Polycystic Ovarian Syndrome:

Exploring Experience and Contesting Knowledge

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Introduction

Polycystic Ovarian Syndrome (PCOS) is the most commonly reported endocrine disease and the most common cause of infertility among women of childbearing age. Additionally, Norman, Dewally, Legro and Hickey report that PCOS is the “most frequent cause of hyperandrogenism and oligo-anovulation, both of which have substantial psychological, social, and economic consequences (2007, 685). Originally reported by Stein and Leventhal in 1935, it is estimated that between five and ten percent of women suffer from PCOS. While the name of the syndrome is indicative of the presence of ovarian cysts, not all women with PCOS exhibit this particular symptom. In fact, women with PCOS may have two or more of a constellation of symptoms which may include amenorrhea (the absence of a regular menstrual cycle), infertility, hirsutism (the abnormal growth of hair in places such as the face, neck, abdomen and chest), acne, weight gain, insulin resistance/type 2 diabetes, high cholesterol, high blood pressure, thinning hair or male pattern baldness, acanthosis nigricans (areas of darkened skin discoloration generally found on the neck, breasts, arms or thighs), skin tags, pelvic pain, anxiety and/or depression generally related towards one’s appearance or the inability to conceive, and sleep apnea.

Moreover, PCOS is more than just a disease related to hormones, the ovaries and the endocrine system. Norman et. al (2007) report that

> The potential health consequences of polycystic ovary syndrome are a life long issue. There is little doubt that the prevalence of impaired glucose tolerance and diabetes mellitus is increased substantially in women with polycystic ovary syndrome, although the magnitude of the increase depends on the prevalence of obesity in the population, and racial influences are evident… The evidence for increased risk of cardiovascular disease in women with polycystic ovary syndrome is less clear, although cardiovascular risk factors are substantially increased, including hyperlipidaemia, hyperandrogenaemia, hypertension, markers of prothrombotic state and markers of inflammation. Altered vascular endothelial function in young women with polycystic ovary syndrome is well documented, and increased death rates from cardiovascular disease have been shown in

> women with menstrual irregularity (possibly with polycystic ovary syndrome) in the Nurses' Health Study.

Such evidence makes it clear that PCOS is a complex condition, requiring careful and attentive treatment over the course of a woman's life. The increased risk across multiple body systems has the potential to put women in a rather precarious position. A recent article published in the New York Times (2009) highlights a salient point: "people with multiple health problems — a condition known as multimorbidity — are largely overlooked both in medical research and in the nation's clinics and hospitals. The default position is to treat complicated patients as collections of malfunctioning body parts rather than as whole human beings." This compartmentalization and medicalization of the body has been widely criticized by feminist scholars in that it poses an increased threat to the health of women in general. I suggest that this risk is further complicated in the case of women who have been diagnosed with PCOS who may be seeing multiple doctors for the treatment of a handful of symptoms which impact overall health and well-being.

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

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

It is important to note that two out of these three hypotheses do no associate the cause of PCOS with the ovaries, and the remaining one posits that it may involve the ovaries in addition to the adrenal glands. Consequently, the name polycystic *ovarian* syndrome might well be a misnomer that potentially adds confusion and frustration to an already difficult disease.

The vast amount of information and research on PCOS has been published by those in the medical field, especially those in the area of endocrinology. This particular fact suggests the need to consider the production of knowledge/discourse. Queer theory, in part, focuses on the organization of discourse. The work of Michel Foucault is germinal to this area of investigation. According to Hall,

> By ‘discourse,’ Foucault meant ‘a group of statements which provide a language for talking about – a way of representing the knowledge about – a particular topic at a particular historical moment… Discourse is about the production of knowledge through language. But… since all social practices entail *meaning*, and meanings shape and influence what we do – our conduct – all practices have a discursive aspect. [2001, 72]

Discourse, then, might be seen to be somewhat circular in nature: discourse organizes and controls the practice of societies, resulting in the further development and transformation of discourse. In *Power/*Knowledge, Foucault argues that

> in a society such as ours, but basically in any society, there are manifold relations of power which permeate, characterise and constitute the social body, and these relations of power cannot themselves be established, consolidated nor implemented without a certain economy of discourses of truth which operates through and on the basis of this association. We are subjected to the production of truth through power and we cannot exercise power except through the production of truth… Power never ceases its interrogation, its inquisition, its registration of truth: it institutionalises, professionalises and rewards its pursuit. [1980, 93]

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

To this end, Foucault states, “’Truth’ is centered on the form of scientific discourse and the institutions which produce it… it is produced and transmitted under the control, dominant if not exclusive, of a few great political and economic apparatuses (university, army, writing, media)… it is the issue of a whole political debate and social confrontation” (1980, 131-132). Medical discourse, or knowledge, is created by an elite class of academic. Sherwin argues that “The dominance structures that are pervasive throughout society are also reproduced in the medical context; both within and without the health care delivery system, sex, race, economic class, able-bodied status are important predictors in determining someone's place in the hierarchy" (1992, 228). The medical system in the United States is dominated by men, serving only to reinscribe patriarchy in the health care arena. The power of the medical establishment lies not only in the production of knowledge, but in its political position. In the United States, biomedicine is so deeply entrenched that it permeates myriad aspects of our everyday existence. This body exercises the power to influence and decide what is "health/unhealthy" and, more importantly, what is "normal." Sherwin argues that "women are caught in multiple double binds with respect to the norms of health and illness. Medical experts have claimed the authority to determine the range of the concepts of health and illness. They have used this authority to declare that many of the conditions that constitute normalcy for women are unhealthy and therefore, suitable subjects for medical management" by the patriarchal health care system which seeks to control the bodies of women (1992:179). Moreover, this authority – this appropriation of truth – has become so institutionalized – so seemingly "natural" – that women often fall into the trap of accepting them without question.

According to Worcester and Whatley, "The normal physiological process of menstruation has been defined and redefined by male 'experts' