was used in many women’s accounts to indicate feelings of being different, standing aside from the ‘normal,’ especially from normal ‘femininity’” (see p. 352). Many of these women described the daily rituals they went about to physically disguise their “freakishness.” Moreover, these same women reported a concern about a lack of information provided by health care professionals and even a general unwillingness by these professionals to take PCOS seriously.

At the heart of this research remains an overarching, guiding question: what are the experiences of women with PCOS and how can their stories help inform the public, including medical practitioners, about PCOS, and in so doing reduce the stigma attached to it?

Research Questions

This thesis research addressed the following questions:

1. What are the stories and experiences of women with PCOS?
 - a. How were these women educated about PCOS, and how does PCOS affect their self-perception and the way they relate to others?
 - b. How, if at all, has the medicalization of PCOS shaped these women’s identities and the way they understand the syndrome and seek treatment?
 - c. If limited education about PCOS was found to be an issue for these women, how and where do they imagine re-education might occur for themselves and others?

Chapter Three: Setting the Context

Introduction

The PCOS body is the site of multiple intersections. In order to situate the research, it is important to review literature on a number of themes, namely: the relationship between biomedicine and alternative medicines, medicalization, and normative femininity and the social construction of the female body. These themes will provide the theoretical framework for the study. First, however, I will establish a definition and brief history of PCOS in order to provide clarity throughout the research.

PCOS: The “Hidden Epidemic”

The term PCOS itself is classified and defined by biomedicine. It was first classified medically in 1935, but was considered rare. In recent years cases have increased significantly; some medical professionals are linking the increase to endocrine disruptors like the plastic, Bisphenol-A (Kandaraki et al., 2010). For the purpose of this research I have defined PCOS from a Western medical perspective because this is the way the academic literature relates to it. However, it is worth noting that PCOS is understood dramatically differently in other medical traditions to the point that there is no exact name for it in, for example, traditional Chinese medicine. To be clear, when referring to “the medical community” or “medical professionals” or “medicalization” in this study, I am alluding to biomedicine unless otherwise specified. I am aware that the term “medical” has a clinical, sterile tone to it, and some medical professionals may prefer the terms “health community” or “health professionals.” I am using the term “medical” because it is commonly referred to in the literature, and to maintain consistency with other terms I use such as medicalization. Despite the fact that I take a critical stance on the medical concept of PCOS, I understand that the medical view is also a health view that has benefitted many people.

From a biomedicine perspective, PCOS is considered an endocrine disorder that impacts women and is caused by a hormonal imbalance. It is typically diagnosed when a female reports two out of three of the following symptoms: hyperandrogenism, chronic anovulation, and polycystic ovaries (Roe & Dokras, 2011).⁴

⁴ The Androgen Excess and PCOS Society, an international organization comprised of basic and clinical scientists, and clinicians, uses the following definitions:

Hyperandrogenism: “Hyperandrogenism, also called androgen excess, refers to the excessive effect of androgens (a.k.a. male hormones) in women which can result in hirsutism [unwanted facial or body hair], acne, androgenic alopecia [thinning hair or hair loss from the scalp], oligo-ovulation, and irregular menstrual bleeding.”

Anovulation: “When ovulation does not occur it is called anovulation. Women with PCOS commonly have difficulty becoming pregnant because they do not ovulate on a regular basis. Women who do not ovulate are said to be anovulatory.”

Polycystic ovaries: “Polycystic is a term that simply means 'many cysts'. Because women with PCOS do not ovulate well the ovaries of these women usually contain many small follicles that have failed to ovulate, located just below the surface (a.k.a. cortex) of the ovary. The presence of these ovarian cysts leads to the typical "polycystic" appearance of the ovaries in PCOS, although this appearance can also be seen in other disorders that cause irregular or abnormal ovulation”

The criteria for diagnosis, however, is under continual debate amongst medical professionals (see March et al., 2010; Lujan, Chizen, & Pierson, 2008). The criteria listed above are based on work by a consensus group that was sponsored by the Rotterdam European Society for Human Reproduction/American Society of Reproductive Medicine (ESHRE/ASRM) in 2003 (Roe & Dokras, 2011). The Rotterdam criteria challenged previous criteria developed by the National Institutes of Health (NIH) in 1990, which excluded the presence of polycystic ovaries from the diagnosis. The NIH diagnosis claimed that only chronic anovulation with clinical and/or biochemical hyperandrogenism was needed to diagnose PCOS. Some scholars have argued that the Rotterdam criterion results in over-diagnosis and mis-diagnosis of PCOS (Roe & Dokras, 2011), a definite cause for concern. In 2009, the Androgen Excess and PCOS Society proposed a new definition for PCOS, stating that it was a hyperandrogenic disorder that required both hyperandrogenism and ovarian dysfunction for diagnosis. They have also suggested that the term “polycystic” be dropped from the name because it misleads the general public into thinking that polycystic ovaries are a necessary symptom (Briden, 2015).

Diagnosis of PCOS is difficult because the medical community does not yet fully understand the spectrum of reproductive disorders. The medical understanding of PCOS is heterogeneous therefore symptoms are diverse, and varied. Sub-symptoms of PCOS include: irregular periods, or a complete lack of periods, irregular ovulation, or no ovulation at all; reduced fertility⁵ (e.g., difficulty becoming pregnant, recurrent miscarriage); unwanted facial or body hair (hirsutism); oily skin, acne; thinning hair or hair loss from the scalp (alopecia); weight gain and difficulty losing weight; sebaceous cysts; and depression and mood changes (Verity, 2008). Due to its heterogeneous nature, it is difficult to visibly recognize a woman with PCOS because she could be fat and hairless, or thin and hairy, or have the less visible irregular menstruation and polycystic ovaries. A woman with PCOS with “textbook” symptoms, however, would be fat⁶, with acne, and with hair growth on her face and other parts of the body such as chest, stomach, and breasts, and hair loss on the top of her head.

Although biomedicine has only recently termed PCOS as another classifiable syndrome that has developed in humans, Azziz, Dumesic, and Goodarzi (2011) argue that PCOS might be an ancient disorder. Ancient records dating as far back as 460 BC-377 BC include the observation of symptoms of what is now described as PCOS (Azziz, Dumesic, & Goodarzi, 2011). In reference to various ancient records, the researchers suggest:

These statements made over a period of more than two millennia describe a combination of signs, including menstrual irregularity, masculine habitus, sub-infertility, and possible obesity, suggestive of PCOS. They also describe the disorder in terms that translate today as “sometimes” or “many”, indicating the condition was sufficiently common to merit description. (p. 2)

<http://www.ae-society.org/>

⁵ The term “infertility” is misleading in that it suggests the complete inability to conceive. Many women with PCOS experience difficulty conceiving, but are eventually able to do so. Therefore, I use the term “reduced fertility” throughout this study.

⁶ Following scholars working in fat studies, I am using the word “fat” here rather than the medicalized word “obese.” Fat activists, in particular, want to reclaim the word fat (see Rothblum & Solovay, 2009).

Other earlier depictions of PCOS were noted by Vallisneri (1721) and Chereau (1844) (as cited in Farquhar, 2007)⁷. It is, however, generally acknowledged that PCOS was first officially diagnosed by modern Biomedicine in 1935 by medical practitioners Stein and Leventhal—hence the syndrome was initially termed the Stein-Leventhal syndrome (Thatcher, 2000). Thatcher (2000) is often acclaimed as the first person to have written a comprehensive book on PCOS, entitled *Polycystic Ovarian Syndrome: The Hidden Epidemic*.

The debate over whether PCOS is an ancient syndrome is problematic for me in that it raises the question as to where the line is drawn between a “syndrome” and what can be interpreted instead as not uncommon diversity amongst reproductive women. The boundaries of medicalization, and how they evolve in time and place affect whose bodies are likely to be medicalized. For example, is all irregular menstruation a “sickness?” How arbitrary is the concept of “regular menstruation?” As a syndrome, the symptoms of PCOS are so varied as to make it difficult to have consistency in diagnosis, especially when viewed from a non-Western medical perspective, as will be discussed later. While I am not a medical professional, I have already noted that several studies suggest that PCOS may in fact be more common than current statistics claim (see March et al., 2010, Lujan, Chizen, & Pierson, 2008). From a medicalization theory perspective (I expand on medicalization in more detail in the upcoming sections), which was developed in the 1960s and 1970s, it is possible to question whether PCOS is yet another example of the over-classification by the medical field of everyday problems into disorders. Furthermore, the word disorder or syndrome can be very stigmatizing.

On the other hand, if PCOS is classified as a primarily hyperandrogenic disorder, it may be less common than statistics suggest. I am not suggesting that the symptoms of PCOS do not warrant medical research and treatment—indeed, they do. However, I think it is safe to say that PCOS is not well understood and that for the time being, the classification is loose and serves to group together similar symptoms in an attempt to diagnose and treat patients based on the most current research. Further, the way that it is classified as an abnormality stigmatizes it.

Within the medical field there is much debate about PCOS. While Farquhar (2007) argues that PCOS might be related to body weight, Azziz, Dumesic, and Goodarzi (2011) argue that PCOS increased minimally when correlated with increase in population body weight. What is generally agreed upon in the medical field is that PCOS is heterogeneous and on a spectrum with varying symptoms (Farquhar, 2007). As Goldzieher (2002) argues:

Polycystic ovary syndrome (PCOS) has special features. First, it is not an area for simple linear thinking: A causes B, B causes C, and so on. PCOS is a complex web of interactions whose connections are still far from resolved and therefore present a perpetually fascinating intellectual challenge. (p. 1)

While referring to PCOS as an intellectually fascinating challenge may be offensive to some women, Goldzieher summarized well that the medical field is still trying to understand exactly what PCOS is, even while it continues to diagnose women as having the syndrome. For example,

⁷ The first study ever published about PCOS was actually in 1921, but is difficult to locate. The title translates roughly to Bearded Lady Diabetics.

Achard C, Thiers J. La virilisme pileire et son association a l'insuffisance glycolytique (diabete des femmes a barb) [in French]. *Bull Acad Natl Med* 1921; 86: 51-64.

criteria on how to diagnose PCOS changed in 1990 and then again in 2002, with consensus still lacking amongst medical professionals (see Azziz, 2004). Depending on how specific or broad the criteria are, the prevalence of PCOS distributed among the population changes dramatically. No wonder then that there is confusion at the level of medical practitioners. In one practitioner's perspective you may have PCOS, in another's you may not. Where is the line drawn between what is "normal" and "abnormal"? I am not arguing that symptoms of PCOS never pose problems—indeed, they often do and arguably should be treated. But how they are viewed and how they are treated can make a significant difference to both the physical and mental health of a patient.

What type of syndrome PCOS may be is not the point of this research, however. Rather, it is the effects of labeling PCOS as a syndrome on the women diagnosed with it that is the focus of this study. It is clear that however you define and describe PCOS, some of its symptoms can be problematic for women. Regardless of the percentage of the population diagnosed with the syndrome, even the lowest estimate at five percent is still a reasonably large portion of the population. Biomedicine offers one way in which to view and treat symptoms of PCOS. A brief look at how traditional Chinese medicine perceives PCOS offers some insights into alternative ways of understanding it.

Biomedicine and Alternatives

I want to reiterate that I am not a medical professional and that I am aware of my limited knowledge on adjudicating what is and is not a "real" medical problem. However, while there are important differences between lay and professional understandings of disease categories, the differences are both valuable. All knowledge, including that of medical professionals, is limited, as all knowledge comes from its own framework. Medical professionals begin from a biomedical framework that is framed by certain types of scientific understandings, and lay people such as me have embodied knowledge that comes from our lived experience. Both are important, but they differ vastly because of where we start from and what we think is most important. For example, as a person who has lived with PCOS, my understanding of the syndrome is different from my gynecologist's. My gynecologist may offer scientific explanations for the mechanics of my reproduction system, such as the possibility that I am not receiving enough progesterone to stimulate follicular growth. On the other hand, I am able to offer insight into what it feels like to anovulate on a day-to-day basis, how it alters my identity, and how it affects the way I relate to others. I would suggest that our society generally treats bodies as "machines", and values the "brain's" insights over those of the "body." However, people who live with syndromes or diseases have a physical and embodied understanding of how it is affecting their body. By listening to their bodies, they can offer valuable insights into how we form opinions and conceptualize disease and illness. Both this lived experience and clinical knowledge are necessary types of knowledge bases. Given that this entire study rests heavily on the valuing of lived experience and how it can enhance medical practitioners' understandings and approaches to PCOS, and my extensive experience as someone diagnosed and living with PCOS, it is worth mentioning that I am cautious of blanket identifications of PCOS as a syndrome.

For many years I sought medical treatment from gynecologists for symptoms of PCOS. This treatment came in the form of birth control or progesterone pills. In my specific case, while

these prescriptions did address the irregular menstrual symptoms of PCOS, they were reactive measures that suppressed the problems as opposed to proactively preventing them. There are a variety of health risks increasingly associated with birth control pills (Harrison, 2013). In addition they are often marketed to prey on women's insecurities by promising to alleviate mood swings or weight gain and to lead to breast enlargement, as in the controversial case of the Yaz/Yasmin birth control pills (Nielson, 2011). Several online forums note the effect of this marketing on women (e.g. "Yahoo Answers," and "The Student Room"). Yaz/Yasmin are birth control pills that were marketed based on a formula that contains a new hormone, drospirenone, that promises less unwanted side effects, such as nausea and irritability, than other leading birth control pills. Marketing approaches also claimed that women may gain less weight than they might with other pills and that their breasts could enlarge. This incentive was very enticing for some women and contributed to Yaz/Yasmin becoming one of the most commonly prescribed birth control pills in the world. The catch to these apparent benefits is that Yaz/Yasmin posits a higher risk of blood clotting than their competitors. As of February, 2013 there were 23 deaths in Canada that were suspected to be related to Yaz/Yasmin (Harison, 2013).

In addition to physical health issues, the encouragement of birth control pills as treatment poses another problem in that it reinforces normative femininity—either by normalizing the 28-day cycle or championing weight loss and breast enlargement—and thus contributes to the "freakish" nature of PCOS. In some cases, the prescription of birth control pills may be necessary and optimal for a person with PCOS. Many in the medical community agree that the endometrial lining should be shed every three months for optimal health. However, it is worth asking if birth control pills are too often resorted to when other measures could be taken. In 2011 alone, doctors wrote more than two million prescriptions for Yasmin in Canada (Nielson, 2011).

In the past year I have sought the treatment and professional advice of a naturopathic doctor. Naturopaths mainly practice traditional Chinese medicine, acupuncture, herbal medicine, clinical nutrition, homeopathy, and lifestyle counseling. In my view all of those practices merit consideration as potential treatments for PCOS, and further research on this by qualified professionals is needed. For the purpose of this paper, I will briefly focus on the philosophical foundation of traditional Chinese medicine in juxtaposition to biomedicine as it sheds light on an alternative way of understanding and approaching medicine and illness.

Kaptchuk's (2000) *The Web That Has No Weaver* is widely viewed as the most influential and comprehensive book that bridges the gap between medical traditions of both "East" and "West" (Caudill, 2000). On the difference between the two medicines, Kaptchuk (2000) writes, "The actual logical structure underlying the methodology, the habitual mental operations that guide the physician's clinical insight and critical judgment, differs radically in the two traditions" (p. 3). Nonetheless, one also finds that the two traditions, when integrated, can complement each other.

Chinese medicine considers important certain aspects of the human body and personality that are not significant to Biomedicine. At the same time, Biomedicine observes and can describe aspects of the human body that are insignificant or not perceptible to Chinese medicine. . . . Chinese medicine does not perceive an endocrine system, yet it treats what Biomedicine calls endocrine disorders. (Kaptchuk, 2000, p. 2)

A major value in understanding traditional Chinese medicine is that it opens a new (to the West) philosophical underpinning to approaching the body that reinvents⁸ how we understand health and disease. For example, it can be argued that traditional Chinese medicine is more concerned with prevention than Biomedicine (see Weil, 2000). To highlight the major differences, I return to Kaptchuk:

Biomedicine, a more accurate name for Biomedicine, is primarily concerned with isolable disease categories or agents of disease, which it zeroes in on, isolates, and tries to change, control, or destroy. . . . The Western physician starts with a symptom, then searches for an underlying mechanism—a precise cause for a specific disease. The disease may affect various parts of the body, but is a relatively well-defined, self-contained phenomenon. The Chinese physician, in contrast, directs his or her attention to the complete physiological and psychological individual. . . . Oriental diagnostic technique does not turn up a specific disease entity or a precise cause, but renders an almost poetic, yet workable description of a whole person. The question of cause and effect is always secondary to the overall pattern. One does not ask, “What *X* is causing *Y*?” but rather, “What is the relationship between *X* and *Y*?” (pp. 3-4)

Thus, while Biomedicine locates specific sites for disease, traditional Chinese medicine is “based on the idea that no single part can be understood except in relation to the whole” (Kapthuck, 2000, p. 7).

In relation to PCOS, traditional Chinese medicine looks at the entire hormonal environment of the reproductive system and addresses PCOS from a holistic point of view, with treatment that is more organic, including acupuncture, and homeopathic and herbal remedies. It sees PCOS as a combination of both excess and deficient conditions, which usually involves the kidney, spleen, and liver (Zhao, 2012). The traditional Chinese medicine approach changes the way we can understand PCOS. Not only does traditional Chinese medicine treatment work to prevent and restore the natural harmony of the reproductive system, it does so by addressing lifestyle choices such as diet and exercise in addition to the prescription of traditional Chinese medicines (Zhao, 2012). This is a proactive approach, addressing a possible root issue. The research findings in Chapter Five reveal that several of the participants noted they were not offered lifestyle treatment options, or alternatives to pharmaceuticals, by their medical practitioners. Yet there is growing research to suggest that exercise and nutritional counseling are beneficial treatment options for women with PCOS (Norman, Davies, Lord, & Moran, 2002).

It can also be argued that traditional Chinese medicine provides a gentler approach to PCOS, viewing it less as a “syndrome,” and more as a disharmony within the body. Still, similar to biomedicine, the use of the word “disharmony” enforces binary thinking, or seeing PCOS as deviant from the normal, rather than thinking of a continuum of hormones where different bodies and people are located and sometimes shift along different places on the spectrum. I will touch more on binary/non-binary thinking in upcoming sections. One limitation to this study is further analysis on how traditional Chinese medicine approached gender boundaries, and whether or not PCOS was or is seen as unfeminine. Furth (1986) writes that at certain points in Chinese history, menstruation was viewed as disgusting and shunned. Without further analysis, it is important to

⁸ Chinese medicine actually predates Biomedicine in that it is thousands of years old.

be careful not to romanticize traditional Chinese medicine as a “purer” alternative to biomedicine.

Traditional Chinese medicine addresses the symptoms of PCOS, but it refrains from labeling those symptoms or searching for an “isolable” disease, thus reducing some of the stigma or deviance attached to it. Each patient is seen as an individual with a different set of imbalances, not a member of the wider PCOS group. This eliminates some of the complications Biomedicine has found in deciphering diagnostic criteria for a very complex set of symptoms. While some aspects of traditional Chinese medicine are beginning to be accepted by Biomedicine, such as acupuncture, which is now covered by some medical insurance companies, it remains a marginalized form of health treatment in Western society, where Biomedicine continues to dominate. A review of medicalization studies will introduce how the rise of Biomedicine has shaped the way PCOS and illness in general are understood in Western society.

Medicalization and the Social Construction of Illness

One cannot address PCOS or the difference between Western and Chinese medicine without referencing medicalization. Indeed medicalization, or medicalization theory as some have termed it, is an increasingly common concept that entered public conversation as part of social movements in the 1960s and 1970s. At that time, for example, women’s rights activists were concerned with reclaiming control and knowledge over women’s bodies.

Riessman (2010/1993) defines medicalization as two interrelated processes:

First, certain behaviors or conditions are given medical meaning—that is, defined in terms of health and illness. Second, medical practice becomes a vehicle for eliminating or controlling problematic experiences that are defined as deviant, for the purpose of securing adherence to social norms. (p. 51)

Similarly, Bell (1987) defines medicalization as “the process and product of defining human experiences as medical problems” (p. 153). Some analysts say that it is “one of the most potent transformations of the last half of the twentieth century in the West” (Conrad, 2007, p. 4). One of the most knowledgeable scholars on medicalization is Conrad, who has written multiple articles and books on the topic. He has asked pertinent questions on the growth of medicalization:

Clearly, the number of life problems that are defined as medical has increased enormously. Does this mean that there is a new epidemic of medical problems or that medicine is better able to treat already existing problems? Or does it mean that a whole range of life’s problems have now received medical diagnoses and are subject to medical treatment, despite dubious evidence of their medical nature? (2007, p. 3)

For example, the number of diagnoses in the Diagnostic and Statistical Manual of Mental Disorders (DSM), which classifies mental disorders, has risen from 106 in the original 1952 edition to almost 300 disorders in the latest DSM IV (Conrad, 2007). This massive growth is indicative of the large number of everyday life events that now have become classified as disorders. As Conrad (2007) notes, common life processes have become medicalized, including menstruation, birth control, reduced fertility, childbirth, menopause, aging, and death. Even laughter has been labeled as an illness called pseudobulbar affect (when a person laughs at inappropriate times and without connection to joy) and the pharmaceutical industry has created a drug as treatment for this “illness” (Conrad, 2007).

The increase in medicalization is problematic in that the line between what is “normal” and what is a mild “disorder” has become blurred. This not only means that people are increasingly becoming consumers of a market culture focused on health and self-medicalizing in their daily lives, but the transformation of everyday life into pathologies is “narrowing the range of what is considered acceptable” (p. 7). As Conrad (2007) cautions, “the great danger here is that transforming all difference into pathology diminishes our tolerance for and appreciation of the diversity of human life” (p. 148).

Furedi (2005) noted that illness is currently so normalized that each person operates under the assumption that they have the potential to be ill, and that even the concept of wellness denotes that we need to actively work to be well, lest we become ill. This type of thinking, however, puts pressure on the individual to constantly work towards a gold standard that is not always optimal for their body. As in the case of the PCOSA hiring of a spokesperson, women with PCOS who are fat and have failed to lose weight may feel they have “failed” to be “well”, or as the research findings show in Chapter Five, their medical practitioners may sometimes assume that they are “ill” solely because of their weight. In summary, the medical community and pharmaceutical industry have developed the authority and social control to produce and reproduce societal norms of behavior and bodies, labeling many as deviant and therefore in need of treatment.

It is also important to note, as Riessman (2010/1993) pointed out, “that the medical profession’s jurisdiction over these and other human conditions extends considerably beyond its demonstrated capacity to “cure” them” (p. 51). Essentially, this is an expression of the shifting motivations behind medicalization. Conrad (2007) noted that the doctor’s role in the expansion of medicalization is shifting towards other entities like pharmaceutical companies and managed care organizations, to name a couple. These entities are motivated by commercial and market interests, as they have made significant financial investment in creating norms that allow them to market their products. In fact, the pharmaceutical company is the single most profitable industry in North America (Conrad, 2007). At the risk of oversimplifying, this shift calls into question *who* is served by increased medicalization: the patient or the profit makers? Clearly there are many other factors involved in the rise of medicalization, like the role of the Internet and even the patient in self-advocating for diagnoses of perceived illnesses. But one must ask: Is the overall goal of medicalization still the health of the patient?

PCOS is a prime example of how women’s bodies have become increasingly medicalized. In fact, Waggoner and Stults (2010) argue that “historically women’s life experiences have been more medicalized than men’s”, however men are increasingly under the medicalization gaze too, for example as with erectile dysfunction and andropause⁹. According to Western medical thought, the PCOS woman has strayed from the “normal” reproductive health of a typical woman. Despite the fact that PCOS is highly heterogeneous and difficult to classify, biomedicine has still labeled it as “deviant” from the norm. Riessman (2010/1993) writes that, “Medicalization has resulted in the construction of medical meanings of normal functions in women—experiences the typical woman goes through” (p. 60). One can ask, then, is PCOS *normal*? Can there be a “normal,” and if so, who should have the power to decide that? Currie and Raoul (1992) claim, “Women’s most private and personal experience—their relationship to

⁹ Waggoner and Stults (2010) describe andropause as “the declining production of testosterone in males resulting in decreased energy and loss of sexual desire” (p. 2). This comes as a result of aging, similar to menopause in women.

their bodies—is mediated by cultural and political processes” (p. 25). What are the consequences of such “private and personal” experiences being medicalized? It could be argued in some cases that medicalization allows for the control and concealment of experiences that women wish to remain private and personal. However, it could also be argued that this privacy contributes toward the silence that enables stigma. In cases where medicalization leads to the classification of a syndrome such as PCOS, it may make it less private by openly placing a formal name and judgment on the reproductive functions of particular female bodies, and in doing so, cultivate stigma. In the case of PCOS, several questions arise including: Are women being properly educated on the syndrome, are they being offered the best treatment, and is the way they are being educated about PCOS affecting the way they perceive themselves, their femininity, and their “normalcy”?

The medicalization of PCOS has meant that its symptoms are treated with drugs, because it is viewed overall as a deficiency despite the fact that some of the symptoms have less to do with health concerns and more to do with what are considered acceptable bodily norms (such as acne and hair growth). Without a doubt, some of the symptoms of PCOS are more physically serious, like irregular menstruation or insulin resistance that have been linked to increased chances of ovarian cancer and diabetes (Carmina & Lobo, 1999). However, from personal experience, I have been offered treatment by gynecologists for bodily or facial hair growth that has no perceived health risk. Riessman (2010/1993) argues that,

Illness is constructed through human action—that is, illness is not inherent in any behavior or condition, but conferred by others. Thus, medical diagnosis becomes an interpretive process through which illnesses are constructed. (p. 53)

In the case of PCOS, one can imagine a more positive interpretation; for example, women with PCOS may have been preferred in Paleolithic hunter-gatherer communities where their low metabolism and larger build would have given them an advantage when faced with food deprivation and heavy labour demands (Azziz, Dumesic, & Goodarzi, 2011). In addition, their difficulty becoming pregnant would have caused their childbirths to be infrequent, a practical advantage for nomadic hunters. With the advent of agricultural settlement, these advantages would have been less emphasized, but still useful. That PCOS may have been favourable at one time clouds the idea of illness as necessarily negative or undesirable. Implicit in the words “illness” or “syndrome” is a negative connotation that is less than desirable. For women with PCOS, as noted, being associated with it can conjure feelings of “freakishness.” Stoppard (1992) writes:

Since women are encouraged to understand their negative experiences as somehow originating in their bodily processes, it is hardly surprising that so many women have ambivalent feelings about their bodies and more particularly about menstruation. . . . Since resistance to the medicalized view of the female body can be achieved only by denying the reality of some women’s experiences of menstruation-related changes, a woman’s wish to have her experiences validated by a medical expert becomes understandable. (pp. 126-127)

As evidenced in Kitzinger and Wilmott’s (2002) study, many women with PCOS feel inadequate compared to other women, and may blame this inadequacy on themselves.

A discussion on medicalization would be incomplete without also mentioning its critiques. Lupton (1997) argues that critiques of medicalization have traditionally pointed out

that medicine has taken on a role of social regulation; that rather than improve patients' health, it can actually undermine it; that more and more social problems are medicalized; and that a dependency cycle is produced. She writes that,

Feminist critics have viewed the medical profession as a largely patriarchal institution that used definitions of illness and disease to maintain the relative inequality of woman by drawing attention to their weakness and susceptibility to illness and by taking control over areas of women's lives such as pregnancy and childbirth that were previously the domain of female lay practitioners and midwives. (p. 96)

Riessman (2010/1993) contends that while feminist writers have actively built a social movement to reclaim knowledge about, and control over, women's bodies for reasons of class, race, and a desire to have their experiences acknowledged, women have also fought for medicalization and sometimes benefited from it. Lupton expands this idea further, stating that "the term 'medicalization' is generally used in the sociological literature in a pejorative manner: to be 'medicalized' is never a desirable state of being" (p. 96). She elaborates:

One major difficulty with the orthodox medicalization critique is its rather black-and-white portrayal of Western medicine as largely detracting from rather than improving people's health status, of doctors as intent on increasing their power over their patients rather than seeking to help them, and of patients as largely helpless, passive, and disempowered, their agency crushed beneath the might of the medical profession. (p. 97)

Lupton (1997) suggests that the medicalization critique has often failed to acknowledge the ambivalence in feelings and opinions people often have in regards to medicine, and that they sometimes actively seek it. She also argues that there is no such thing as an "authentic" human body even outside of medicine, but that the body is always understood as constructed through discourses and practices, and that "de-medicalizing" will lead to "different, but not more 'authentic' modes of subjectivity and embodiment" (p. 107). Furthermore, she states that individually seeking greater control of our own bodies by actively informing ourselves on medical matters can paradoxically lead to a less clinical medicalization that moves medical and health concerns into everyday life, but nonetheless remain.

Bell and Figert (2010) argue that critiques of medicalization run the risk of assuming binaries of men/women, femininity/masculinity, and sex/gender. Additionally, such critiques are often set within a Eurocentric worldview that focus on processes in the "West." I discuss the limitations of binary thinking in this study (see the following section), and an overall aim of this study is to challenge such binary thinking specifically in relation to gender. However, this study is still set within a Eurocentric focus that addresses medicalization processes in the "West." Bell and Figert write that parts of the world are overmedicalized, while others are undermedicalized. While this study does not attempt to address this issue in relation to the varying medicalization of PCOS, it would be valuable research to explore women's experiences living with PCOS in different parts of the world.

Other critiques of medicalization include the limitations of the concept itself, claiming it is not complex enough to capture the current globalised world. Bell and Figert (2010) suggest that concepts like pharmaceuticalization, biomedicalization, and geneticization¹⁰ are related to

¹⁰ For an introduction to these concepts, please see: Bell & Figert (2010).

medicalization, but capture nuances that it misses. They argue that biomedicalization goes beyond treatment to include health maintenance, enhancement, and optimization. As Annandale (2014) puts it, this type of optimization goes “beyond what is necessary to restore or sustain health” (p. 212). For example, this can include aesthetic surgery such as breast implants in women, or the taking of steroids for bodybuilding. Biomedicalization also differs from medicalization in that it does not see gender categorically. Rather, it sees gender as an outcome of performance (Bell & Figert, 2010). Despite this acknowledgement of gender as built within relations of power, biomedicalization is still problematic. Frank (2004) raises the question of whether biomedicalization is “fitting the body to the demands of society rather than calling on society to create accommodations for different bodies” (p. 23). In the context of PCOS, this discussion raises questions again as to how biomedicalization can reinforce gender norms, or change the expectations or even lived experiences of women with PCOS. For example, it may change their perspective on body hair growth and by extension encourage women with PCOS to take pharmaceuticals to reduce hair growth, outside of physical health concerns.

Bell and Figert (2010) reassure that medicalization is still a necessary and useful concept, when understood amongst a broader discussion of related concepts. As Annandale (2014) writes, “medicalization is a more complex process than might appear at first glance, being elastic, multi-directional, both accepted and resisted” (p. 212). It is not my intention in this study to deny the benefits of medicalization or to demonize it. Undoubtedly, at times it is necessary and certainly beneficial. However, as Conrad (2007) argues, “these particular benefits should not be dismissed, but they also should not necessarily justify the social consequences of widespread medicalization” (p. 148). While Lupton (1997), Riessman (2010/1993), and Conrad contend that patients have also advocated for the medicalization of health issues, in the case of PCOS, we can question the motivations behind this choice. Did women who sought medical understanding of and treatment for their PCOS symptoms do so because they were unaware of alternatives? In addition, were they motivated by fear of the stigma associated with the symptoms?

The powerful control of social norms and normative femininity may be enough to lead any person to consider medicalization. Bartky (2010/1985) argues that a woman’s identity is usually deeply tied up with notions of femininity and maintaining gender normativity requires skill. She writes:

To have a body felt to be “feminine” – a body socially constructed through the appropriate practices – is in most cases crucial to a woman’s sense of herself as female and, since persons can currently be only seen as male or female, to her sense of herself as an existing individual (p. 91).

While the conversation about gender has slowly expanded since this article was written to include other gender identities such as transgendered persons, most women are still taking great measures to maintain the artifice of a feminine body, whether by their hair, skin, body size, or their approach to menstruation or fertility. As I will outline next, feminist theory provides an insightful lens on how PCOS is full of potential in the way it disrupts normative femininity and gender expectations.

Normative Femininity and the Social Construction of the Female Body

Feminist theory is the backbone of this research. In particular, I draw from post-structural feminist theory that argues that “knowledge is socially produced and inherently unstable” (Gavey, 1989, p. 1). Britzman (1993) concisely points to key ideas in feminist post-structuralism: “all categories are unstable, all experiences are constructed, all reality is imagined, all identities are produced, and all knowledge provokes uncertainties, misrecognitions, ignorances, and silences” (p. 22). Post-structural feminist theory argues that gender, and even sex, categories are socially constructed and stable categories simply do not exist (Butler, 1990; St-Pierre, 2000). In the words of Weitz (2010/1993):

“Social construction” refers to the process through which ideas become culturally accepted . . . [in] an intensely political process, reflecting different groups, competing vested interests and differential access to power . . . socially constructed ideas are reinforced both through the actions of teachers, doctors, and others in positions of power, as well as by each of us, as we come to internalize these ideas and to police our own bodies and actions. (p. 1)

Regarding gender, certain criteria have developed that act as demarcations of what is “male” and “female,” and based upon those, a person is automatically gendered, with males being forced into a limited notion of “masculine” and females into “feminine.” In the 19th century if a person lacked ovaries they were not considered a woman by some because a woman was classified as someone who could procreate (see Lorber, 2010/1993). Based on this criterion, women with PCOS might not have even been considered women, or at the very least been discriminated against if they could not bear children.

Binaries, like man/woman, are false dichotomies and usually privilege males (St. Pierre, 2000); other binaries have been similarly analyzed, including White/non-White, straight/queer, abled/disabled, thin/fat, culture/nature, and human/animal. Post-structural feminists analyze how the dynamic of oppression operates in similar ways amongst all such binaries and additionally address the ways in which identities intersect; for example, the experiences of an impoverished White woman will have both commonalities with and differences from an impoverished Indigenous woman given their shared gender and class identity but different racial identity. Gender, sexuality, race, ethnicity, nationality, class, ability, body size (see Russell, Cameron, Socha, & McNinch, 2013), and species (see Kahn & Humes, 2009) have all featured in such intersectional analyses.

The PCOS body troubles gender binaries and normative femininity. What, then, is femininity? If a woman is identified as the female sex, but exhibits body characteristics that are considered masculine, what does this say about her gender? The PCOS body, therefore, exemplifies how such categories can be reductive and overly simplify the complex nature of human existence.

“Masculine” traits are generally equated with power and status and “feminine” traits with passiveness and submission. Lorber (2010/1993) sheds light on the problems of binary thinking when it comes to sex categories:

Neither sex nor gender are pure categories. [...] Menstruation, lactation, and gestation do not demarcate women from men. Only some women are pregnant and then only some of the time; some women do not have a uterus or ovaries. Some women have stopped menstruating temporarily, others have reached menopause, and some have had hysterectomies. Some women breast-feed some of the time, but some men lactate (Jaggar, 1983, 165 fn). Menstruation, lactation, and gestation are individual experiences of womanhood (Levesque-Lopman, 1988), but not determinants of the social category “woman,” or even “female.” (p. 15)

Despite the fact that there is obviously much more diversity amongst sex categories than “male” and “female,” for the purpose of this thesis research, I refer to women with PCOS as “women” given the limitations of our language and for ease of communication. It is worth noting, however, that this is an artificial category and is essentially an exclusionary term as it does not include the diversity that actually exists, such as intersex or transgendered people who can also be living with PCOS.

Butler’s (1990) theory of gender performance is a classic example of post-structural feminist thought. She argues that gender is performative and that “there is no gender identity behind the expressions of gender” (pp. 24-25). As Fisanick (2005) argues, if femininity is an illusion, “a complex performance of acts, then it seems possible that that illusion can be shattered or at least interrupted in a way that allows other forms of embodiment to exist as well” (para. 5). Therefore, from a post-structural feminist point of view, the PCOS body presents a potential entry point for disrupting normative femininity.

St. Pierre (2000) argues that subjects construct themselves by taking up available discourses and cultural practices, but at the same time are also forced into particular subjectivities by those discourses and cultural practices. Thus, resistance to dominant discourse is not simple, but an example of “both/and,” an act of agency, and a part of the very reproduction it may resist. As Bartky (2010/1985) mentions, women may not always want to resist femininity, even when they are conscious of its constructions. Furthermore, understanding complicity/resistance as a non-dynamic binary is another overly simplistic and unrealistic way of thinking. This is not an end point to the conversation on normative femininity, but something to keep in mind when considering how PCOS can be used as resistance to it.

Lorber (2010/1993) argues that norms and expectations regarding gender get internalized into our individual self-worth and therefore most people subscribe to them. In some cases, women do not want to resist them because their identity is tied so deeply to the practices and skills of being feminine. In the case of women, normative femininity includes the set of roles, behaviours, and attributes to which a woman is expected to adhere. In terms of appearance, Bartky (2010/1985) argues that “the current body of fashion is taut, small-breasted, narrow-hipped, and of a slimness bordering on emaciation” (p. 80). Moreover, she posits from an aesthetic angle that, “a woman’s skin must be soft, supple, hairless, and smooth.... Hair must be removed not only from the face but from...legs and thighs” (p. 83). Although these expectations are generally true, perhaps with the exception of breast size, it is worth noting that notions of sex and gender have changed drastically in the last few decades, and some expectations are becoming less rigid. These leniencies exist still in smaller pockets of society, however, and should be considered as counter-cultural to marketing, advertising, and media that continue to push traditional representations of masculinity and femininity.

In order to maintain the aesthetic of femininity, many women go through daily procedures. For example, women use various strategies for hair removal including waxing, shaving, and electrolysis. There are innumerable dieting and exercise plans targeted at women's need to achieve a fit and slim body. As Bartky (2010/1985) notes, femininity is, at its core, an artifice which requires such extreme bodily transformations that every woman is in some way destined to fail. As Bartky suggests, this failure to achieve ideal femininity can negatively harm a woman's perception of herself and produce shame by making her feel like she didn't try hard enough. In the case of PCOS, this sense of failure can be intense as, depending on the symptoms, the woman straying so far off the ideal mark of "feminine" that she is considered "masculine." Again, as in the case of the PCOSA hiring a spokeswoman who had "overcome" her PCOS body, "success" is based on whether the individual can transform her body into a particular ideal. Since achieving femininity is tied up with self-worth, those who "fail" may have low perceptions of themselves.

The symptoms of PCOS are in direct conflict with normative femininity. Rather than looking as the female body is *supposed* to—thin with clear skin and very little body hair (Chrisler, 2011)—the PCOS body can be fat, have acne, and "excessive" body and facial hair. In addition to this outward physical appearance, normative femininity also includes fertility of the reproductive system. Healthy women are "supposed" to have 28-day menstrual cycles that are ripe for childbearing, since femininity is often equated with motherhood as the "natural" goal of women. This is an expectation of both society at large and the medical field. These expectations pose a great challenge for the typical PCOS body. As Fisanick (2009/2005) writes:

The PCOS body is at once a condition of excess: too much hair, too much fat, too much testosterone; and a condition of lack: too little hair, too little progesterone, too little ovulation. It is at once the body of the fertility goddess/mother: large breasts, wide hips, round belly, and infertile. It has too much facial hair and not enough head hair. It is both male (excess testosterone) and female (genitalia). (p. 107)

The PCOS body resides far enough outside of the norm to be even resistant to the norm. Fisanick warns, however, that this resistance may be too miniscule to make a real difference in disrupting normative femininity; perhaps otherwise women would not shave and would not be so concerned about their weight. Instead, she argues, new ways must be developed to put PCOS in the spotlight so as to continually challenge the façade of femininity and encourage acceptance of different bodies and aesthetics.

Although I do not exhibit all of the extreme visible symptoms of PCOS, I have still experienced the discomfort and stigma that comes with having symptoms that conflict with normative femininity. A fifty-eight day period of menstruation seems deviant to the four to five-day menstruation women are taught to expect. For physiological reasons as well as personal preference, for me, normative femininity is unattainable. It is, therefore, an exclusionary and highly problematic expectation to try to uphold. However, due to the intense stigmatization of anything outside the regime of normative femininity, most women with PCOS are afraid to speak publicly about their experience out of shame. As the Kitzinger and Wilmott (2002) study reveals, some women with PCOS can go through life without revealing their PCOS even to their spouses and they most certainly go to great lengths to hide it visibly and verbally. Women have internalized the message that the symptoms of PCOS are not appropriate to speak about in public. One message implicit in this silence is that PCOS must be a trivial thing to worry about

and thus even discussing it becomes something one must constantly defend. The Facebook group for the PCOS Foundation recently had a post where members argued over whether an awareness campaign month dedicated to PCOS would “steal the thunder” from other, more terminal illnesses. If women with PCOS themselves have a difficult time feeling worthy enough to speak about the syndrome, how will they or the public be further educated? This thesis, as with the awareness campaign, is not about proving that PCOS is less or more debilitating than any other illness. It is about recognizing what PCOS is and how women struggle with it. Further research that places PCOS in the spotlight, in a raw and unapologetic way, may both break the silence and disrupt normative femininity. With each story that is told, the artifice of normative femininity may lose a little more of its grip and create more space for a diversity of bodies and appearances. Perhaps more importantly, with each story that is told, a woman with PCOS may see her story mirrored back to her and find comfort in knowing that she is not the only one.

Concluding Thoughts

Medicalization, tensions between Biomedicine and alternative medicines, and normative femininity and the social construction of the female body are challenging themes, more so when coupled with the PCOS body. Is PCOS a product of over-medicalization? How can alternatives to biomedicine enhance our understanding of PCOS and aid in its treatment? How does normative femininity affect women with PCOS, and how do these women negotiate and possibly resist it? It is not within the scope of this study to provide answers to these questions. Nonetheless, by sharing the stories of women with PCOS, this thesis aims to cast some light, and provide context for, what women with PCOS themselves have experienced in relation to these themes.

Kitzinger and Wilmott (2002) concluded their study by stating, “future research on how women experience PCOS is desperately needed in order to give voice to women with PCOS who are currently marginalised, stigmatised and silenced in public debate” (p. 359). Since PCOS is so seldom spoken about, most people do not know what it is. I have had PCOS, or symptoms of PCOS, for more than half my life, yet until undertaking this study, I have never knowingly met another person with it. PCOS affects around five to 10 percent of women (Verity, 2008). If Lakehead University has around 8000 students, half of who are women, statistically speaking, as many as 400 of my Lakehead cystors have some degree of PCOS. Yet I have no way of knowing this since we rarely speak of PCOS in either public *or* private spaces, as the Kitzinger and Wilmott (2002) study found and which has also been my experience. At the outset of my study, then, I wondered how these other women with PCOS who were in my midst, experienced medicalization, tensions between Biomedicine and alternative forms of medicine, and normative femininity and the social construction of the female body. To what extent are they publicly (un)educated about PCOS? What stories might they tell that can help educate the general public, as well as medical practitioners, and in doing so perhaps reduce the stigma attached to the syndrome?

Chapter Four: Methodology

Introduction

In the previous chapter, I shared the purpose of the research and laid out the theoretical frameworks that ground it. To reiterate, the following are the research questions that guided my thesis research:

1. What are the stories and experiences of women with PCOS?
 - a. How were these women educated about PCOS, and how does PCOS affect their self-perception and the way they relate to others?
 - b. How, if at all, has the medicalization of PCOS shaped these women's identities and the way they understand the syndrome and seek treatment?
 - c. If limited education about PCOS is found to be an issue for these women, how and where do they imagine re-education might occur for themselves and others?

To explore these questions, I used a feminist methodological approach guided in particular by arts-informed research.

Feminist Research

Feminist research is an appropriate methodology because its underlying assumptions align with those of this study. Feminist research is “inclusive of emotions and events as experienced” (Sarantakos, 2012, p. 55). Feminists challenge conventional assumptions about research roles and relationships and argue that they traditionally view research participants as “distant others” or “objects” (Chase, 2005, p. 655). Taking a new turn, these feminist researchers “were interested in women as social actors in their own right and in the subjective meanings that women assigned to events and conditions in their lives” (p. 655). In particular, feminist research “recognizes the importance of women's lived experiences to the goal of unearthing subjugated knowledge” (Hesse-Biber, 2012, p. 3). Lived experience and personal story are valued as significant indicators of reality (Sarantakos, 2012); a particular way of knowing. These experiences and stories become essential primary documents (Chase, 2005). To use my thesis research as an example, the narratives of women with PCOS are significant indicators of how they are educated about PCOS and how PCOS may shape their identity. In valuing lived experience, feminist research also considers feeling and emotion as necessary and inseparable parts to the knowledge building and meaning making process (Hesse-Biber, 2012). When considering women's experiences with PCOS, it is paramount that the research approach is one that appreciates and values experience and feelings. This is especially important in the context of Biomedicine, where lived, or “lay,” experience has been dominated by clinical expertise, although this is changing in more recent social-scientific research (Prior, 2003).

Another main tenet of feminist research is the rejection of the notion that research is value-free (Sarantakos, 2012). While feminist research does acknowledge that there are always unequal power relations between the researcher and the researched, it seeks to acknowledge this inequality and does not see the research or interview process as one-way; transparency between researcher and researched is considered best practice. Feminist research argues that there is

always an emotional relationship between researcher and researched, and that openness and transparency are the best ways to move through the entire research process. Thus, in this study, full details of the purpose and scope of the research were disclosed to research participants. Furthermore, participants had the opportunity to review coded transcripts and make adjustments where they saw fit. In this way, while they were not the primary researcher who writes the final product, they were invited to act as collaborators in the research and to assert some control over the representation of their “voice.”

Regarding the dissemination of results, feminist research values certain processes that correspond particularly well with the motivations of this research—the emphasis of activism and accessibility of research. As Hesse-Biber (2012) notes, feminist research “forges links between feminism, activism, and the academy and women’s everyday lives” (p. 3). Clearly, I want this thesis to be educative for participants and other readers. Further, I included the visual portions of the research as a means to express ideas that emerged in images and not just words. It is my hope that this will make my thesis research more accessible. On this point, I turn now to the methodology I used to conduct my research, arts-informed inquiry.

Arts-Informed Inquiry and Accessibility

Coles and Knowles (2008) suggest that the formation and dissemination of knowledge in academia is often separate from the way that individuals in society experience and process the world. Similarly, Coles (2008) colloquially writes: “Life is lived and knowledge made through kitchen table conversations and yarnin’ at the wharf” (p. 59). Arts-informed inquiry aims to build a bridge between academia and these lived experiences. Arts-informed inquiry differs from arts-based research in that it is influenced by the arts, generally speaking, but not founded in them. These arts include many ways of engaging in the world such as literal, visual, and embodied (Coles & Knowles, 2008). Coles and Knowles describe the central tenet of arts-informed research as “to enhance understanding of the human condition through alternative (as opposed to conventional) processes and representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible” (p. 59). The University of Alberta Faculty of Education website states that, as with feminist research, “Art is seen as a way of knowing and the creative process as a way of making meaning.”¹¹ Physical, emotional, cultural, social, and spiritual ways of being and knowing are welcomed in arts-informed research not only because they better represent lived experiences, but also because they engage audiences (Coles & Knowles, 2008).

I chose to use art in this research because it was a means of capturing the lived experiences of women with PCOS in addition to using traditional text-based approaches. Moreover, having participants themselves create their own art pieces helped make them active collaborators in the research and gave them more control over their representation, a process in line with the principles of feminist research. As a group, participants (including myself) were given the opportunity to create one piece of visual art (see Figures 2 and 3) that captures what they feel represents some of their experience with PCOS. However, only two participants

11

<http://www.secondaryed.ualberta.ca/en/GraduatePrograms/AreasOfStudyOrientationsAndResearchTraditions/ArtsBasedResearchAndParticipatoryResearch.aspx>

attended the focus group where the art was encouraged. Those that did not attend were unable either because they were out of town, or had prior engagements. Delia specifically stated that she was uncomfortable attending the group because she felt she was too young. Due to time limitations, two of the three art pieces were not finished. This was an oversight in planning and part of the research learning curve.

It was ambitious to expect all participants to attend the focus group, and on top of that to expect them to produce possibly challenging pieces of art during a half-day workshop. In the end, this study did not include arts-informed research to the extent that I had hoped. With the advantage of hindsight, I see that the methodological approach to this study should have been more carefully thought through. While it was not as successful as I had hoped, I still think that involving women with PCOS in art making is a worthwhile project that could have the potential to reach public audiences in important and informative ways. A larger participant pool would aid in higher turnouts. More discussion on how art can be a powerful tool for self-expression, and that art making is more about the process than the finished work, may help eliminate concerns for those who were intimidated by making “art.” Additionally, it might be useful to have a specific method of art making for everyone, like mask-making for example, where participants have some structure to guide them but still have the opportunity to express themselves in unique ways.

Although Judy’s art piece was unfinished, she was energized by the process and asked to take it home with her to complete. Judy mentioned that the act of water color painting did reflect some of her emotions about PCOS.



Figure 2. Art piece by Judy, (2015).
Hope spiraling out, engulfing the darkness of PCOS. Water colour on canvas.

Astrid’s piece was more comical in nature. Interestingly, the day before she was diagnosed with PCOS or even knew what it was, she dreamed that she had grown a full beard.

Although she does not currently have symptoms of facial hair growth, she found this an odd



coincidence.

Figure 3 Art piece by Astrid, (2015). Pencil on paper.

My intention was that the art that participants made would not be merely art for art's sake, valuable as that may be. In the words of Barone (2008), who identifies as an arts-based researcher, the type of art I am seeking,

challenges the uncomfortable, familiar, dominant master-narrative, not by proffering a new, totalizing, counter-narrative, but by luring an audience into an appreciation of an array of diverse, complex, nuanced images and partial, local portraits of human growth and possibility. (p. 39)

Arts integrated research then, is inherently political and at its core aims to make a difference—albeit small or large—in the lives of ordinary citizens. In fact, as I discuss in more detail in Chapter Six, my painting *The naked skinny cystor*, was hung in the medical school at Lakehead and was subject to criticism. This sparked a larger conversation on women's bodies and health, and what type of art is appropriate for certain spaces.

The criticisms that my painting received demonstrate that the stigma attached to PCOS can make it difficult not only for those who have the syndrome and want to talk about it, but also for audiences to want to engage or even comprehend the subject. Further, discussion of medicalization and alternative medicines can be controversial, especially when framed by someone like myself who is not a medical professional. I do not expect readers to “agree” with the research per se, primarily because there isn’t necessarily a central theme to agree with. Rather, the intention behind my research is to spark conversation. Barone (2008) argues that, At their best socially engaged arts-based research projects aim to entice into meaningful dialogue not merely, on the one hand, with the progressivist faithful, nor, on the other hand, politically entrenched neo-conservative ideologues. They aim to conspire, rather, with all potential allies who have been temporarily mesmerized by the spectacle. (p. 41) I intended this arts-informed research to do the same. Art may be interpreted and reinterpreted, and “ideas and ideals may be shared” or “plots may be hatched against inadequate present conditions” (p. 39). I understand that the reach of the art may be limited, and that once it is “set free” it can be understood in myriad ways. Still, as Barone (2008) noted, “as artists and arts-based researchers we can never, strictly speaking, change minds. We must believe that people within genuine dialogue, change their own minds” (p. 44). Thus, this research aimed to open up questions rather than answer them, in the hopes that what is considered “normal” might be expanded, even slightly, or at the very least, questioned.

Methods

Under the direction of feminist methodology and arts-informed inquiry, I included six participants in the research using the following methods to address my research questions: interviews, visual art, and life-writing.

Participants

As noted in the introductory chapter, I interviewed six participants for this study. The participants were recruited by email, postering, and Facebook. Participants came from Thunder Bay, except one who lives in Southern Ontario. All were women diagnosed with PCOS between the ages of 18-41. All of them self-identified as White or European with various heritages. As such, it must be acknowledged that this study may be limited in scope. Further research on how PCOS intersects with ethnicity, race, and class is needed. All six participants were interviewed, and two of the participants also participated in a focus group.

Interviews

I am intrigued by Ellis, Adams and Bochner’s (2011) explanation of reflexive, dyadic interviews.

Though the focus is on the participant and her or his story, the words, thoughts, and feelings of the researcher also are considered, e.g., personal motivation for doing a project, knowledge of the topics discussed, emotional responses to an interview, and ways in which the interviewer may have been changed by the process of interviewing.

Even though the researcher's experience isn't the main focus, personal reflection adds context and layers to the story being told about participants. (para. 18)

In the interview process I intentionally considered the meaning and emotions conveyed by all participants, myself included. It is my hope that this act allowed me to remain conscious of how I filtered and made meaning out of the narratives.

I conducted individual semi-structured interviews (see Appendix A for the interview guide). These interviews lasted between 60-90 minutes and were scheduled at a time and place of the interviewee's choosing. Interviews were carried out in conversation style to enable the interview to flow naturally. Five of the interviews were conducted in person and one over the telephone. All interviews were audio-recorded. I transcribed all audio-recordings verbatim and returned them to the participants for checking. I also sent participants their written profiles for review.

I listened to all of the interviews carefully, making notes of any initial words or themes that surfaced. I specifically searched for themes that related to the research questions and the broader literature with which I framed the study. Listening to the interviews allowed me to reconnect to the voices and personalities of the participants. In addition, I read each transcript, highlighting in color and making notes in the margins where I saw major themes in relation to my research questions. While I looked for passages that related to the research questions, I also searched for any emergent themes from each participant. Emergent themes include responses and experiences that participants shared that were unexpected, or outside of the research questions. Searching for these themes allows experiences and insights that are important to the participants, and that I could not have anticipated, to be included in the research. I sought a balance between pre-determined themes and themes that arose more organically. I then selected relevant passages and put them into a chart for each participant, with a column for each related theme. Based on these initial themes I created a "mind map" for each major theme of education, self-perception, and medicalization. According to Budd (2003), "a mind map is an outline in which the major categories radiate from a central image and lesser categories are captured as branches of larger branches." This tool is especially helpful for mapping out lots of ideas in a non-linear fashion, while still capturing the interconnections. The mind map allowed me to create sub-themes and view the connections between them. From there I was able to condense and reorder themes where fitting. I then created a linear list of the themes that could be easily followed by a reader.

Visual Art

Jocelyn Burkhart¹² was hired to lead a guided-art focus group with all participants, although in the end only two participants and I were involved in this phase. I chose Burkhart because she has a presence in our local community as a competent holistic facilitator who uses arts-guided practices in her work. This experience was valuable in establishing a safe and creative space for the focus group. Hiring a professional also allowed me to be a participant observer in the focus group without having concern over the flow of the day.

¹² Jocelyn Burkhart is a holistic facilitator and compassionate listening presence. She offers one-on-one self-inquiry sessions as well as guided retreats. Her website can be found at: <http://www.jocelynburkhart.com/about/>

The focus group was a four-hour long workshop session held on a Saturday. It took place after all the interviews had been completed. The focus group was intended to create a space for all of the participants to come together and share stories and experiences with one another as a collective, as well as to explore their experiences with PCOS through art. Three participants signed up, but only two participants attended the focus group (Judy and Astrid), so it became more intimate in nature. Burkhart guided the group through various activities. They included a breathing and movement exercise, guided meditations, embodied theatre art, and personal space to work on art pieces.

For the embodiment theatre piece, participants were instructed to sculpt other participants' bodies into tableaux in a way that represented their experiences with PCOS in the past, present, and future. In particular, Judy's embodiment exercise evoked strong emotions in her as she realized, through her past and present tableaux, that she had felt very alone and suppressed in dealing with her PCOS. By contrast, her future portrait showed movement toward a much more open and comfortable relationship with PCOS. Embodiment theatre allows people to connect to their bodies in a way that unearths feelings that are not always conscious, even if we think they are (Jennings et al., 2005). In this way, I think it can be a powerful tool. Jennings et al. (2005) calls this type of theatre "dramatherapy," and suggests that historically it has been an especially powerful tool for facilitating personal growth and mental health but that has been sidelined in the technological push of the 21st century. The focus group did not engage in "dramatherapy," but Judy's reaction demonstrated how PCOS has deeply affected her, and that spaces that support personal inquiry and sharing may offer moments of insight and even healing.

The final activity of the day involved participants creating their own space to work on individual paintings or sketches. Judy in particular gathered much energy from this process and commented that she found it an engaging and healing process. Participants were not able to finish their art pieces as time ran short. Judy took her piece home to finish.

While the setting of the focus group was intimate, I think it would have been beneficial to have had more participants. I came to realize that I had expected other participants to be excited about attending the focus group; that they might see it as an opportunity to connect with other women with PCOS. This may have been the case for those who came, and even for those who did not because of other commitments. Still, I question whether I was projecting my feelings onto them. As a woman living with PCOS, I have often wished for a place where I could share experiences with others. I also highly value art and enjoy painting as a mode of expression, but this is not a familiar or comfortable medium for everybody. Furthermore, as primary researcher of this study, my investment and therefore interest may be much deeper than the other participants. Although my experiences do overlap significantly with those of the participants, I must remind myself that they are not the same. I did my best to honour this in my presentation of the research findings.

As a result of the research learning curve, in future scenarios I would take more careful steps in promoting and designing the focus group stage so that more women might be interested in participating. I do believe that future focus groups for women with PCOS could be a valuable place to share experiences and learn from one another.

Life Writing

I also included personal text-based life writing of my own as another form of data. Smith (2012) argues that life writing is an act of human recovery and healing. He states that: The [life] writing process in a disciplined way allows for the “coming through” of life experiences that don’t count in conventional registers of value, mainly because these registers (status ideologies of intelligence, beauty, etc.) can’t allow for true complexity and deep interdependence of all of life, to say nothing of its subtleties. Life writing is a form of permission-giving, a granting of permission to feel and sense life-responses that have been repressed under dominant dispensations of worthiness. . . . More importantly, it is the life reading of life writing that ensures my own accounts of my own experience do not drown in the pool of my reflection, since awareness of the lives of others rescues me from myself and produces the kind of forgetfulness that is truly life-giving. (p. xv)

I draw inspiration from Smith’s words. Not only do I believe that life writing can act as a tool of resistance against “status ideologies” of femininity, but I argue that in sharing our experience of PCOS, others with PCOS can relate, and be inspired, to share their own story. For example, if a woman menstruates for two months continuously, but feels she is unable to discuss this, her expression with regard to a significant experience in her life is drastically limited. What are the consequences of remaining silent about something experienced on a *daily* basis that appears to be so different from what is taught as normal?

Lee (2010/1994) conducted research that revealed girls are taught early on to hide menstruation from boys and men, including family members. Lee argues that through the telling of stories, women can share insight and analysis on the discourses related to menstruation. In regard to the interviews she conducted, she wrote:

Usually, when the tape had been switched off and women were leaving, they would comment on the benefits of speaking about something that they had never really spoken of in any public way before, something that was an important experience in their lives, but which the society in which they lived, as well as academia, has tended to ignore. (p. 112)

Several of the participants in this study left the interviews commenting on how liberating it was to share their experiences. Sharing our stories can not only open up conversation, but be healing. When I read Kitzinger and Wilmott’s (2002) study, for example, it was the first time I had read about PCOS outside of a clinical context. I thus argue that discussing PCOS in the open and unabashedly, can not only diminish the taboo attached to it but can be a source of healing for other women who have the syndrome.

The text-based life writing I used encompassed a portion of the research. I return to Leggo (2008) who, in defense of life writing, wrote:

It is not easy to write autobiographically, especially in the academy, especially with honesty about many issues, including experiences of failure, fear, and frustration. We need a different culture, a culture that supports autobiographical writing that is marked by an understanding that writing about personal experiences is not merely egoism, solipsism, unseemly confession, boring prattle, and salacious revelation. We need to write personally because we live personally, and our personal living is always braided with our other ways of living – professional, academic, administrative, social, and political. (p. 91)

I also employed self-reflection throughout the study. I wanted to be mindful of my reactions and my own stories throughout the study given my deeply personal connection to the

study (as researcher and a woman living with PCOS). I thus used memoing as a means in which to organize my self-reflection process. According to Groenewald (2004), memoing “is the researcher’s field notes recording what the researcher hears, sees, experiences and thinks in the course of collecting and reflecting on the process” (p. 13). I thus documented what I saw, heard, and experienced throughout the data collection and analysis process.

Ethics

Prior to data collection with participants, formal approval for this study was obtained through the Lakehead University Research Ethics Board. Potential participants were approached by word of mouth (using the snowballing technique), or posters (Appendix J), email (Appendix B), or Facebook (Appendix I). Emails were sent to various university listservs. Posters were placed in the university and in major businesses downtown. Upon expressed interest in participating, potential participants received an official letter (Appendices C and D) explaining the study in more detail, as well as the appropriate consent form (Appendices E, F, and G). These forms were exchanged in person or by email, and informed the potential participants that participation in the study was voluntary and that they had the right to withdraw from the study at any time. Once consent was confirmed, interviews and the group art session were arranged. For those who participated in the focus group, consent also included their agreement to protect the anonymity of other participants. All data collected remains confidential and the anonymity of research participants for those who requested it is protected.

Putting PCOS in the Spotlight

Fisanick argues that “The problem is that [PCOS] lacks visibility” (Fisanick, 2009, p. 109). Kitzinger and Wilmott (2002) argue that more research on how women experience PCOS is “desperately needed,” not only for de-stigmatizing the syndrome and empowering women with PCOS, but for contributing to how medical practitioners understand the ways it affects women as well. Menstrual cycles are not spoken about openly in most forums. In addition, facial and body hair, weight gain, and gendered body expectations in general are also uncomfortable topics. Stoppard (1992) argues that we need new ways of naming women’s experiences that are free from negative connotation. How can we not only talk about PCOS *more*, but also reframe the way we talk about it? Stoppard writes that:

Only when women have a shared knowledge of what a normal woman, complete with normal menstrual cycles, is like will there be a basis for determining when there is deviation from a normal pattern—such woman centered knowledge, properly disseminated, would make possible the validation of women’s experiences in their own right without deferring to a male-defined standard of normal human function. (p. 127)

While it is problematic to recreate norms under the justification that they are woman-centered, it is extremely critical that women have more frequent and safer opportunities to share their experiences with one another openly in order for them to have better control over the health of their own bodies, minds, and spirits.

Personally, using the arts as a method of research has been an act of self-recovery for me. Judy, who attended the focus group, also commented that the art process was energizing, and

discussed how it moved her. Given my own experience and that of Judy, I suggest that it perhaps can be a tool for other women with PCOS as well to work through their relationship with the syndrome. In the words of Chambers, Hasebe-Ludt, Leggo, and Sinner (2012), “By writing about our experiences, often in vulnerable, confessional, personal ways, we are creating spaces for others to join us in conversation about their vulnerable and personal stories” (p. xxvi).

Chapter Five: Stories of the Cystorhood

The (PCOS) 28-day Cycle

I watched Ms. Jacobs walk across the room as she spoke, “And women get their period on a 28-day cycle, give or take a day or two.”

I subtly glanced at the classmates around me, searching for any odd reactions: shock, confusion, anything.

Nothing.

Just a few snickers from those who seemed to feel awkward having this conversation about menstruation.

I glanced down at my notes. Bare. Bare like my period. Bare like my uterus, apparently. I hadn't had a period in almost a year. What the hell was wrong with me? Was I on a 288-day cycle? Maybe she forgot an 8? Maybe if I applied a quadratic equation I could somehow get the number 28?

Ugh, stop grasping at ways to normalize my periods.

Ms. Jacobs continued apace. “And once the period comes, it only lasts around three to five days.”

Shit. My last period, over a year ago, lasted six weeks and I bled enough to fill the Titanic. Why? I wanted to raise my hand, but couldn't risk the exposure. Couldn't risk the hallway questions that would follow. So I sat, quiet and suddenly nauseous.

(Re)Situating Myself

Much time has passed since I began the data collection phase of this study, and I have experienced only one menstrual period. It reminds me of how inseparable my personal story is from the heart of the research itself. I find myself asking, “Am I really discussing my menstrual period in my thesis?” The “delete” key is always present and near, yet I hesitate to censor this aspect of my life that so mirrors the very research I am doing, fueling me with a passion to keep searching deeper and unraveling the layers.

When I think about a women’s menstrual cycle, I think about the 28-day cycle as the golden ticket, the number to achieve in order to be the perfect, healthy woman. How did this number get engrained in my head? Where did it come from? Taking inspiration from the various smartphone apps that now allow you to track your period daily on your phone, I created this painting as a way to contradict the certainty of the 28-day cycle. Period tracker applications for smartphones are new technologies that allow women to track their periods easily. Some of them attempt to estimate when a woman is ovulating based on the data imputed. However, the applications cannot accommodate cycles outside the 21-35 day predicible cycles. In this painting (Figure 2), I have created a period tracker calendar where the woman has indicated she has bled every day of the month. (On many period tracker applications there is a little symbol on the calendar to indicate you have menstruated.)



Figure 4: McKellar, L (2015). *The (PCOS) 28-day cycle* [Acrylic on canvas, 11” x 14”]. Thunder Bay: Canada.

Having been on the birth control pill since I was 13 and for the 10 years following, the visual image of the package with its four rows, 21 hormonal pills, and seven placebo sugar pills is well engrained in my head. The pill is another indicator of how the 28-day cycle has become a standard in relation to menstrual health. Yet as Briden (2015) says:

Pill withdrawal bleeds are not periods. They do not equate in any sense, to the cycling of your own hormones. Pill bleeds are pharmaceutically induced bleeds which are arbitrarily coordinated into a 28-day pattern (solely to reassure you that your body is doing something natural). Pill bleeds could just as easily be coordinated to 56 days or 83 days, or any number of days that the drug company chooses. In 2003, drug companies dropped the masquerade of the monthly cycle, and introduced pills that could be dosed to bleed only twice per year. This is no less “natural” than monthly pill-bleeding, but it did not catch on. (p. 15)

While the medical community does generally agree that a “natural” menstrual cycle for women should occur within 21-35 days, 28 days being the average, Briden makes it clear that a 28-day menstrual cycle on the pill is still an artificial construct. When I first heard from some co-workers of mine that women were beginning to choose birth control pills that forced menstrual cycles to occur only twice a year, I couldn’t help but see the irony. Having tried (and failed) to synchronize my period to the 28-day cycle my whole life, it seemed strange that women would deliberately choose to synthetically induce their periods to occur less frequently. It raised some questions for me. What is a healthy or “natural” cycle for a woman? How important is it that a woman menstruates every 28 days or somewhere close to that interval? I have personally asked gynecologists, doctors, naturopaths, and many other women this question and received different answers.

Briden (2015) claims that pill bleeds are not real periods, that they are artificial because the woman is not actually ovulating and the hormones are synthetic. She claims that the birth control pill is an antiquated medicine that does more harm than good for the female body. It is important to note that Briden is a naturopathic doctor, and while she has over 20 years of experience in working with female reproductive issues, her approach and medical philosophy is often at odds with Biomedicine, a medical community that heavily supports the birth control pill. The pill is the most common treatment of PCOS. It is also prescribed to millions of women across the world for reasons other than contraception, such as for acne, mood swings, and regulation of periods. Yet Briden claims it is harmful to women’s bodies. Indeed, more and more women are choosing not to take the pill because of such concerns. Yet biomedicine offers few alternatives.

I have to stop and ask again: what is healthy for a women’s reproductive system? If women are sometimes being told to have a period at least every three months in order to avoid abnormal growth in their uterine lining, then why are they being prescribed birth control that causes them to bleed less than that? What is clear is that when it comes to their health, women are getting a lot of contradictory messages, and sorting through them to decipher what is best for their own bodies is no easy task. It seems that there are no simple or easy answers to women’s health, even in 2015. In fact, the research findings of this study suggest that there is a lot that we still do not know about women’s reproductive health, and women are living with the consequences.

In the time since I began conducting my thesis research, I have found that the questions I have regarding women's bodies are only growing. In the many conversations I have shared with participants, friends, and women in general, my concern and frustration also has grown. One of the inspiring parts of this thesis journey has been witnessing my own perspective evolve and transform along with those of the women around me. I now find myself asking additional questions to my original research questions, such as: "How many women are being misdiagnosed with PCOS?" and, "Are there different types of PCOS?" as Briden has suggested (pp. 125-127).

On the one hand, it is encouraging to have new questions unfold. It indicates that this is an important area of research with much to explore. On the other hand, I also recognize that because of my deep personal connection to this research, and the various emotions I have experienced along the way, including inspiration as well as frustration and anger, I must be careful in how I proceed. I see now that the overarching theme of my research process has been a somewhat unexpected one: personal transformation. This is more evident to me after speaking to the research participants than it was in the beginning. Many of the questions I have asked, while relevant to all women, have sprung from my own personal desire to discover what is right for my body, and to negotiate how I can come to terms with learning how to live with PCOS. I am very grateful to other women, including the participants, who have helped me along the way to develop a more grounded sense of self, and of a sense of living with PCOS, not simply being a victim of it as an affliction. It is my continued intent to be mindful of the feelings of frustration and anger I have encountered, and not to separate them from the research—which would be impossible even if I so desired—but to be careful in naming when they are present in order to be transparent about how they may be biasing my interpretations and perspectives.

To repeat what I said earlier in this thesis, realizing that this research has largely revolved around personal transformation does not diminish its worth in my eyes. In fact, I understand that my own journey is reflected in the journeys of other women with PCOS, and theirs in mine, and I find comfort and encouragement in knowing that my experience is reflected in a larger community.

Introduction to the Research Findings

This chapter focuses on sharing my and the participants' experiences of living with PCOS. What did they have to say and how can their experiences help to reveal insights for medical practitioners, the participants themselves, other women, and the wider public, on what it is like to live with PCOS? I present and unpack the major themes that emerged mostly from the participant interviews, with a small amount of data from the focus group. These themes were: self-perception, education, and medicalization. Within each theme, participants had a wealth of experiences to share, thus I have broken each theme into sub-categories to make it easier to follow.

Education

How are women educated about PCOS? This was the first research question of this study. This section addresses that question by breaking it into two sub-categories: the Patient-Practitioner Relationship, and Knowledge and Accessibility. The theme of education is of major

importance. As illustrated in the literature review, education on PCOS can mean the difference between proper and improper diagnosis, treatment, and a healthy self-perception. Scholar and medical doctor, Teutsch (2003) argues that communication between the patient and the practitioner that is compassionate and respectful is essential for quality care, and that “Patient–doctor communication serves as a modality for educating patients about their care, including disease evaluation, diagnosis, and prognosis” and that how this is enacted can affect a patients’ perception of their illness (p. 1115). Further, Teustch outlines that the practitioner has the challenge of working with the patient to understand how their quality of life is being impacted, and to what degree they can guide the patient to make appropriate and well-informed decisions on these personal health issues.

Across the board for all participants, they were underwhelmed by the education they received on PCOS from public schools, the general public, and especially from medical practitioners.

Patient-Practitioner Relationship

Visits with a practitioner are where official diagnoses take place and where patients access professional knowledge. Three of the participants were diagnosed by a gynecologist, one by an endocrinologist, one by a general practitioner, and one by a nurse practitioner. Throughout this section I will use the term “practitioner,” unless otherwise specified, to simplify the language. However in this context it refers to any of the medical professionals to which the participants related.

All of the participants described at least one negative or less than satisfactory experience with their practitioner(s). Of these negative experiences, three of the participants used the word “dismissed” to describe how they felt their practitioner treated them. Other words that surfaced included “frustrated,” “insulted,” and “disgusted.” General themes included: a lack of explanation about the pathology of PCOS by the practitioner; late diagnosis; the patient claiming to know more than her practitioner; practitioner insensitivity, judgment, and patronization; patients’ feelings of fear and defeat; lack of support; patient frustration with uncertainty and lack of information; patients’ feeling a sense of powerlessness; and practitioners preoccupied with weight.

It is important to note that all of the participants did acknowledge that their practitioners have, or had, good intentions, or that practitioners cannot be expected to be “human encyclopedias” (Astrid), and that the state of the medical system, which is heavily burdened, does not always support healthy practitioner-patient relationships. These are important points; indeed, the ratio of practitioners-to-patients in Thunder Bay is less than ideal, often resulting in hour-long waits for scheduled appointments, and visits of less than 10 minutes given pressure on the practitioner to move on to the next patient. It is also easy to adopt an accusatory tone when it comes to matters of personal health. Still, these caveats do not discount the experiences of the six participants who, across the board, had varying degrees of frustration and dissatisfaction with their practitioners. The following research findings are not intended to “point the finger” at practitioners, or adopt an “us vs. them” approach, but instead to shed light on ways in which the practitioner-patient relationship may be less than ideal.

In addition to feeling “dismissed” and “frustrated,” four participants went years or even decades without gaining a diagnosis. Furthermore, five of the participants felt that their practitioners did not inquire further into why they were experiencing symptoms, sometimes telling them they simply had “hormonal imbalances” and other times not having any explanation whatsoever. In three cases, when the participants suggested they may have PCOS, they felt their general practitioners did not really know what it is. Four participants felt “babied” or patronized, or that explanations of PCOS, when offered, were over-simplified. Delia stated that her gynecologist told her she did not need to know certain details about PCOS. Two noted that they had less than ten minutes with the practitioner. Treatment offered for irregular menstruation was consistently the birth control pill. Tracy remarked how she is a “textbook” case of PCOS, yet she was never diagnosed with it until she herself brought it up with her doctor. She also noted how no brochures or literature were ever shared with her by her doctor.

The fact sheet [that my nurse practitioner gave me is], like, basic facts for “patient level” understanding. It’s insulting.... they just went into talking about treatment options, and without really explaining what the benefits of taking these treatment options [are]. (Astrid)

I feel like women's concerns with PCOS are often kind of dismissed.... And I really feel like that was my experience. It was sort of, like, “Oh you have this thing, don’t worry about it, here is the birth control pill.” (Fran)

So my laser lady was the one who brought [PCOS] to my attention. Not the doctors earlier when I had even gone in and said, you know, “Why am I so hairy?” (Judy)

In Tracy’s case, she actually “diagnosed” herself. Tracy asserted that she felt she always knew more than her doctor about PCOS. In fact, she felt like she may never have been diagnosed at all had she not done her own research. Similarly, Judy presented the option of having PCOS to her practitioner after the woman who does her laser treatment suggested she might have it. Astrid also stated that she had to explain to her nurse practitioner why the diaphragm was a viable alternative option to the birth control pill. While both Judy and Tracy played a direct role in getting a diagnosis, all of the participants stated that they felt they had to take their health into their own hands and do their own research in order to compensate for what they believed was “inadequate information” from their practitioners.

My doctor's never spoke to me about symptom managing.... Is it because the doctors don't know? Or that they couldn't be bothered to actually teach me about it? It wasn't really a choice. I had to educate myself, or just be uneducated... And I don't think that's fair. They never mentioned that I now have an increased risk of ovarian cancer... I have a cousin with PCOS, and my best friend has PCOS...the doctor's have never, *ever*, talked to them about symptom management, or connected them with any kind of resources. (Tracy)

While I expected that participants had likely done a lot of their own research, I was surprised at the extent to which almost all of them felt like this research was the only substantial information they had on PCOS. Although the Internet is certainly helpful for accessing information, it is not

the sole replacement for education that could (or should) be offered by a medically trained professional. Yet, participants did not feel they had the luxury of this option.

In addition to feeling like their practitioners provided them with inadequate information, participants also felt that their practitioner was matter-of-fact or insensitive when delivering the diagnoses. In some cases, they felt that their practitioner was judging them or made them feel “filthy, dirty and disgusting.”

I remember [my gynecologist] was super matter-of-fact about it, and I didn't think too much of it and... I was at work and I Googled it, and I just started bawling... And then I had to call her back and be like, “What the hell is wrong with me?” ... And so I just remember it being like, “You have a cold. You have PCOS maybe.”
(Zoe)

The very first time I had a long period I was freaked... It's been three weeks, why am I still bleeding? And not just spotting, bleeding. And I was exhausted, and it hurt, and I was feeling pale... So I went to the [emergency]. I was treated awfully. Everyone who dealt with me acted disgusted by me. The doctor had to give me a physical examination, and I could hear the blood clots plopping. When I got up to go put myself back together, I could see the globs of my blood on the floor. And the look on the doctor's face and specifically the look on the nurse's face... it was like she was watching a car accident. I was treated so poorly and I was so embarrassed and ashamed that I never wanted to ever talk to a doctor about my period again. It was so brutal. And ... they didn't really even treat me.
(Tracy)

If some of the participants felt unsafe to discuss their menstrual health and patterns, it is hard to imagine how they could receive proper treatment. In response to feeling judged by their practitioner, some participants felt fearful of asking questions or as though they had to justify themselves in either wanting to know more information or second-guessing what their practitioner said, despite the fact that they were inquiring about the health of their *own* bodies. Fran mentioned that she feels hesitant to bring concerns up with her doctor because she is afraid her doctor does not listen to or believe her. Fran's practitioner in particular had lost or misplaced her records several times, and forgotten her previous diagnosis with PCOS. In response, Fran actively had her records from her gynecologist sent to her practitioner to prove her diagnosis. Fran also brought her partner to the office as she felt having a male presence would cause her doctor to take her more seriously. The fact that Fran had to bring her partner in to feel heard is concerning. If a patient does not feel like she can express her concern about her own body, how can she get proper medical attention? This feeling of fear often led to many participants having unanswered questions around their health.

Participants shared feelings of defeat and exhaustion from trying to find answers to their questions and solutions to deal with their symptoms. In some cases, participants had spent years and even decades trying to get rid of unwanted hair, become pregnant, lose weight, or regulate periods, with either little or no success. Worse, they often felt like they were alone in their efforts. Tracy mentioned the fact that she felt there was no emotional support offered through the long and complicated medical process of trying to conceive, which she said caused her to want to give up.

Related to feelings of defeat and exasperation were also feelings of powerlessness. Defeat denotes participants' desire to give up, whereas powerlessness involved feeling like the situation was out of their hands or like they were not in control of all the decisions concerning their health. Not only did participants indicate that they had limited treatment options to choose from, but Tracy felt like the medical system would not allow her to switch practitioners even though she was very unsatisfied with her current one. Tracy also commented on how previous visits with the doctors had caused her to feel shame, and like her period was something that she should have dealt with on her own, privately. Similarly, Astrid noted that she could only get health tests done if her medical practitioner agreed it was called for. Both their stories denote the power imbalance in the patient-practitioner relationship, and leaving them with a sense of powerlessness. Unless her nurse practitioner *felt* that tests were required, none would be ordered. The decision was always out of Astrid's hands.

A continual theme, then, in the participants' comments was that their health was in the hands of their practitioners, who they too often had little faith in. As Astrid's comment suggests, if her practitioner didn't feel the need to look further into her symptoms, she was unable to seek medical diagnosis and treatment. To be fair, if practitioners ordered tests for every concern their patients had, it would be an enormous cost to the medical system. But where is the line drawn between unnecessary and necessary testing? When does or should expert opinion override "lay" or lived experience?

It is important to highlight that the word "powerlessness" that participants used does not denote a complete lack of agency. As noted by Fran's fight to order her medical records and present them to her practitioner in order to prove she had PCOS, participants often did vigorously advocate for themselves to secure diagnoses and receive treatment. As mentioned, participants also went to great efforts to do their own research about PCOS.

Participants were not only frustrated and concerned about the lack of support, but also about the amount of uncertainty they felt about their health, whether due to their relationship with their practitioner or the limited amount of research on PCOS in general. For instance, Fran was unsure as to whether living with PCOS has long term affects on your health, beyond daily inconvenience or stigma. Astrid expressed how it is difficult to have your expectations broken, for example around planning to have children. It was clear that most of the participants did not have substantial explanations as to why their bodies were functioning the way they were, or whether their health was at risk.

Participants also felt that the treatment options presented to them were limited. For treatment of irregular menstruation only the birth control pill was offered to all six participants. Metformin and/or spironolactone were prescribed for weight gain, acne, and hair growth to two participants. Two participants noted that alternative medicine, such as traditional Chinese medicine, or specific lifestyle changes were not presented as options. This was frustrating to participants. For example, although Fran cannot be sure if the two are related, she has found that since she began weightlifting her periods have been more regular. After researching this topic herself, she discovered that weightlifting has helped many women with PCOS, and was frustrated that this had never been presented as an option.

Conversely, two participants who had symptoms of weight gain and difficulty losing weight had more experience of practitioners suggesting lifestyle options like weight loss and dieting.

...the thing that troubled me was the specialist I was seeing was so heavily focused on my weight all the time. Without any kind of examination of my body. Just, "Lose weight, lose weight, lose weight" every single time I would see him.... He sent me to see a dietician and there was no connection between polycystic ovary syndrome and difficulty losing weight. (Tracy)

Fran mentioned that her practitioner felt she was not "fat enough" to have PCOS. This raises some questions on how practitioners are diagnosing PCOS. Has being "overweight" become so associated with PCOS that it is one of the only symptoms popularly seen to mark the syndrome? Hall's (2002) article in *The Guardian* suggests that this may be the case. In our weight-obsessed society, this suggests that some practitioners may be isolating their diagnosis and treatment of women with PCOS purely based on weight without accounting for other contributing symptoms and factors. The participants also suggested that their practitioners equated weight with being unhealthy or as contributing to PCOS, again without considering other factors. This weight bias is highly problematic. The medical practitioners focus on managing participants' body weight resonates with writing in fat studies, which makes clear that fat is a feminist issue with society, including mainstream medicine, being obsessed with women's weight (Rothblum & Solovay, 2009).

The research findings left no doubt that the women in this study were less than satisfied with all or some of their practitioner(s) and felt they received inadequate diagnoses, treatment, and information. PCOS is clearly a complex issue and no single cause can be determined. As previously noted, practitioners cannot be expected to know everything; they have significant pressures and expectations on them, and many patients to see. Furthermore, as indicated by changing diagnostic criteria, research on PCOS is contradictory and inconclusive, making it difficult for practitioners to keep up to date with the latest findings and to provide solid answers to their patients. However, this does not lessen the concerns of the participants whose experiences point out that the patient-practitioner relationship is less than satisfactory. To what degree do practitioners have a responsibility to keep up to date with the latest research on PCOS, particularly if they are specialists in women's health? If practitioners are not up to date, or if research is inconclusive, can we at least expect them to name this in their conversations with patients? These are questions not to be ignored.

Knowledge and Accessibility

The main theme discussed in this section is the general lack of information on, and knowledge about, PCOS outside of the practitioner-patient relationship. The following ideas emerged within this theme: limited public knowledge of PCOS; inaccessible information; women's health as under-researched; gendered information; and the absence of a discussion of PCOS in elementary and secondary schools.

Despite the fact that all of the participants researched PCOS on their own time in order to better inform themselves, most still struggled to get a comprehensive grasp on what PCOS is and how it may be affecting their bodies. When asked how they would explain PCOS to somebody, participants struggled to produce definitions. As might be expected with the name "Polycystic Ovarian Syndrome," four participants explained PCOS as having extra cysts in their ovaries. What is interesting about this explanation is that, within the last decade, many medical

professionals have argued that PCOS cannot be diagnosed based solely on the existence of cysts in the ovaries; indeed, in 2013 an independent panel assembled by the National Institutes of Health suggested changing the name of the syndrome based on the argument that it is misleading and raises barriers to “research progress and effective patient care” (“Panel recommends changing name of common disorder in women”, 2013). In fact, it is possible to have PCOS and have no cysts in your ovaries, and it is not uncommon for the “average” woman to have multiple cysts in her ovaries at some point in her life without the symptoms of PCOS (“Panel recommends”, 2013; Briden, 2015, Clayton et al., 1992). Participants either did not mention or did not know this. Judy did offer a deeper explanation of PCOS by describing some common symptoms. To be fair, I asked participants to explain PCOS at the beginning of the interview when some participants may not have been comfortable yet; the question may have caught some participants off guard or even felt like a test. I also asked participants how they would describe PCOS to *another person*. This changed the answer as three indicated that they would describe PCOS to another person in a less detailed, and more simplified way than their fuller understanding of it. For example, Tracy called her explanation to someone a “sound bite version.” Furthermore, explaining anything, especially scientifically, can be a challenge when put on the spot. Still, two participants admitted that their knowledge of how PCOS is actually affecting their body is limited. Zoe said that her knowledge is very limited and she feels confused.

Participants also remarked that they had difficulty accessing quality information about PCOS and that it was not well known in the general population. Three participants remarked that very few of their friends had known PCOS existed prior to discussions with them and that conversations they had with people about PCOS tended to be brief unless they were close friends.

The subject of limited access to quality information about PCOS raised the broader issue of woman’s health and women’s bodies being undervalued and under-researched in comparison to men’s (Vidaver et al., 2000; National Research Council, 2010). Wong (1998) argues that historically there has been a hierarchy of diseases, where women’s diseases are said to matter less than men’s; that women’s health research has been isolated to reproductive issues and that clinical trials have not included women as frequently as men due to the diffuse, less “clear-cut” symptoms in their bodies. Essentially, this means that in some cases women have been treated with medicine designed for men. Fortunately, this trend is currently changing (National Research Council, 2010).

Many participants recognized that a lack of information was not isolated to PCOS, but that knowledge about women’s bodies in general is still outdated in comparison to men’s. Tracy commented that she felt women’s issues in health care are often “overlooked”, and Astrid remarked that even though she went to a hospital specifically for women, she still felt that she was given insufficient information. Astrid went on to assert that, “A lot of our health care suffers because of systemic ways of studying things that are based on male bodies.” In reference to this issue, it was a common response for participants to say that as women they had to go out of their way to understand their bodies. It is very troubling that they feel that their own health care has been marginalized, and when extrapolating this to the larger questions about women’s health care in general (National Research Council, 2010), it is disturbing to ponder the repercussions this imbalance must have for half of the world’s population.

As noted, participants did much personal research about PCOS. They were actively advocating for themselves in order to gain a better understanding of, and treatment for, their health concerns. Tracy asserted that women's health is generally undervalued so that women are forced to fight to make people more aware of their health issues and to advocate for more research on women's health:

I think it's really uncomfortable for people to talk about women's periods, women's bodies, body hair; it makes everyone uncomfortable.... For example, it was only 1996 that it was discovered that the clitoris is more than just the little nub that sticks out. 1996! You know what I mean? Women's bodies—things that are specific to women, we have to fight to make people aware about it. (Tracy)

Although it may be uncomfortable talking about PCOS, not talking about it only serves to enhance the discomfort. To complicate things, the information available about PCOS is itself sometimes explicitly and strangely gendered in that PCOS disrupts normative femininity. For example, Astrid brought to the interview a fact sheet that her nurse practitioner had given her and that explained that women with PCOS might expect “male patterned hair growth and hair loss.” Such a statement is clearly gendered given its implicit assertion that certain types of body hair do not belong on women's bodies. While it is easy to understand how such a statement might be considered an acceptable way to explain the hair growth, it indicates how deeply rooted and limited gender expectations are in our society (Lorber, 2010). The way in which PCOS and gender is medicalized is a strong theme later in this chapter.

All of the participants felt that PCOS should be discussed in health classes in elementary and secondary schools as long as it was raised with other relevant topics. In their experience, however, it wasn't. Some participants noted that they were not taught to expect anything other than the 28-day menstrual cycle and so were confused when their menstrual periods were irregular or absent.

I guess when I learnt about sex ed and whatever, I never learned about [what] doesn't always happen... And, so when you don't get what you are expecting to happen, I was just waiting. I was like, “When is it gonna happen?” ... I am like, “Why am I not going through this?” (Delia)

When I was 13, 14, and taking health class, it might have been comforting for somebody to say these are different syndromes and diseases. ... I could have been sitting there as a 14 year old going, “I have a mustache, and maybe this is why?” And not feeling like, “Oh my god I am just this hairy, unfeminine thing”.... Because, yeah you tell girls [they] have 28-day cycles, and that's gonna mess them up. (Judy)

I never received any kind of formal education about the woman's reproductive system beyond women having a uterus, ovaries, and a vagina. You know what I mean? ... “And once a month a woman sheds the lining of her uterus”... for someone who's watching all their friends talk about how they started their periods, and that not happening for me. When you're 15 years old and every last one of your friends has had their period for a couple of years, and you still

don't—I lied about it. I told people that I had my period. Because I felt like such an outcast. (Tracy)

As Astrid noted, discussion of PCOS gives rise to uncomfortable topics that many people are hesitant to discuss. The outcome of people refraining from discussion, however, is someone like Tracy feeling like she had to lie about herself in order to feel accepted or “normal.” Tracy didn't even feel like her practitioner felt comfortable discussing her period, let alone her health class teacher.

As is demonstrated by the participants' stories, if young women are only being taught about the 28-day cycle, when they do not experience this themselves, they can be confused, feel marginalized, or even think something is seriously wrong with them. Given that estimates say PCOS affects five to 10 percent of the population (Verity, 2008), one in 10 young women could be learning material in health class that is not related to her body. That is making a generous assumption that the rest of the young women in the class have 28-day cycles, which is unlikely. The consequences of this are that women can be seriously under-educated about their bodies and feel marginalized for not being “normal.” Culturally, female reproductive issues are awkward to discuss (Lee, 2010/1994). Lee (2010/1994) argues that women learn early that “to talk of menstruation in contemporary Western culture is to articulate its secretive, emotionally laden, and shame-filled aspects” (p. 102), and that women learn from a very young age to “hide all evidence of menstruation from boys and men, brothers and fathers” (p. 110). Discussing menstrual issues in the context of health class would thus have to be done sensitively, giving consideration to those who may be experiencing “unusual” symptoms and may feel vulnerable. The fact that it is uncomfortable, however, clearly does not mean it should be avoided, as the participants' stories confirm. Moreover, the consequences of not learning about their bodies at a young age can carry over into adulthood, as Astrid's story illustrates:

I found just talking to other women in the [Women and Trans Centre], most women did not have a very good idea what their vaginas, or vulvas, or cervixes actually looked like, or how things actually functioned. Which I found sort of disturbing, the lack of information that women had on their own bodies that they live with every single day.... Interesting at the same time that university educated women, most of them in their 20s, didn't know very basic things about their own anatomy. And that means that there is a huge gap. And then talking to women about sex, and, reproduction, and sexuality, you really realize how much women don't actually know. Unless you are willing to have conversations about your body and how it functions...you are not really gonna know. (Astrid)

Part of the reason I depicted female anatomy in my “The naked skinny cystor” painting (Figure 1) was in an effort to learn more about the female reproductive anatomy myself. I also do not recall ever learning about anatomy or how the female body works in health class; the focus was primarily on contraception and sexually transmitted diseases. If women do not know how their bodies work, how can they take agency over their health?

Education on PCOS, whether through the practitioner-patient relationship or among the general population, was a major area of concern for these participants. Their experiences suggest potential areas for improvement such as the need for more research about PCOS, the need for practitioners to be more aware of PCOS, including its psychological effects on women, and the need for schools to share more inclusive information about girls' and women's bodies in health

class. Lack of education also relates to the topic discussed in the next section: the effects PCOS has on the self-perception of women with PCOS.

Self-Perception

I was curious how PCOS might affect the self-perception of women. What the participants living with PCOS on a daily basis described illuminated some troubling patterns. It was clear that PCOS did affect their self-perception and identity negatively, some more than others, although it is important to state that not *all* experiences were negative in nature. The participants all found themselves in a state of flux, continually reassessing their relationship with PCOS and how much they wanted to let it define themselves. To some degree, the participants have no control over this, but they nonetheless all actively sought to come to a place where they were “at peace” with, or accepting of PCOS and their bodies. Since several important themes on this topic emerged in the study, this section is broken down into five subcategories: PCOS as Challenging Normative Femininity; Internal Struggle; Depression as an Unacknowledged Symptom; Division/Competition Amongst PCOS Women; and Personal Transformation.

PCOS as Challenging Normative Femininity

All of the participants felt that symptoms of PCOS posed a major challenge to normative femininity, stating that they felt less feminine because of facial hair or irregular periods, for example. Participants spent a lot of time on this topic in the interviews; it was clearly a major concern to them. The themes that they discussed overlapped extensively with the findings of the Kitzinger and Wilmott (2002) study. I am including this sub-category in this section because the overlap serves to amplify its relevance. In particular, the participant perspectives on failing to “achieve” femininity resonated deeply with that of the Kitzinger and Wilmott finding that the word “freak” was commonly used in this context. The words “shame,” “embarrassed,” and “gross” also surfaced multiple times.

Participants described the stigma they felt was associated with the symptoms of PCOS—especially surrounding irregular menstruation, body size, reduced fertility, and facial and body hair—and how they felt marginalized as women as a result. Many participants felt that the symptoms of PCOS can be considered masculine, and how this caused them to struggle with feeling feminine. Zoe spoke about how PCOS makes her feel “less than adequate”, and Delia remarked that it’s hard for women to feel attractive when they have what are considered to be “masculine” traits. Fran noted that irregular menstruation has been very distressing for her, especially since she already had difficulty feeling accepted as a teenager.

All of the participants experienced irregular menstruation at some point in their lives, while four of them continue to have this experience. They commented on how the irregularity challenged their notion of femininity, or on how they perceived that others, including medical practitioners, viewed them as grotesque. Fran recalled how her period would come suddenly at school and leak through her clothes, which led to brutal teasing by classmates. Tracy shared how irregular menstruation affected her femininity.

Not having regular periods caused me to struggle with my femininity. I kind of disconnected for a few years with my identity as a feminine women. I went

through a whole phase of, like, well my body isn't gonna be feminine, then I am not gonna act or dress feminine. For me it was definitely like I can't relate to other women because I haven't had a period in two years. (Tracy)

Some participants also alluded to regular menstruation as being an essential symbol of entrance into womanhood. Zoe mentioned that she viewed menstruation as "sacred." When some participants either had irregular periods or did not get a period until very late in their teens, this made them feel even less feminine. Interestingly, their friends often considered them lucky for bleeding less often, perhaps without considering the effects it had on participants' fertility.

It is interesting that some people considered the participants lucky for having infrequent periods as this suggests that some people do not make the connection between irregular menstruation and issues of reproductive health. For these people, perhaps a period merely represents a few days or a week of inconvenience. In my life, it has also been common to have friends or acquaintances say I am lucky that I have periods less often. However, some people may not know that when women have less frequent periods it is not uncommon for them to be horribly heavy and to last weeks at a time, up to even six months, alongside the potential of being unable to conceive or having a higher risk of cancer (Carmina & Lobo, 1999; Chittenden, Fullerton, Maheshwari, & Bhattacharya, 2009; Dumesic & Lobo, 2013). This situation only further reinforces how little menstruation is spoken of in public circles.

In order to regulate their periods, all of the participants went on the birth control pill at some point in their lives. Zoe mentioned that even though the pill allowed her to regulate her periods and have a 28-day cycle, she still felt unfeminine. Periods induced by synthetic hormones made her feel artificial.

This is the other part that makes me question that whole woman thing is that my period is to a degree falsified, right? It's not natural. I'm choosing when it happens, and that makes me think then: are my periods fake? Am I just a fake woman? (Zoe)

If menstruation is commonly viewed as the "marker of womanhood," then having to artificially induce periods can feel like a façade. Furthermore, birth control does not help regulate periods over the long term, in fact it only makes it harder as many women experience post-pill withdrawal where they cannot experience regular periods for years afterwards (Briden, 2015).

The subject of irregular menstruation was closely linked to discussions of fertility. Irregular periods, or a lack of periods altogether, was a constant reminder to participants that becoming pregnant might be difficult. When the body menstruates on a regular cycle, it is an indicator of health and of a body that is prepared to conceive; when it does not, it is essentially telling you that you are not ready for pregnancy (Briden, 2015). Several participants noted that the possibility of having difficulty conceiving affected them more than any of their other symptoms.

[Infertility has] been the biggest one out of all of it. ... But I remember just feeling like it was a defect. To me the big struggle that I keep thinking about is: does this still make me a woman? How does this hamper my ability to be a woman, if I can't have kids? If I can't, can I still be a mother figure? (Zoe)

I don't know, the kids, the possibility of not being able to have kids was ridiculous. Because it's so drilled into girls' minds when they are younger that... "Here is a doll, play baby"... I always grew up and I was, like, when I am old I am going to have family, and I am gonna make a family, and when I was diagnosed with PCOS I was like, "What am I gonna do? Where is my future headed?" (Delia)

For these participants, having children, somewhat like menstruation, was an essential aspect of being a woman and it almost felt a loss of identity when they were confronted with the possibility that they may not be able to do so. Tracy remarked on how having children has become so synonymous with being a woman that people expect it, to the point that they feel free to question why a woman does not have a child

If you're not a mom, then you're not a complete woman. Right? Cause most women are [mothers]. The vast majority of women have a child at some point in their life. [...] But, when you're the "odd man out" in any scenario there is always this stigma of you're not doing women right somehow.... You don't hear a lot of people asking men, "So when are you gonna have a baby?" They don't ask men that.... But people really feel free asking women that question all the time without even a second thought [what] that question might be really triggering. (Tracy)

Zoe and Astrid felt that their potentially reduced fertility might affect their worthiness as people and desirability as a partner. Zoe said she was worried that her possible inability to have kids would be a "make-it-or-break-it" situation with her new partner. Astrid admitted that she feels more pressure to have another child because she is 34. Tracy also commented on how increased risk of complications with childbirth after the age of 35, or 40, puts pressure on women to conceive earlier or faster. In Tracy's case, she has tried to conceive for several years with no success, and feels the pressure to begin to start thinking about adoption as an alternative. Both Tracy and Delia described adoption as a last resort option, noting that the adoption process is not without its own struggles. Delia felt that adoption would not be the same as giving birth to her own child. This suggests that there may be wider societal attitudes towards adoption being perceived less "real" than biological childbirth. Bartholet (1993) discusses how the language around adoption favours the genetic parent. For example, adoptive parents are often asked if they know about their child's "real parents", and that language and attitudes frame "adoptive parenting relationships as less powerful, less meaningful, less loving than blood relationships" (p. 167). Miall (1996) notes the social construction of infertility as a "problem," to which extensive and costly technology has been produced, reinforces the notion that adoption is always a last resort. This is problematic for several reasons including the repercussions it poses to the development of both parent and child in an adoptive relationship. For the interest of this study, it indicates the deeply entrenched stigma that is associated with reduced fertility. It is associated with a failing of the individual, and adoption as something to be avoided at all costs.

Although not explicitly stated, I suspected a sense of loss or grief amongst four of the participants who faced the prospect of never having their own children. This has been my own experience as well, so I recognize that I may be projecting this onto the participants. Still, when girls are raised to be mothers, and they grow up hearing stories of how long other women were in labour, or what it was like to hold their baby for the first time, these are marked as pivotal experiences that many women look forward to. It is not uncommon for women to say the

happiest day of their life was either when they got married or the moment their child was born. Facing the prospect that these moments may never occur can induce, then, a sense of loss and mourning. It is important to also note that while these sentiments are common to many women, they certainly are not representative of all. Indeed, it can be argued that motherhood is too closely tied with womanhood to the point where women who are voluntarily childless are also stigmatized (Park, 2002; Chancey & Dumais, 2009). Fran noted that the prospect of reduced fertility did not bother her as she has no desire to have children. She and her partner solidified this intention when he recently got a vasectomy.

Facial and body hair growth is another symptom that also caused a lot of turmoil for participants. Such hair growth causes considerable anguish because it is more visible than some of the other symptoms, and participants went to great lengths to hide unwanted hair. Facial hair is considered strictly masculine in conventional Western society (Kitzinger & Wilmott, 2002), so it is no surprise that this symptom caused participants to wrestle with feeling unfeminine. Tracy stated that facial hair was the biggest struggle for her of all the other symptoms she experiences.

I think the facial hair is absolutely the hardest one, over and above the fertility. It's the biggest one for me.... There are days where if I am out all day, and then in the evening I happen to rest my chin on my hand and I can feel my five o'clock shadow, I feel a lot of shame and embarrassment about that. And I will find that I start tipping my chin down, in case someone else can see it. (Tracy)

Of the three participants who experienced unwanted hair growth, two of them spoke about how they spent time in their daily routine disguising hair growth, especially on the face, not wanting it to be seen publicly. Tracy commented on how many women not only hide their facial hair, but avoid all talk of it whatsoever.

I feel it causes so many symptoms in women that I think makes them disconnect from their femininity, or makes them feel like they haven't earned their femininity. Or that they're too masculine because of these symptoms brings a lot of shame. So it's embarrassing to talk out loud about a thing that makes you more masculine. You know? Especially if you don't wanna be. I don't wanna be seen as masculine. So, to walk around, talking about how I have to deal with facial hair is ... counter-intuitive to me expressing as a feminine woman. (Tracy)

Judy also discussed how she has struggled with unwanted hair growth. She mentioned that she has made an effort to discuss PCOS with her two children who have seen her shaving and found it strange that a “mom” would shave her face. She also admitted how dependent she is on the tools she uses to remove her hair, including razors and electrolysis. She reflected on a reaction she had to a book she recently read where a major disaster happens and sends the world into a pre-industrial state:

[As I was reading this book] this horrible thing...popped into my head...: “Oh my god, if that happened... Eventually there would be no more razors. I certainly wouldn't be able to have laser treatment. What would happen?” ... In that book, it's the end of civilization as we know it. “Oh my god, what am I gonna do about my beard?” The *end* of civilization, you know? ... How have I been programmed to think that that's gonna be the worst of my problems? I'm gonna have children that I gotta make sure that those kids get fed, and they survive. But, one of the first things in my head as I read that book is what am I gonna do about my

hairyness? [...] And how would that affect how I present myself to the world?
(Judy)

Judy acknowledges that hair removal has become an inseparable part of who she is. Her fear of what would happen to her if her tools were taken away reveals how vulnerable she would feel in that situation and the degree to which her unwanted hair makes her feel abnormal. She believes the hair alters her identify and how others perceive her. Zoe similarly commented on how hair growth has affected her socially, saying she has felt so uncomfortable that she has hindered herself from engaging in certain activities, and she was hesitant to even mention it as a symptom during our interview until the very end. The fact that Zoe would avoid certain activities because of unwanted hair growth reflects how deep the associated stigma goes, to the point that the hair is affecting her quality of life.

Some participants even remarked that their hair growth affected their relationships and ability to be intimate.

I am really comfortable with my partner.... I will let him watch me wash my armpits.... But he can't see me shave my chin. I feel like that's the most unfeminine thing I have to do in my daily routine. (Tracy)

Zoe mentioned that she brought it up with one partner and worried that she seemed “freakish” in his eyes. It is really concerning that women feel they have to hide hair from their partners. As Judy commented, depending on the nature of your relationship, your partner is commonly perceived to be the one person in your life whom you can share everything with. The fact that women would feel this way indicates how much they are afraid it will affect their ability to be loved or accepted. Yet men grow hair on their face and chest and it isn't second guessed. The arbitrary line that has been drawn around something arguably as harmless as hair growth has, for these women, become very harmful to their sense of worthiness as women.

On top of hair growth, weight gain was also a symptom that affected some participants' intimacy with their partner. Only two of the six participants named weight gain as a symptom of their PCOS, a small number given that “extra” weight is commonly associated with the syndrome and said to be a symptom for 80% of women with PCOS (Briden, 2015). Both Judy and Tracy discussed how weight gain has affected them.

...hormones can have a very physical effect on your body, and the increased levels of testosterone were present in my body from who knows at what point, we didn't check until I was 18. And I have to wonder, cause I have very broad shoulders, and I have very large feet, and I have very large hands, and I have to wonder if letting those hormones run through my body unchecked kind of shifted the way my body developed.... So that was part of my connection with femininity too.... Am I even really a woman? I went through a whole thing with that. I've kind of reclaimed my femininity now, so it's not really as much of an issue, but yeah.
(Tracy)

I remember being thirteen or something and sitting down... I think I was sitting on the toilet, and I was looking at how my belly just sort of sat on top of my thighs.... Even with [my husband] who I am very open with, I can't [have sex]

with the lights on. I'm okay with you touching me, I don't want you looking at me. (Judy)

While weight gain and difficulty losing weight made Judy and Tracy question their femininity, they also asserted that they were generally body positive and learning to love bodies of all sizes, most importantly their own. On the topic of body positivity, Tracy and Fran made two relevant points that I think shed light, not only on how becoming body positive is an ongoing practice, but how deeply the idea of “thin as attractive” is engrained in our culture. Tracy noted that body positivity does not occur overnight, but that it is a lifelong process, and Fran noted that it took her a lot longer to develop a consciousness about body positivity than other aspects of her femininity. She also observed that there are a lot of women with PCOS in the Health at Every Size movement¹³. However, Tracy and Fran discussed how difficult it was and still is for them to accept their bodies as they are, although Tracy says for the most part, she no longer says negative things to herself in front of the mirror. The stigma of weight gain on women is so strong that it can take a lifetime to come to a place where someone can accept and love her body. Their attempts at body positivity could be seen as part of what has been called the “fat acceptance” movement in fat studies circles (Wann, 1998), and their awareness of, and interest in, the Health at Every Size movement (Burgard, (2009) was encouraging.

Between body size, reduced fertility, irregular menstruation, and body and facial hair, most of these women living with PCOS have been struggling to live openly with their symptoms while still feeling like “complete” women, as Zoe said, or identifying somewhere along a feminine spectrum. One symptom of PCOS not yet mentioned is depression. In the next section, I reveal that several participants experienced depression and perceived it as a possible symptom of PCOS that may be insufficiently addressed.

Depression as an Unacknowledged Symptom of PCOS

Depression has been listed as a symptom of PCOS, and some research has been done on the ways it interacts with women with PCOS (Eggers & Kirchengast, 2001, Hollinrake et al., 2006). Most of this research comes from a medical context. I myself have wondered to what degree depression is connected to hormonal changes or to deflated self-esteem caused by other symptoms, or both. A study by Hahn et al. (2005) concluded that biochemical, endocrine and metabolic parameters had less of an impact on quality-of-life, psychosocial well-being and sexual satisfaction than symptoms of weight gain and hair growth. Bazarganipour et al. (2013) as well as Barnard et al (2007) suggest that there is enough correlation between PCOS and anxiety and depression to warrant medical practitioners to evaluate women with PCOS for mental health disorders. Deeks, Gibson-Helm, & Teede (2009) found that anxiety existed at higher levels than depression in women with PCOS, but that it is underdiagnosed.

Four participants mentioned depression as either something they personally experienced or had not been warned about as a potential symptom by their practitioners. Two participants were unsure of whether or not their depression was even related to PCOS. Tracy said her doctor never spoke to her about dealing with the psychological issues connected to PCOS or the way

¹³ The Health at Every Size Movement supports healthy habits and workout routines that encourage wellbeing, instead of weight control, with the overall goal of reducing obesity discrimination.

one can feel about the impact of hormones on the body. Delia also noted that PCOS can give women really negative self-esteem. Fran's reflection reveals just how much PCOS can affect a woman's life:

Even if it's not seriously impacting your life, even if you don't feel sick, or something actively, it does sort of feel like your body's out to get you or something when [you experience symptoms]. And to have that dismissed is like somebody doesn't care about your self-perception or your self-identity. How you feel in yourself as a person.... Your hair falling out, or getting hair where you don't want hair, you know what I mean? Or weight gain, or any number of those sort of symptoms that I think aren't taken seriously because they are not life-threatening but they do impact somebody's quality of life. (Fran)

These participant's experiences resonate with my own. I do not ever recall a practitioner discussing the possibility of depression with me. More research in the area of depression and how it interacts with PCOS, as well as training medical practitioners on how to approach depression as a symptom, could be beneficial for enhancing the quality of life for women with PCOS. Fran suggested that the fact that depression is apparently not being addressed with patients may indicate that it is not taken seriously by medical professionals. In her case, she felt that she was dismissed based on her history with mental health issues.

I think there is a certain mode of health care, of prioritizing particular people or concerns over others.... So, even from the perspective of mental health professionals too, I think, it would be good for them to be aware and realize that [PCOS] does have a lot of emotional affects and I think that there is a tendency to medicalize those much too easily as, "Oh this person is depressed," or something like that. When, it's rooted in experience in your life. (Fran)

Fran suggests that she was actually discriminated against due to her mental health history, whether or not it was related to PCOS, and that this may have led her practitioner to take her less seriously and not look into possible causes and treatment.

The participants' stories suggest that perhaps depression is not addressed as often as it should be as a possible symptom of PCOS. Unfortunately, as Fran suggests, this may have adverse consequences for women living with the syndrome. I am not necessarily suggesting that depression should be medicalized more for women with PCOS, although this may true in some cases, but that more research on how it is related to PCOS and how women experience it may be beneficial in how they are educated.

Division/Competition among PCOS Women

In addition to feeling stigmatized by society in general for the symptoms of PCOS, participants also reported feeling division within the "PCOS community" depending on which symptoms they experienced. Some participants noted that the symptoms of PCOS can be ranked somehow on a scale. Participants also remarked that during their interactions with other women with PCOS they sometimes felt guilty if they did not exhibit as many symptoms as the other person. Fran noted that people had told her she doesn't look like she has PCOS.

I guess I am lucky that I didn't have more symptoms. I have had other women with PCOS say that to me too. I certainly sympathize but I also don't really know what to say to that. (Fran)

The idea that PCOS can be detected by looking at someone reveals the high association PCOS often has with facial hair and weight gain particularly around the waist area. It is concerning that Fran's practitioner felt that PCOS can be diagnosed based on appearance when accurate diagnosis for PCOS can only be done with various blood and ultrasound testing (Robinson et al., 2005; Briden, 2015). Again, this focus on weight indicates how weight is too often seen as the "problem" over other health factors.

It is important to state that the majority of participants did not actually have symptoms of both weight gain and facial hair. This underscores the challenges involved in determining exactly how to define PCOS, including how understandings of PCOS are linked with symptoms with high visibility and stigma, and perhaps also a general lack of awareness of the different "types" of PCOS. Although these participants were still diagnosed, as discussed above, it was not always right away. Briden (2015) suggests, for example, that there are four types of PCOS, not all of which include weight gain as a symptom. I will address this subject in more depth in Chapter Six. One thing that is certain is that PCOS cannot be diagnosed based on outer appearance alone. Yet some women feel that they have to prove or justify their PCOS if they don't demonstrate all the symptoms. For example, Delia was unsure whether she even wanted to participate in the research because she felt she might not have enough experience with PCOS.

I was hesitant as to whether or not I wanted to talk about it. Because I also thought my experiences with this don't have an impact. What I have to say doesn't matter really. I am pretty young, I am not as affected by it. 'Cause I know a lot of other women are. (Delia)

She suggests that some women's experiences with PCOS are more important than others. Are certain symptoms of PCOS so stigmatized that some women with PCOS internalize them and resent those who do not have those same symptoms? Might they even engage in competition over who has the worst experience of PCOS? Tracy said she could see how some women would judge other women with PCOS based on their symptoms, thinking, "Like, oh, so you have PCOS? Well, whatever, suck it up. I have PCOS worse than you do" (Tracy). Judy discussed how she felt resented by some women with PCOS because she was able to have two children without major issues.

When I mentioned to Judy that women who have PCOS but do not exhibit weight gain are called "skinny cystors," she was surprised. She felt that this term actively separated certain women with PCOS from others. Judy noted that she has been hesitant to join support groups because she felt like she had to "meet all the things on the symptom checklist" in order to be supported. The fact that some women with PCOS feel they have to prove or justify that they even have the syndrome, or that others resent one another for lacking certain symptoms, shows how deeply PCOS can affect women's self-perception.

Internal Struggle: To Shave or Not to Shave?

Although participants variously acknowledged that standards of normative femininity are unrealistic, supported body positivity, or didn't agree with the stigmas associated with the symptoms of PCOS, they nonetheless spoke of experiencing internal struggles around acceptance of themselves and their own bodies. This indicates that the repercussions of culturally enforced gender standards often fall on the individual, who in the case of women with PCOS may be struggling with low self-esteem. The participants spoke about their continual love/hate relationship with themselves, their effort to accept themselves for who they are, and their disappointment with themselves when self-acceptance remained so difficult.

You just feel caught in this mess of what are my values, and am I letting myself down? ... I don't like that flip flopping of feeling bad about something and then feeling okay about it. I don't want to feel apologetic as a human being, let alone as a woman. (Zoe)

Regarding shaving, Delia mentioned it can be a double-edged sword: if women do shave, they are often viewed as insecure, but that if they do not, they can be judged as "gross." Judy noted that she has wanted to be feminist, but is also embarrassed by her beard, as if the embarrassing disqualified her from being a "real" feminist. She also shared that even though she consciously wants to admire women who do not pluck or shave their chin hairs, at the same time she is also sometimes disgusted by them.

I find it very concerning how often the blame seems put on the individual, who as the experiences of participants' demonstrate, can be caught in turmoil no matter which choice she makes, whether she shaves or not. Although some participants wanted to be able to let their hair grow out, for example, the risk of discrimination felt too great. While some participants felt disappointment about their personal reactions, at the same time they recognized they are not simply "victims." Rather, they displayed honesty and resilience in their commitment to continue reflecting on their relationship with PCOS and are working to find a place of inner peace or at least to acknowledge and live within the tension. This element of personal transformation is the subject of the next section.

Personal Transformation

Despite the various negative ways in which PCOS affected the participants, it is important to note that they were also in various stages of becoming comfortable with their diagnoses and symptoms. Three stated that PCOS has challenged them to grow as people. Judy remarked on the humor she has developed with regards to PCOS: "I can make jokes about it. I call myself the bearded lady to my boys, and stuff like that. But, not everybody is as comfortable with that." Zoe and Tracy shared how PCOS has challenged them to grow.

I think it's just made me more curious about what it means to be a woman.... And I don't feel I have an answer, and I don't feel at all that I am comfortable with what I've figured out, and I don't feel like I am comfortable with myself as a woman yet, but it's making me figure it out more.... All those things, I think my

view on what it means to be a woman really stemmed from me figuring out from that first moment that: does it mean to be a woman to have children or not? Does it mean to be a woman to have hair on my body or not? Those were the things that really came up along the lines of discovering that I had PCOS. [...] But then I do feel thankful that I am in a situation to focus on what it means to be a woman. It's that love-hate relationship. I hate that I am having to figure it out but I love that I am having to figure it out. (Zoe)

You know there's part of me that's, like, "I think I am attractive." If I saw myself walking into a room, I would be like, "Damn, who is that? And why isn't she like getting with me right now?" But then there's that subconscious voice that, like, "Everyone can see that mustache hair. Everybody's judging you 'cause they are thinking that you are a man now...." I've rejected [that phase where I didn't want to act or dress feminine] now, because I am a feminine woman and I am not gonna not wear frilly things or pink socks like I am wearing today just because I don't ovulate regularly. Like, that's absolutely ridiculous. (Tracy)

While these participants felt like they lived in a state of constant contradiction, as indicated by these passages, they also had the tenacity to be comfortable with that tension. Some participants may have questioned their "feminism" because they shaved or otherwise took measures to "adhere" to normative femininity, but their understanding that such acts are much more complicated, and their resiliency and resolve to sit within this tension, is arguably the most feminist act of all.

Medicalization

The topic of medicalization was the focus of the last research question I address in this section: How, if at all, has the medicalization of PCOS shaped these women's identities and the way they understand the syndrome and seek treatment? Three major themes emerged from the interviews that will be explored in this section: Illness, Biomedicine as Limited, and Biomedicine as Beneficial.

Illness

The way the social construction and stigma of illness affected participants came up in relation to several themes, including the limitations of language, the body as failing the patient, and hierarchies of illness. Throughout this section I will use the term "illness" to refer to health issues such as syndromes and diseases. I am aware that this term is general and can be perceived to have a negative connotation. However, given the limitations of language, I think it best captures the stigma related to the array of health issues I will address here.

The common vocabulary we use for discussing illnesses can be very limiting. Astrid was the only participant who spoke specifically about feeling frustrated about the types of words that are commonly used to describe illnesses like PCOS, stating that they were negative and stigmatizing and make people feel inadequate. Throughout the interview she hesitated to use words like "abnormal" or "dysfunctional," but struggled to come up with better words to replace

them. Words like “abnormal” and “dysfunctional” have discriminatory undertones and cause unease to women like Astrid. The fact that our language does not have alternative words that frame illness in a more positive manner reveals how the stigma of illness is part and parcel of our culture.

Perhaps in relation to these words, many participants alluded to feeling that their body was somehow deficient or failing them. There was a sense of disappointment and as though their bodies were broken or somehow less adequate. Fran said that sometimes PCOS makes her feel like her body is “against her.” Some participants also suggested that they felt they had no control over their bodies. This was very upsetting for Delia, who discussed how the labeling of PCOS as “abnormal” made her feel a sense of loss in how she understood her identity, stating that the word “syndrome” has made her feel like less of a person.

In two cases, participants were shown an ultrasound of their polycystic ovaries next to an image of “normal” ovaries. Both Delia and Judy spoke about how the image shocked them and made them feel like their bodies were even more abnormal.

And I couldn't believe how many [holes] are there. It essentially just looked like somebody just shot my ovaries full of holes. (Judy)

Not all participants were “disturbed” by their bodies, however. Astrid spoke about how she wasn't ashamed of her body even though she still didn't think it was functioning as it should.

I don't think of my body as dysfunctional, although obviously it's not functioning as it's supposed to. In an ideal world. [...] I have had this body, I've been menstruating for almost twenty years. And it's always been messed up and that's just how my body is. (Astrid)

As can be expected, participants were at various places in terms of how they perceived their bodies as “ill.”

I told participants how some members of the PCOS Association Facebook group have debated about whether to have an awareness month for PCOS, with certain members thinking PCOS wasn't “fatal enough,” compared to other syndromes or diseases, to have a month to its own. In response, some participants noted that there is almost a hierarchy of illnesses in which some are deemed more fatal or “worthy of awareness” than others. In response to this, Judy said PCOS can be “fatal” in the way that it affects a woman's self-esteem and quality of life. Tracy also commented on the ranking of illnesses based on rates of fatality:

[PCOS] doesn't have the same power as a disease that will eventually lead to your death. But it also, in a way does, because I mean there's a significantly increased risk of cervical cancer, for women with PCOS...But, there's a lot of people who'd be like, "Oh, who cares about PCOS, it's not like you're gonna die from it." [...] [PCOS] definitely negatively impacts a lot of women emotionally, and psychologically. (Tracy)

Tracy and Judy noted that PCOS can indeed lead to increased risks of cancer, heart disease, and diabetes, although the research on this is inconclusive. Aside from the physical risks, they also noted the emotional and psychological aspects of living with PCOS. Again, it would seem that the mental health and wellbeing of women, as it can be affected by PCOS, is often overlooked. Illnesses with higher immediate fatality rates should undoubtedly be treated seriously. However, paying attention to fatal illnesses does not negate the fact that illnesses which may not prove fatal, or as fatal, are still worthy of our attention, and in fact may affect people in ways we did

not originally anticipate.

Biomedicine as Limited

Two of the participants discussed how biomedicine is limited in its scope, claiming that it has created very narrow, ideal health standards that do not necessarily represent the “average” person. For these women, they found such understandings of health limiting and difficult to place themselves within. The work of Lorber (2010/1993) and Butler (1990) on binary thought is reflected in how biomedicine restricts bodies to being healthy/unhealthy with not much of a spectrum. The result is that many bodies are “unhealthy” or “abnormal.” Astrid and Zoe compared the approaches of biomedicine and traditional Chinese medicine in explaining what they meant by this. Astrid noted that being “normal and healthy” according to biomedicine is almost statistically impossible. Both noted that biomedicine can represent a “boxed” way of thinking that can stigmatize bodies. Zoe noted that biomedicine is quick and efficient to “get to the masses” and that this is very different from naturopathic medicine that works with individual body types. Both Zoe and Astrid suggested that naturopathic or traditional Chinese medicine viewed the body and illness in a more holistic manner that they found less stigmatizing. That being said, neither of them has had success yet with those methods. Three of the participants reported that they had tried alternative medicine, with one claiming she had had some success. A consistent observation from these three participants was that alternative medicines are too expensive to commit to in the long term, yet they often take years to fully work. Judy also mentioned that the schedule she had to follow for taking supplements was very regimented, requiring her to take them at various times during the day. This made it difficult for her to follow as a mom of two who is running her own business.

This fact that alternative medicines often require long-term commitment is seen as a downside by some. They are not always straightforward and fast-acting approaches like Biomedicine. Treatments can be complicated and individualized, and it therefore takes time to decipher what works best for each person (Briden, 2015). Yet, although Biomedicine typically works quickly, it is often seen to mask health problems in the short-term as opposed to proactively treating them. Furthermore, Biomedicine often creates side effects that can sometimes be just as problematic as the original health-related issue at hand. Snyderman MD, Chancellor Emeritus of Duke University, summed this up well in his address during the 2009 Summit on Integrative Medicine and the Health of the Public: “What we have now is a ‘sick care’ system that is reactive to problems.” Indeed, pharmaceutical companies comprise the most profitable industry in the United States (Conrad, 2007). Many alternative medicines, however, such as traditional Chinese medicine, work to realign the balances of the body, and although they may take a longer time to achieve the desired results, treatment can often last a lifetime (Briden, 2015, Kapthcuk, 2000). Briden (2015) illustrates this comparison well with the example of the birth control pill:

The pill is a predictable band-aid solution. It delivers a strong synthetic estrogen, so it clears up pimples. It forces a withdrawal bleed, so it reassures you that you’ve had a period (when you really haven’t). It overrides your own hormones and literally erases any pesky report card symptoms.

On the face of it, it's difficult for natural period repair to compete with pill medicine. Natural period repair cannot force a bleed, but instead must persuade your body to have one. Natural period repair cannot override your own hormones, but instead must work with them.

The advantage of natural period repair is that it is gentle and without side effects. The biggest advantage of natural period repair is that when it does work, it works forever. Improve your period with natural treatment, and it will stay improved, for as long as you remain healthy. In that way, period repair is a far more powerful and permanent solution than the pill could ever be (p. 5).

Despite the claimed long-term advantages to “natural period repair,” practitioners have never once offered this option to me.

Participants also mentioned how they were offered few, if any, alternative treatment options to the birth control pill or other Western prescriptions. Fran discussed how she felt she had never been given options for treatment. She noted that some of the pharmaceuticals she had taken were causing more problems perhaps than they were helping with, and that the medical system does not offer enough lifestyle management approaches or alternatives to pharmaceutical treatment.

The contrast between Western and alternative medicines became more visible to me personally in a recent visit I made to my gynecologist. I wanted to find the root cause behind why I do not ovulate. Briden (2015) claims that this knowledge could aid women like me in finding the best treatment since naturopathic medicine has an array of treatment options for irregular menstruation depending upon the causes. However, since the birth control pill is the only treatment offered for irregular menstruation by Biomedicine, my gynecologist saw no benefit to deciphering exactly why I wasn't ovulating. Regardless of the reason, the birth control pill would be what was prescribed. Yet the pill itself hinders ovulation. It is a short-term solution. Although I would like to regain ovulation with the long-term vision of conceiving, the Western approach is to continue birth control until desired pregnancy and then begin fertility treatments—both short-term pharmaceutical solutions. The problem with this approach is that in order to conceive, a woman *must* ovulate. Most affordable fertility treatments only work when a woman has somewhat of a regular cycle. If a woman experienced irregular menstruation before going on the pill, chances are it would be even worse afterwards. The short-term benefit of Biomedicine can come with consequences, and one must weigh the pros and cons. Zoe mentioned that, while the birth control she was on helped regulate her periods, it also made her feel unnatural. While she was thankful for the birth control pill, she also acknowledged that she didn't want to be dependent on it. Ultimately, she was looking for treatment that could bring her body into natural harmony.

In this section, I want to be clear that I am not suggesting that alternative medicines are *better* than Biomedicines. Such a claim is not something I can make given my lack of professional qualifications. Rather, I want to highlight that treatment routes are not straightforward for women with PCOS or irregular menstruation. And while Biomedicines come with their side effects, alternative medicines are simply not affordable for most women and are not always successful. Again, this only further demonstrates how challenging it can be for women to nurture healthy bodies when faced with a phenomenon like PCOS.

Biomedicine as Beneficial

As mentioned earlier, it is easy to point fingers at the shortcomings of Biomedicine when we are seeking answers to our health challenges or looking for someone to blame. While participants did indeed have many concerns about Biomedicine, there was also general agreement that it was helpful and appreciated, especially given that it provided some of the only options for immediate treatment of the symptoms of PCOS. The participants reminded me that biomedicine has helped manage symptoms that participants found too difficult to live with, such as hair growth or reduced fertility.

I am also on spironolactone to deal with that, and it's completely helped. It totally helps me, and that's because it's medicalized... [Unwanted hair] was just constantly on my mind. So then I was taking this pill and I don't have to think about it anymore, I can think about other things. (Zoe)

Fran noted that she was glad she went on the pill because, being a teenager at the time, it reduced her stress significantly. But she also observed that, had she been in a more supportive environment, she might not have needed it.

When faced with immediate discomfort around unwanted hair growth, for example, Western medications like spironolactone allowed participants to feel less inhibited, significantly improving their quality of life. Three participants reported that they are very grateful for Western medications, and Tracy, for one, remarked that she did not believe naturopathic medicines were a viable alternative for her. Undeniably, Biomedicine is hugely beneficial to people around the world on a daily basis. I would argue, then, that rather than choosing either Western or alternative medicines, paired together the two approaches might complement each other and create more well-rounded treatment options for women.

Summary

To summarize, in Chapter Five I discussed the research findings in relation to the research questions. To review, the research questions included the following:

1. What are the stories and experiences of women with PCOS?
 - a. How were these women educated about PCOS, and how does PCOS affect their self-perception and the way they relate to others?
 - b. How, if at all, has the medicalization of PCOS shaped these women's identities and the way they understand the syndrome and seek treatment?
 - c. If limited education about PCOS is found to be an issue for these women, how and where do they imagine re-education might occur for themselves and others?

These questions were ambitious and broad, and while I think that the research findings offer only an introductory look into the possible answers, I believe they do offer some valuable insights.

Regarding education, the research findings revealed that the patient-practitioner relationship was insufficiently helpful. The participants felt inadequately educated about PCOS by their practitioners. Participants reported that their practitioners did not explain PCOS to them, and in many cases they received a very late diagnosis, sometimes because their practitioner was unaware of PCOS or did not wish to test for it. Many of the participants felt they were more

knowledgeable about PCOS than their doctor, and almost all of them felt they had to research PCOS on their own to understand it better. They were also generally unsatisfied with their relationship with their practitioners, often feeling dismissed for their concerns or that their practitioner was insensitive. Several of the participants felt fearful of approaching their practitioner to inquire more information, or felt thwarted in their attempts to do so. Participants often felt alone and that there was a lack of support for them. They were particularly frustrated over the lack of information provided to them. They found the many uncertainties they were presented with troubling as this impeded their ability to make decisions about the health of their bodies. Several of the participants exhibited a sense of “powerlessness” as a patient, encountering barriers to gaining adequate diagnosis or treatment. Other participants also remarked that their practitioner focused primarily on their weight without considering other factors of PCOS.

Another compelling theme that emerged was the general lack of information on, and knowledge about, PCOS outside of the practitioner-patient relationship. Participants felt that the general public does not know much about PCOS. Several also pointed out that women’s health in general is under-researched, and that PCOS is medicalized in a gendered manner. Further, participants noted that PCOS is not discussed in public schools.

In relation to self-perception and how women with PCOS relate to others, all of the participants felt that symptoms of PCOS pose a major challenge to normative femininity, most stating that they had felt at times less feminine because of facial hair, weight gain, reduced fertility, or irregular periods. Participant used the words “shame,” “embarrassed,” and “gross” multiple times and spoke about the stigma they felt was associated with the symptoms of PCOS. Many participants also felt that many of the symptoms of PCOS can be considered masculine, and that this notion caused them to struggle with their sense of femininity. The topic of depression as a symptom of PCOS also surfaced, and many participants were unaware to what degree depression was related to PCOS, and disappointed that it was not addressed by their practitioners. Some participants also discussed how they felt there was a division among women with PCOS, and that they either had to prove they had it or felt guilty if they did not exhibit certain symptoms. It was also common for participants to question their feminism and struggle internally with accepting their bodies as they are versus changing them to adhere to standards of normative femininity. In the end, most felt that living within this tension was a feminist act in and of itself. In most cases, participants had come to a place of peace with PCOS. Finally, participants also reported personal transformation, stating that PCOS has challenged them to grow as people and that it doesn’t define them.

In relation to medicalization and how PCOS is described linguistically, one participant noted that the language for discussing illnesses is limited and often negative. She stated that new, more positive, vocabulary is needed. Participants also suggested that they felt their bodies were failing or acting against them, and expressed discomfort at their lack of control. It was also noted that certain illnesses are prioritized over others like PCOS, particularly fatal illnesses. This does not negate the fact that illnesses that may not prove fatal, or as fatal, are still worthy of our attention, and in fact may affect people in unanticipated ways. Another issue that was raised was that biomedicine is limited in its scope. Participants felt that they had limited treatment options. At the same time, not all participants believed naturopathic medicine is a viable alternative.

Almost all of the participants noted that, while limited, biomedicine is also beneficial and needed, and that it had improved their quality of life.

I now move to Chapter Six where I will focus on the future by reporting on participant responses to the final research question: If limited education about PCOS is found to be an issue for these women, how and where do they imagine re-education might occur for themselves and others?

Chapter Six: Putting it All Together

This study has integrated my own narrative with that of the narratives of others. It is only appropriate, then, that the concluding thoughts speak to my personal journey and interpretation of that journey, as well as the journeys of the participants. In this chapter I turn to the future by reporting on participant responses to the final research question: “If limited education about PCOS is found to be an issue for these women, how and where do they imagine re-education might occur for themselves and others?” I will then conclude with some closing thoughts.

Before addressing the final research findings in relation to participants’ reimagining education about PCOS, I first want to revisit my painting (Figure 1) because it is a tangible example of how much stigma is attached to the symptoms of PCOS and how difficult it is to discuss women’s bodies and gender roles in public. I noted at the outset of the thesis how this painting has been a transformative tool for me in my journey to better “understand” PCOS. This painting brought to the surface the inner thoughts I had harboured about PCOS for many years. However, in hindsight, I realize I have changed since I first created the painting in February 2014. At the time I had long cultivated feelings of frustration and guilt. These feelings co-mingled with the shock I experienced in my teenage years when my doctor recommended spironolactone for “excessive” hair growth, as if hair growth was somehow a disease on a woman’s body. I had been frustrated with a lack of treatment options and explanations for why I didn’t menstruate regularly. In talking to many women with PCOS since that time, I was able to share and have these feelings heard, as well as hear the feelings of others living with PCOS. The resulting sense of community transformed my consciousness of PCOS, shifting my focus away from feelings of anger toward motivation and commitment. I saw that other women refused to be defined by PCOS or its associated stigmas; rather, they were defining themselves.

When I first created my painting, my intention was for the piece to explore the female body as experienced by a person living with PCOS. For centuries artists have painted portraits of nude/naked woman. A “nude” woman was painted as sweet, innocent, and a virgin (Cranach, 1530-34; Titian, 1538). The “naked” woman, however, was painted with connotations of shame and humiliation (Clark, 1956). Over the centuries artists have altered conventional ways of representing the nude by painting masculine or “grotesque” versions of the naked female body (Matisse, 1907; Picasso, 1936). The woman in my painting is lying in a position typical of classical nude paintings, yet I altered the notion of an innocent female body by adding elements of perceived shame, humiliation, and “shoulds.” This woman’s body does not conform to all standard gender expectations. As typical of someone with PCOS, she is hairy where she “should” not be, and hairless where she “should” have hair. She has small breasts and she is fairly thin despite the fact that a common symptom of PCOS is weight gain. As previously mentioned, PCOS women who are thin are referred to in jest as “skinny cystors” because they fall outside the norm of PCOS. This suggests that PCOS is not something that can be labeled specifically but rather is a box of sorts in which women who have various reproductive issues are placed. PCOS, then, like gender, is a construct and includes a full spectrum or range of expression.

While earlier naked paintings were traditionally done from the male point of view, this painting adopts more of a medical perspective. We see the woman’s anatomy through the lens of PCOS; for example, her ovaries have extra cysts in them. I labeled the woman’s body parts to mimic the labeling of medical diagrams. However, I used stigmatizations instead of anatomical

names. The medical perspective extends to her posture, which mimics the popularly depicted position a patient might take in a therapy session. I chose this “double take” to express the internal emotional issues that can accompany PCOS and the way the diagnosis of PCOS as a “syndrome” can problematize the patient and turn her into someone who is not “normal.” This medicalization of the female body reinforces stigmatization by continuing a dichotomy of what is feminine and what is not. Images of birth control are on her uterus to symbolize the medical treatment of PCOS with synthetic hormones that do not harmonize the natural cycle of the body but artificially manufacture it. Women are strongly associated with their ability to reproduce and give birth to new life. As discussed, if a woman cannot conceive and give birth, her identity as a woman can be challenged.

I have found that some of my perspectives on PCOS and my response to this painting have changed in the time that has passed. After I began this study, Lakehead’s Canada Research Chair in Arts-Integrated Studies, Pauline Sameshima, opened three new galleries in September of 2014. My painting was featured in “The Junction: Where Science Meets Art” gallery that is located in the Northern Ontario School of Medicine (NOSM). These galleries intend to share research and learning from Lakehead faculty and students in artistic and accessible ways. Within a few days of the gallery opening, several complaints were made. Five to 10 people and/or employees of NOSM were agitated or offended by my painting and some asked that it be removed. No other art pieces at that gallery received complaints. Concerns included that it was a potential workplace hazard that could offend or agitate employees, and that it was aesthetically displeasing in nature. Once art is released into the world, it is open to interpretation. Its meaning can significantly change based on the person viewing the art and their own personal experiences and backgrounds. Having now talked to women with PCOS, I know that not all of them feel comfortable speaking publicly about having the syndrome, for their own reasons. I wonder, then, if the painting may be considered too “public” for those who perhaps are made uncomfortable or even feel shame about PCOS, and would prefer to keep it quiet and out of sight. For others, the painting may be seen as gratuitous in its representation of female anatomy, or perhaps it represents too great a challenge to the conventional notion of what is considered beautiful?

In the time since I made this painting, I have questioned some of the choices I made. For example, why did I make the woman bald? While a symptom of PCOS is hair loss, I chose to take an extreme approach and made her completely bald. I asked myself, then, if I was distorting PCOS to provoke the viewer. It is true that I wanted to stimulate critical thought. Because the bald head was the only “symptom” on the painting that I did not personally experience, I then began to wonder if it was appropriate to paint an experience I did not have and therefore could not necessarily relate to in the same way. Was my painting not “honest”? Is it easier to represent something if you don’t face the stigma or repercussions of the experience itself? At the same time, some women choose to be bald as an aesthetic preference. For some, it is seen as an act of resistance to feminine ideals. On the other hand, bald heads have also become symbolic of the “sick” body or of someone with cancer.

It seemed like what I thought was an innocent act of expression had become much more complicated when placed before the public. I have come to understand that this painting was indeed an expression of my relationship to PCOS at the time that I made it. The choices I made when creating the painting weren’t really choices in that they were not necessarily conscious or intentional. The canvas, rather, was a space for me to represent my internal thoughts and

feelings. This space and process is one aspect of what art is. It can capture a moment or thought in time.

The reaction to the painting caused me to think more deeply about how PCOS can or should be depicted in public. How might education be beneficial, how might it do harm, who does it support, and what does it accomplish? Some women with PCOS would rather keep PCOS hidden, while others see visibility as normalizing. The reaction of the NOSM employees only confirmed to me that what our culture currently accepts as beautiful and acceptable for the female body is limited, and that stepping or being pushed outside of those limitations can cause discomfort. I am reminded of a statement by Tracy who commented on how challenging it is to speak publicly about women's bodies.

When it comes to women's bodies and discussions in the media, it's a very sticky place. People feel free to comment negatively about a women's body or femininity. Like women's bodies are public property. So, you know, being open about something that causes or that is linked to obesity, that causes increased risk of acne, that can cause loss of hair on your head, that can cause body hair to grow where it doesn't normally grow on women's bodies. To talk about that stuff openly, it's making yourself a target. It's putting yourself in a uniquely vulnerable place. Because women's bodies are supposed to be one way, and one way only.

And that's attractive, submissive, and the property of others. (Tracy)

Tracy's comments are sobering. Discussing women's bodies publicly is risky because the stigmatization is so strong. I don't think people would have reacted so negatively to my painting had it not triggered strong discomfort. While it takes more and more aware and assertive people to be willing to publicly speak on women's bodies to change these norms, being one of the first is, as Tracy says, putting oneself in a vulnerable place. Not everyone wants or can be expected to do this.

It strikes me as even more profound as well as curious that the reaction to the painting came from faculty and others in a medical school, where students are being trained to be medical practitioners who will deal with women's bodies and health. (Interestingly, when the painting was displayed in the Faculty of Education building, in the Lakehead Arts-Integrated Research (LAIR) gallery, there was not a single complaint.) These medical professors and staff arguably should be the most open and accepting of conversations around women's bodies. NOSM recently developed a Humanities Working Group, which is interested in the ways in which humanities subjects such as art, literature, film, music, and theatre can enhance medical education. Some believe the humanities can enrich the teaching of medical science in the curriculum (Grant, 2001). They can offer insight into how medicine interacts, and could interact, with society, for example by increasing empathy and compassion in practitioners (Reilly, Ring, & Duke, 2005). If NOSM is an environment dedicated to raising awareness about health and wellness, how did my painting contribute, or not, to that goal? Are medical practitioners educated enough on the effects of PCOS on women, not only physically, but psychologically and emotionally? This experience with my painting, and my thesis research, suggests they are not. If this is the case, I argue that this painting was hung in precisely the right place! I am not suggesting that my painting represents any absolute, universal truth about PCOS; it is a representation of my own personal journey with PCOS. What it offers is an opportunity for discussion on topics we too often avoid.

Based on the reactions to my painting, which I shared with participants, I asked them whether or not they thought there should be more awareness about PCOS and whether they would like it to be “more in the open.” This also relates to my final research question: “If limited education about PCOS is found to be an issue for these women, how and where do they imagine re-education might occur for themselves and others?” The responses of participants were varied and interesting.

Participants suggested that awareness on PCOS should be increased, and four placed particular emphasis on the education of medical practitioners in relation to PCOS and how it affects women. Fran noted that because what medical practitioners know about PCOS is so inconsistent, she felt that distributing information to them, as well as to counselors, was most important. Astrid stated that, as an example, because she could have known she had PCOS 15 years ago but didn't, this suggests that women's health should be taken more seriously. As Judy mentioned, earlier diagnosis could be very beneficial in preventing heart disease or in efforts to increase fertility. Tracy and Fran raised some particular insightful questions when it comes to responsibility:

Maybe it wasn't a failing of [doctors] to inform us, it was a failing of them to even know about it. Maybe. But then does that fault lead back to where they were educated? Where they went to school, or how far back do you draw the line? [...] I think it's really important for any doctor who deals with women ever, should really know about it, because I am finding that a lot of women, more and more, are getting this diagnosis of PCOS, and have really no idea how it's gonna impact them long term. (Tracy)

I do think awareness would be good though, because PCOS really does impact your life. I had a lot less symptoms than a lot of people and it did impact my life. Especially as a young person. Right? And, nobody really understood what I was going through. You know? Like even my parents didn't really? It was just sort of this very quick brush with this gynecologist, and like, "Oh she is on the pill now, don't worry about it." So even from the perspective of mental health professionals too, I think it would be good for them to be aware and realize that it does have a lot of emotional effects. (Fran)

As noted earlier, participants spent a considerable amount of time during the interviews discussing their relationship with their practitioner. A lot of their emotional intensity was connected to this, especially feelings of frustration and anger. Increased training for medical practitioners about PCOS and how it affects women could make a huge difference in how women are diagnosed and live with PCOS on a daily basis. Fran also mentioned how increased awareness about PCOS in general can be beneficial for people who know women who have PCOS and may not know how to be supportive.

Participants also discussed their opinions on whose responsibility it is to educate women on PCOS. While they agreed that medical practitioners should be more educated, they also acknowledged that education is a shared responsibility.

I mean, whose responsibility is it? It is always at least somewhat the responsibility of the person who is affected by it. Obviously. Because you have to take ownership of your own body and your own health. And it's really important to

educate yourself. But for a doctor to give you a diagnosis and never tell you anything about it, that seems like it's a failing of the medical field.... I definitely feel like there needs to be more information available. The fact that, you know, I am talking to women in their mid-twenties and telling them to ask their doctor about it, and they've never heard of it, and they have all the symptoms. There's obviously a disconnect there. (Tracy)

While I agree that women do have responsibility to educate themselves about their bodies, I also think it is important to note that not all women have the same educational backgrounds or experiences. I worry that placing too much responsibility on women to educate themselves could enhance the class divide, where those who do not have access to knowledge on how to access resources would be at a disadvantage. For this reason, I regard Tracy's and Zoe's point as crucial: medical professionals and organizations should help to guide women to the appropriate resources. My research also suggests that more adequate resources need to be easily accessible.

Participants commented on how increased education could enable the symptoms of PCOS to be more easily understood and accepted in society. At the same time, it is clear that increasing awareness is not as simple as hosting a "Walk for PCOS" campaign each year; it is more complicated. Zoe and Tracy spoke about how difficult it is as individuals to speak openly about women's bodies.

Maybe one day I will have a baby and, you know, I will find all these great ways of dealing with body hair. But the fact is that I am still having to deal in a way to make me fit in. And, it's *not* fair. And you know what? I don't want to be the person to change that. I want it to change but I don't want to be the woman that lets it all hang out. And says "accept me for who I am." I don't wanna deal with it. And I wish I did. I wish I could make that statement and have that self-confidence to do that, and that drive to say, "Fuck you", but I don't. . . . There's definitely things in [this interview] that I would totally be so embarrassed about to have shared in public... I don't mind my thoughts and stuff being shared because other woman are going through it—but like I said, I just don't want to be the frickin' poster child. I'm not ready to do that. (Zoe)

It is unfortunate that women can be stigmatized both when they resist gender norms, for example by not shaving, or when they try to adhere to them but can never completely "achieve" them. In both cases, the discrimination falls on the individual. Yet in order for this cycle to be broken, people must begin to speak out. The situation leads to conflicting feelings as Zoe has demonstrated above.

Still, Astrid asserts that the more women share their stories with each other, the more normalized they will become.

It's important to have conversations with other people about their menstrual cycles and how much they bleed. Cause you are not gonna know. So it's a lack of a conversation around things because people either just accept things as normal, or they are uncomfortable about talking about things. It is super nice to talk to women. And until people value that, and having women's spaces where women can actually have conversations, we are always gonna be walking around thinking that we are completely abnormal, or normal, or have distorted notions of what's within the scope. [...] Cause as soon as you are able to have those conversations,

it creates space for other people to have those conversations. And normalizes it.

Which I think has a huge impact socially. (Astrid)

A thesis like this one may be one small step toward having those conversations with women. I know that Astrid's comments really resonate with me. The more I had conversations with the women in this study about my experience with PCOS, and the more I heard about their experiences, the more I felt connected to a community. During the focus group, both participants reflected that the interviews had left them with a lot to process in regards to PCOS. Judy thus stated that she was very excited to participate in the focus group and that she felt it could be very relevant to many women, not just those with PCOS. In reference to the power of sharing, during the interview Delia said "I think it would be really comforting to feel, to know that I am not the only person who knows about it." Zoe also said something at the end of the interview that was particularly humbling: "But it feels really free, I've never talked about this aspect with anyone. My mom, yes, but I have never talked about the hair aspect with anyone, *ever*."

Academic journals are not always accessible to the public, even if they include arts-integrated research. I thus want my thesis research to be more accessible and available to anyone who wants to read it. This thesis will be shared with all the participants and on various PCOS Facebook groups. I will also endeavor to have parts of the thesis published. While I don't expect this thesis to change the world's perspective on PCOS, I do hope that the conversations I had with participants might impact in some small way the lives of the women who were involved. At the very least, I know that my personal transformation has been significant.

A few weeks ago I visited my gynecologist. Briden's (2015) new book on period health addressed a lot of questions I had related to PCOS and my irregular menstruation. I even began to wonder if I even have PCOS. How amusing, and ironic, that I find myself asking that question after over a year of researching the topic. Yet, the fact that I ask that question is indicative, yet again, of how much we simply do not know enough about women's reproductive health. The question of whether or not I have PCOS does not take away merit from this study, but reinforces the serious concerns around how women are being diagnosed and treated for reproductive issues.

When I came across Briden's (2015) book, a lot of my own questions and concerns around PCOS were addressed. I felt empowered with more affirmation and direction in my quest to secure an accurate diagnosis. Finally, I thought, someone else (Briden) was asking and even answering some of the questions I have had for so long. Briden claims that PCOS is being misdiagnosed and overdiagnosed, and she is not alone in this assertion (Roe & Dokras, 2011). According to her, and the Androgen Excess and PCOS Society, women must exhibit excess androgens in order to qualify as having PCOS. I had often wondered why I did not have the "common symptoms" of PCOS associated with excess androgen such as facial hair and acne. It seemed strange to me that PCOS could include women with *and* without these symptoms, as they lead to markedly different bodies and experiences.

At my gynecologist's office, I confirmed through reviewing past blood tests that I do not have excess androgens, and so according to some medical professionals, I do not have PCOS. When I asked my gynecologist about this, he insisted that this criterion is incorrect and was unwilling to discuss with me other possibilities. He also showed disinterest, and even agitation, when I pressed the issue by asking questions in an effort to decipher what might be the cause of my irregular menstruation. He essentially told me he did not want to discuss any further whether or not I have PCOS and that I simply needed to choose whether to go on the birth control pill or

not. I left the office feeling frustrated, confused, and as unsure as ever as to the cause of my lack of ovulation and how to treat it.

Sadly, as this research suggests, this is not my experience alone. By far, the most common thread amongst interviews was participants' frustration, confusion, and despair relative to their relationship with their practitioner. What are the larger societal consequences if women are being misdiagnosed with PCOS? What are the consequences if their concerns are being dismissed? While some understanding and compassion must be shown to members of the medical community given that they cannot be expected to know everything, it is also fair to say that our current medical system, and culture, tends to look for quick answers and easy fixes. Perhaps this is partly where prescribing the birth control pill comes in—it offers a quick though short-term solution to a complicated problem. One need not ask more questions if one takes the pill. This allows women to deny, delay, and/or enjoy some respite and comfort.

Yet, if the medical community does not know everything, surely we can we at least expect our medical practitioners to acknowledge this. Many of the participants revealed that their medical practitioners were unwilling to engage in conversation to explain how little is known about PCOS. They also did not want to discuss any alternative options. How can we say we are looking out for the health of women when we are not assessing the full spectrum of treatment options? Furthermore, why do we know so little about PCOS? Is it fair to say that the reproductive health of women should be of considerable concern to our society? Participants also alluded to how women's health has been historically under-researched, a highly problematic reality.

Briden (2015) reminds me of some of the benefits of approaching health from a standpoint alternative to biomedicine. She argues we are currently in the midst of a movement:

Women's periods are coming out in to the open. They are no longer something to be endured and concealed and regulated with the birth control. . . . More and more women are saying *No* to the pill. (p. 2)

She claims that before contraception was culturally accepted, the birth control pill was initially prescribed as a cover to treat "female disorders" and "normalize periods" (p. 12). It has stuck ever since. She argues that the technology for male contraception exists, but is not currently marketed because convincing men to take a pill that would alter their libido and cause other side effects like depression would never catch. Even though placing the responsibility of contraception on men, who do not live with the nine month consequence of pregnancy, might be risky in some women's minds, Briden's point is clear: medicalization is complicit in undermining women's health and supporting gender inequality. The birth control pill is not necessarily the best treatment for women, and its use (or overuse) demonstrates how women's bodies have been historically, and continue to be, undervalued.

Most of the participants expressed concern about the lack of accessible information on PCOS. It has become clear to me while conducting this study that PCOS is an umbrella term used by the medical community to try to understand women with similar, *though not necessarily relating*, symptoms. In a way, you could argue that PCOS itself does not exist in the specific way it is currently medically represented given its loose definition. In fact, you could argue that every woman needs her own individual diagnosis that may not be replicable in other women. This is why PCOS is a syndrome and not a disease, and its diagnostic criteria are constantly changing; we simply do not know enough about it. This is also why a woman can be diagnosed with PCOS

even if her only symptom is irregular menstruation. There simply is not another applicable classification to apply. Further, Biomedicine has not needed to get more specific with diagnosis because the “treatment” is always the same: the birth control pill.

Briden’s (2015) book is written from a naturopathic perspective and the approach of naturopathic medicine includes various treatments for PCOS depending on which symptoms one presents. Her book demonstrates that there is reason to try to define more specific causes for reproductive issues. Briden suggests that there are four types of PCOS each with different alternative treatment options. Beyond PCOS, she mentions various other causes of irregular menstruation that were never mentioned to me by my gynecologist, such as hypothalamic amenorrhea, progesterone deficiency, low iron, thyroid issues, and celiac disease. This opens the door to other possibilities and treatment, and may explain why I do not have all the symptoms of PCOS. At the same time, deciphering what the root cause is usually requires extensive blood testing. The research revealed that women cannot always be tested for such possibilities unless their practitioners think it is necessary. This leaves them with little power to secure proper diagnosis, especially if their practitioner is pushing the pill.

Being a modern woman brings with it many questions. In many ways, we have the best health care system we have ever had with access to things like organ transplants and antibiotics. Yet the very health care that is designed to serve our health does not always act in our best interests. We can be prescribed medication like the birth control pill that gives short-term benefits in exchange for long-term risks. To what degree does the environment, the endocrine disruptors that now come with some of the food and plastics we ingest, hurt our bodies and our reproductive systems? How do our genetics affect PCOS and how can we address this issue? What are the long-term effects of living with PCOS? While it would seem like we might have answers to some of these questions, there is still so much we do not know. Since I began this study, I have talked to many women who are unsure about the health effects of the birth control pill or IUDs, and have no answers. On the one hand, we must learn to live within this place of the unknown and understand that we can’t know everything. It takes time to build research knowledge. On the other hand, how does this lack of information reflect the prioritization, or lack thereof, of research on women’s health? In the meantime, women will fight to gain more information on their bodies, but is this enough?

Howson (2013) recalls how during the women’s health movement in the “West”, “feminists argued that acquiring knowledge of one’s own body was vital to challenging medical culture and its problematic definitions of female embodiment” (p. 166). As a result, women began ‘learning the language of the professional’ in order to challenge medical authority (Ehrenreich & English, 1979). This is still relevant today, as is indicated by the participants in this study who sought to teach themselves about PCOS in an effort to challenge their practitioners. However, somewhat differently, the participants in this study challenged their practitioners not only by disagreeing, but in many cases by informing their practitioners about PCOS in the first place. In essence, they became the distributors of both embodied and specialized (if limited) knowledge, perhaps blurring the barriers between the two in the process¹⁴.

¹⁴ For a more detailed discussion on the relationship between lay and expert knowledge, how they overlap, and how they are distinguished, see Prior (2003). Prior (2003) discusses how lay knowledge contributes to medical knowledge, as well as the dangers of romanticising lay knowledge and where it is limited.

A constant theme throughout this study, though perhaps not explicitly raised, is the tensions that exist between expert knowledge and embodied experience, or in other words between “specialized” and “lay” knowledge. This study suggests that these tensions, which are fused with issues of power and authority, have an added gender element to them. Annandale (2014) cites a recent research study conducted by Arber et al. (2006) that found “women ‘patients’ were asked fewer questions, received fewer examinations, fewer diagnostic tests, and were prescribed the least medication” (p. 223). She goes on to add that “issues of gender (moral evaluations of appropriate femininity, for example), social class, ‘race’, and age all influence clinical decision-making” (p.223).

Feminist health studies have recognized the gaps in our understanding of women’s experiences of embodiment and of the medicalization of women’s bodies in health care. The findings in this study point to these gaps and the ways in which medicalization has managed women’s bodies and experiences for them. The stories of the participants in this study remind us how embodied and lay knowledge offer critical insight into the medicalization and health experience. I have used arts-informed research, by including life writing and paintings, to deepen this expression of embodied experience. I believe they allow the audience to *experience* what it is like for one person to live with PCOS in a more personal manner, and there is power in the personal.

In Chapter Four I wrote that arts-informed inquiry aims to build a bridge between academia and lived experiences. Similarly, I aim for the life writing and paintings to build a bridge between embodied and expert knowledge in relation to medicalization. The boundaries between lay and expert knowledge may be blurred, and indeed, both are critical for optimal healthcare. Still, stories of the lived experiences of women with PCOS can enhance our medical knowledge of the syndrome, and in the process improve how it is diagnosed and treated. It is my hope that they will remind us that the women’s health movement is not a “thing of the past” but still relevant and necessary today. Indeed, we need to continue to fight for women’s health, which includes fighting for embodied patient or lay knowledge to be taken seriously and not dismissed by medical practitioners.

In closing, I want to share the final painting see (Figure 4) I made for this study. I am moved by the way it illuminates how my own sentiments have changed. While my first painting adopted a critical lens of inquiry, my latest painting exhibits a sense of healing, of movement, and of unity with other cystors.

I sense that safety radiates out of this painting. I chose to have the main reproductive system as the focal point because I recognize that in many ways this study has primarily been about me and my own journey with PCOS. Yet, there remains a sense of connection to others. This is why the colors are bright, and the ovaries and fallopian tubes are linked with others, suggesting a sense of community. I think the fact that I did not include the entire reproductive systems of others suggests to me that while I feel a sense of community, it needs to be nurtured; it is not as strong as it could become. Something is holding the community back, something that requires more contemplation and discernment.

It is difficult to bring this study to an end when in many ways it feels like just the beginning. For every question that I have sought to answer, new ones have emerged. In many ways this study does not necessarily say anything “new” in a scholarly sense; many of us with PCOS, and without, can relate to the stories it shares in some way. But is it something new that

we seek, or can we find immense value in looking deeper into issues that affect our daily lives and health? I believe there is power in pondering and probing these stories and asking ourselves why they matter and what will we do about them? For me, it is of great concern that women may be misdiagnosed with PCOS, and it is of great concern that women feel dismissed and face barriers to proper diagnosis and treatment. To what degree is it our own responsibility to educate ourselves and seek proper treatment? I would suggest that it is a joint responsibility of both the patient and practitioner. What this study points to is that more training on PCOS, including how it affects women, is needed for medical practitioners, and that women's health concerns should be considered more seriously in our medical community.



Figure 4: McKellar, L. (2015).
Solidarity [Acrylic on canvas, 11" x 14"]. Thunder Bay: Canada.

Based on the research findings, this study suggests that more information and literature on PCOS explained in “lay” terms is needed for women living with PCOS, that more training should be supplied for medical and mental health practitioners both on the details of PCOS but also how it affects women's daily lives, and that more research is needed on how alternative lifestyles and medicines may be helpful treatment options for women.

I want to end with the words of Brown (2010), who reminds us that something as simple, and yet as difficult as facing our shame, can be one of our most powerful motivations for personal and collective activism:

Shame hates it when we reach out and tell our story. It hates having words wrapped around it—it can't survive being shared. The most dangerous thing to do after a shaming experience is hide or bury our story. When we bury our story, the shame metastasizes.
(pp. 9-10)

Bringing PCOS out into the open is a way of confronting our shaming experiences and inviting others to do the same, and in the process changing what we consider to be shameful in the first place. When PCOS is brought into the open, it becomes harder to ignore the questions that come with it, including why women, and even medical practitioners, are undereducated about PCOS, how the process of medicalization is contributing to this under-education, and what can be done to meet these challenges.

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Appendixes

Appendix A—Interview Guide for PCOS Participants*Interview Guide*

1. How old are you?
2. What ethnicity(ies) do you identify with?
3. With what gender do you identify/what pronoun do you prefer to be called by?
4. How would you explain PCOS to someone? What is PCOS?
5. In what year were you diagnosed with PCOS?
6. Who diagnosed you with PCOS?
7. How were you educated on PCOS? What were you informed about?
8. Do you think you were adequately informed about PCOS?
9. Did you do personal research on PCOS?
10. What was your reaction to your diagnosis?
11. What symptoms of PCOS do you have?
12. Are you taking treatment for PCOS? If yes, what type?
13. Have you ever considered alternative treatments for PCOS?
14. Does having PCOS affect your daily life? How?
15. Do you speak about PCOS to your friends? Relatives? Partner? Why or why not?
16. Has PCOS changed the way you perceive yourself? If so, how?
17. Does your experience with PCOS make you feel less feminine?
18. Do you think there are stigmas attached to PCOS? If yes, what are they?
19. What changes, if any, in your life have you noticed connected to your experiences with PCOS?
20. What insights, if any, did you come to through that change or experience?
21. What are some key experiences you have had with PCOS?
22. Who do you think is responsible for educating about PCOS?
23. Do you think PCOS should be taught in health education in public school? Were you ever taught about it in school?
24. Do you think PCOS should be classified as a syndrome? Why or why not?
25. If you had to tell one story of your experience of PCOS, what would it be?
26. Is there anything else you would like to share?

Appendix B—Initial Introductory E-Mail to PCOS Participants

Dear [potential participant's name],

Hello! I am writing to introduce you to a research study that is being conducted on polycystic ovarian syndrome (PCOS). I am searching for women diagnosed with PCOS to participate in this research.

The study is entitled “**Exploring women’s experiences with PCOS**”. The purpose of this research is to explore the experiences of women with PCOS in more detail so as to provide further knowledge on the way women are educated about and experience the syndrome. This study is part of my Master’s thesis research at Lakehead University.

If you choose to participate, your commitment would involve participating in one 60-90 minute audio-recorded interview, in person and in a location of your choice. The interview would take place during the month of November or December 2014. If you so desire, you would also have the opportunity to review the transcript of your interview for accuracy, and to review the analysis of the transcript prior to it being used in the thesis. In addition, there will be an optional facilitated focus group session where all participants will be invited to create one piece (painting, clay or other multimedia) that is an expression of their experience with PCOS. Participants are not expected to be artists or make ‘masterpieces’. The focus is on the *process* of making the piece and on the learning that occurs in the reflection involved, thus there can be no such thing as ‘bad’ art in this setting. This emergent experience will take place during one session, for 3-5 hours, including a break, in November or December 2014. A professional facilitator will facilitate it. All participants will be required to not share the identities of other participants with anyone else to protect your and others’ anonymity. As the focus group will take place in a group setting and although participants are asked to maintain confidentiality, the research team cannot guarantee that the discussions and data disclosed in these group settings will remain confidential.

To ensure your anonymity, data collected will be kept confidential and pseudonyms will be used in my thesis and any associated writing, art pieces, exhibitions and presentations. By participating, you would have full right to decline to answer any interview question, do as little or as much of the focus group session as you want, and/or to withdraw from the research at any time.

This research has been approved by Lakehead University’s Office of Research Services. If you would like to further discuss your potential participation, and/or speak to my supervisor Dr. Pauline Sameshima, please do not hesitate to contact us through the channels outlined below. As well, if you are interested in participating, please let me know by contacting me through email. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team please contact Rebecca Scott at the Office of Research Services, contact information outlined below.



Thank you for taking the time to consider this invitation, and have a great day!

Ledah McKellar

lpmkell@lakeheadu.ca; 807-707-3543

Faculty of Education, Lakehead University

Supervisor: Dr. Pauline Sameshima

psameshima@lakeheadu.ca; 807-343-8222

Faculty of Education, Lakehead University

Research Ethics Coordinator: Rebecca Scott

rkscott1@lakeheadu.ca; Phone: 807-343-8933

Appendix C—Cover Letter to PCOS Participants

Dear Potential Participant,

Thank you for your interest in participating in the research initiative, entitled “**Exploring women’s experiences with polycystic ovarian syndrome (PCOS).**” This study is part of my Master’s thesis research at Lakehead University. The purpose of this research is to explore the experiences of women with PCOS in more detail so as to provide further knowledge on the way women are educated about and experience the syndrome.

Your participation in this research would involve one 60-90 minute interview that will be audio-recorded, and will take place in person. The interviews will take a semi-structured format to ensure that we cover topics of interest to me but that also matter most to you. As well, if you choose to participate, I will ask you to select a location for the interview. In addition, there will be a professionally facilitated focus group session where all participants will be invited to create explore with painting, clay or other multimedia that that explores your experiences with PCOS. This session is optional. You are not expected to be an artist or make a ‘masterpiece.’ The focus is on the *process* of making the piece and on the learning that occurs in the reflection involved, thus there can be no such thing as ‘bad’ art in this setting. The interview and focus group will take place during one session, for 3-5 hours, including a break, in November or December 2014.

If you so desire, you will have the opportunity to review the transcript of your interview for accuracy prior to analysis, and to review the analysis of the research prior to its submission. By participating, you will have full right to decline to answer any interview question, and/or to withdraw from the research at any time. You will also have control over the level of anonymity concerning your contributions to the research. All data collected, including the art pieces, will be kept confidential and, if you so wish, pseudonyms will be employed in any associated writing and presentations. However, if you wish for your name to be associated with your contributions, then I will do so. All participants will be required to not share the identities of other participants with anyone else to protect your and others’ anonymity. As the focus group will take place in a group setting and although participants have been asked to maintain confidentiality, the research team cannot guarantee that the discussions and data disclosed in these group settings will remain confidential.

The Lakehead University Research Ethics Board has approved this research project. This study poses minimal risks to the psychological health of the participants. There is the possibility that you may engage in personal subject matter that has the opportunity to unearth emotional and sensitive topics. Due to this, you will be reminded that you are welcome to withdraw your participation from the interview at any time. Furthermore, you will be reminded that the following counseling services are available to you on campus:

Student Health and Counselling
Room UC 1007 - University Centre
Phone: +1 (807) 343-8361

Lakehead University Chaplaincy

Contact Sister Alice at:

UC 1002

Phone: (807) 343-8002

Good2Talk

Good2Talk is a free, confidential and anonymous helpline providing professional counselling and information and referrals for mental health, addictions and well-being to post-secondary students in Ontario, 24/7/365.

Phone: 1-866-925-5454 or connect through 2-1-1

Once the research is complete the data will be stored in the primary investigators office, which is secure and locked within the Faculty of Education, for at least five years, in compliance with all REB requirements.

The findings of this project will be made available to you at your request upon the completion of the project. The completed thesis will also be available at the Education Library at Lakehead University. If you wish to participate, please complete and sign the attached consent form. If you have any questions or concerns, please do not hesitate to contact me (phone: (807) 707-3543, email: lpmckell@lakeheadu.ca). You are also welcome to contact my faculty supervisor, Dr.

Pauline Sameshima (phone: 807-343-8222, email: psameshima@lakeheadu.ca). Rebecca Scott, Research Ethics Coordinator, Lakehead University (phone: (809) 343-8933, email: rkscott1@lakeheadu.ca), is also available for contact.

Thank you very much for considering this letter.

Sincerely,

Ledah McKellar

Appendix D—Cover Letter to PCOS Participants Outside Lakehead

Dear Potential Participant,

Thank you for your interest in participating in the research initiative, entitled “**Exploring women’s experiences with polycystic ovarian syndrome (PCOS).**” This study is part of my Master’s thesis research at Lakehead University. The purpose of this research is to explore the experiences of women with PCOS in more detail so as to provide further knowledge on the way women are educated about and experience the syndrome.

Your participation in this research would involve one 60-90 minute interview that will be audio-recorded, and will take place in person. The interviews will take a semi-structured format to ensure that we cover topics of interest to me but that also matter most to you. As well, if you choose to participate, I will ask you to select a location for the interview. In addition, there will be a professionally facilitated focus group session where all participants will be invited to create explore with painting, clay or other multimedia that that explores your experiences with PCOS. This session is optional. You are not expected to be an artist or make a ‘masterpiece.’ The focus is on the *process* of making the piece and on the learning that occurs in the reflection involved, thus there can be no such thing as ‘bad’ art in this setting. The interview and focus group will take place during one session, for 3-5 hours, including a break, in November or December 2014.

If you so desire, you will have the opportunity to review the transcript of your interview for accuracy prior to analysis, and to review the analysis of the research prior to its submission. By participating, you will have full right to decline to answer any interview question, and/or to withdraw from the research at any time. You will also have control over the level of anonymity concerning your contributions to the research. All data collected, including the art pieces, will be kept confidential and, if you so wish, pseudonyms will be employed in any associated writing and presentations. However, if you wish for your name to be associated with your contributions, then I will do so. All participants will be required to not share the identities of other participants with anyone else to protect your and others’ anonymity. As the focus group will take place in a group setting and although participants have been asked to maintain confidentiality, the research team cannot guarantee that the discussions and data disclosed in these group settings will remain confidential.

The Lakehead University Research Ethics Board has approved this research project. This study poses minimal risks to the psychological health of the participants. There is the possibility that you may engage in personal subject matter that has the opportunity to unearth emotional and sensitive topics. Due to this, you will be reminded that you are welcome to withdraw your participation from the interview at any time. Furthermore, you will be reminded that the following counseling services are available to you:

Ontario Mental Health Helpline with free health services information at 1-866-531-2600.

Once the research is complete the data will be stored in the primary investigators office, which is secure and locked within the Faculty of Education, for at least five years, in compliance with all REB requirements.

The findings of this project will be made available to you at your request upon the completion of the project. The completed thesis will also be available at the Education Library at Lakehead University. If you wish to participate, please complete and sign the attached consent form. If you have any questions or concerns, please do not hesitate to contact me (phone: (807) 707-3543, email: lpmckell@lakeheadu.ca). You are also welcome to contact my faculty supervisor, Dr.

Pauline Sameshima (phone: 807-343-8222, email: psameshima@lakeheadu.ca). Rebecca Scott, Research Ethics Coordinator, Lakehead University (phone: (809) 343-8933, email: rkscott1@lakeheadu.ca), is also available for contact.

Thank you very much for considering this letter.

Sincerely,
Ledah McKellar

Dr. Pauline Sameshima
807-343-8222
psameshima@lakeheadu.ca

Ledah McKellar
807-707-3543
lpmkell@lakeheadu.ca

Rebecca Scott, Research Ethics Coordinator
807-343-8933
rkscott1@lakeheadu.ca

Appendix E—Consent Form for PCOS Participants

Date, 2014

I, _____, agree to participate in the study, “**Exploring women’s experiences with polycystic ovarian syndrome (PCOS).**” I have read the attached cover letter. I understand the purpose and intent of this study. I realise my participation is entirely voluntary. Should I choose to participate, I may decline to answer any question, attend the focus group, or leave the focus group early. I may choose to withdraw from the study at any point without repercussions.

I understand that I must ensure the anonymity of all participants involved in the focus group session. I also understand that, as the focus group will take place in a group setting and although participants have been asked to maintain confidentiality, the research team cannot guarantee that the discussions and data disclosed in these group settings will remain confidential.

I understand that there is the possibility that I may engage in personal subject matter that has the opportunity to unearth emotional and sensitive topics. I am aware that the following services are available to me on campus:

Student Health and Counselling
Room UC 1007 - University Centre
Phone: +1 (807) 343-8361

Lakehead University Chaplaincy
Contact Sister Alice at:
UC 1002
Phone: (807) 343-8002

Good2Talk

Good2Talk is a free, confidential and anonymous helpline providing professional counselling and information and referrals for mental health, addictions and well-being to post-secondary students in Ontario, 24/7/365.

Phone: 1-866-925-5454 or connect through 2-1-1

I understand that I am welcome to withdraw my participation from the research at any time.

I understand that I will be audio-taped as part of the study. I understand that the data will be securely stored in the locked research store room in the Faculty of Education at Lakehead University for a period of at least five years, after which time it will be destroyed.

I recognize the study is intended to explore the experiences of women with PCOS. I recognize that it will contribute to the available research on PCOS. I understand that the research may be presented at academic conferences and in academic journals. I understand that I will receive a summary of the research results at the completion of the research.

Please check the appropriate box below. You may change your mind at any time by contacting either member of the research team (Ledah McKellar or Pauline Sameshima).

I choose to have my name in the dissemination of this research and statements made attributed to me.

I wish for my name to remain anonymous.

Signature

Date

If you are interested in receiving a summary of the research, please check the appropriate box, and provide the corresponding information. Thanks!

Name: _____

I would like to receive an electronic copy of the completed thesis by email

Email Address:

I would like to receive a hard copy of this research by mail

Mailing Address:

Dr. Pauline Sameshima
807-343-8222
psameshima@lakeheadu.ca

Ledah McKellar
807-707-3543
lpmkell@lakeheadu.ca

Rebecca Scott, Research Ethics Coordinator
807-343-8933
rkscott1@lakeheadu.ca

Appendix F—Consent Form for PCOS Participants Outside Lakehead

Date, 2014

I, _____, agree to participate in the study, “**Exploring women’s experiences with polycystic ovarian syndrome (PCOS).**” I have read the attached cover letter. I understand the purpose and intent of this study. I realise my participation is entirely voluntary. Should I choose to participate, I may decline to answer any question, attend the focus group, or leave the focus group early. I may choose to withdraw from the study at any point without repercussions.

I understand that I must ensure the anonymity of all participants involved in the focus group session. I also understand that, as the focus group will take place in a group setting and although participants have been asked to maintain confidentiality, the research team cannot guarantee that the discussions and data disclosed in these group settings will remain confidential.

I understand that there is the possibility that I may engage in personal subject matter that has the opportunity to unearth emotional and sensitive topics. I am aware that the following services are available to me:

Ontario Mental Health Helpline with free health services information at 1-866-531-2600.

I understand that I am welcome to withdraw my participation from the research at any time.

I understand that I will be audio-taped as part of the study. I understand that the data will be securely stored in the locked research store room in the Faculty of Education at Lakehead University for a period of at least five years, after which time it will be destroyed.

I recognize the study is intended to explore the experiences of women with PCOS. I recognize that it will contribute to the available research on PCOS. I understand that the research may be presented at academic conferences and in academic journals. I understand that I will receive a summary of the research results at the completion of the research.

Please check the appropriate box below. You may change your mind at any time by contacting either member of the research team (Ledah McKellar or Pauline Sameshima).

I choose to have my name in the dissemination of this research and statements made attributed to me.

I wish for my name to remain anonymous.

Signature

Date

If you are interested in receiving a summary of the research, please check the appropriate box, and provide the corresponding information. Thanks!

Name: _____

I would like to receive an electronic copy of the completed thesis by email

Email Address:

I would like to receive a hard copy of this research by mail

Mailing Address:

Dr. Pauline Sameshima
807-343-8222
psameshima@lakeheadu.ca

Ledah McKellar
807-707-3543
lpmkell@lakeheadu.ca

Rebecca Scott, Research Ethics Coordinator
807-343-8933
rkscott1@lakeheadu.ca

Appendix G—Consent Form for Facilitator

Date, 2014

I, _____, agree to facilitate a focus group session for the participants in the study, **“Exploring women’s experiences with polycystic ovarian syndrome (PCOS).”** I understand the purpose and intent of this study.

I understand that I must ensure the anonymity of all participants involved in the focus group session.

I recognize the study is intended to explore the experiences of women with PCOS. I recognize that it will contribute to the available research on PCOS. I understand that the research may be presented at academic conferences and in academic journals. I understand that I will receive a summary of the research results at the completion of the research.

Please check the appropriate box below. You may change your mind at any time by contacting either member of the research team (Ledah McKellar or Pauline Sameshima).

I choose to have my name in the dissemination of this research and statements made attributed to me.

I wish for my name to remain anonymous.

Signature

Date

If you are interested in receiving a summary of the research, please check the appropriate box, and provide the corresponding information. Thanks!

Name: _____

I would like to receive an electronic copy of the completed thesis by email

Email Address:

I would like to receive a hard copy of this research by mail

Mailing Address:

Dr. Pauline Sameshima
807-343-8222
psameshima@lakeheadu.ca

Ledah McKellar
807-707-3543
lpmkell@lakeheadu.ca

Rebecca Scott, Research Ethics Coordinator
807-343-8933
rkscott1@lakeheadu.ca

Appendix H—Follow-Up Consent Form for PCOS Participants

Date, 2014

I, _____, agree to submit my art piece(s) I created in the focus group session for the study, “**Exploring women’s experiences with polycystic ovarian syndrome (PCOS)**” to a local art exhibit. I realise my participation is entirely voluntary. Should I choose to participate I may remain anonymous. I may choose to withdraw from the gallery at any point without repercussions.

I see no foreseeable risk to participating in the art gallery.

Please check the appropriate box below. You may change your mind at any time by contacting any one of the research team.

I choose to have my art piece(s) displayed in a local art exhibit.

I choose not to have my art piece(s) displayed in a local art exhibit.

I choose to have my name in the dissemination of this research and statements made attributed to me.

I wish for my name to remain anonymous.

Signature

Date

If you are interested in receiving a summary of the research, please check the appropriate box, and provide the corresponding information. Thanks!

Name: _____

I would like to receive an electronic copy of the completed thesis by email

Email Address:

I would like to receive a hard copy of this research by mail

Mailing Address:

Appendix I—Facebook Ad

Dear Potential Participant,

I am searching for women diagnosed with PCOS to participate in this research

The purpose of this research is to explore the experiences of women with PCOS in more detail so as to provide further knowledge on the way women are educated about and experience the syndrome.

Participants can remain anonymous and must be older than 18. Your commitment would involve participating in one 60-90 minute audio-recorded interview. There is an OPTIONAL and professionally facilitated focus group session where all participants are invited to explore their experiences via various arts-based activities. This will occur in November or December 2014.

For more information, please contact either:

Ledah McKellar
lpmckell@lakeheadu.ca; 807-707-3543
Faculty of Education, Lakehead University

Supervisor: Dr. Pauline Sameshima
psameshima@lakeheadu.ca; 807-343-8222
Faculty of Education, Lakehead University

This study is part of a Master's thesis research at Lakehead University. It has been approved by the Office of Research Services.

DO YOU HAVE POLYCYSTIC OVARIAN SYNDROME (PCOS)?

.....

**I am searching for women diagnosed with PCOS
to participate in this research**

.....

**The purpose of this research is to explore the
experiences of women with PCOS in more detail
so as to provide further knowledge on the way
women are educated about and experience the
syndrome.**

**Participants can remain anonymous and must be older than 18.
Your commitment would involve participating in one 60-90 min-
ute audio-recorded interview. There is an OPTIONAL and profes-
sionally facilitated focus group session where all participants are
invited to explore their experiences via various arts-based activi-
ties. This will occur in November or December 2014.**

For more information, please contact either:

**Ledah McKellar
lpmckell@lakeheadu.ca; 807-707-3543
Faculty of Education, Lakehead University**

**Supervisor: Dr. Pauline Sameshima
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Faculty of Education, Lakehead University**

This study is part of a Master's thesis research at Lakehead University.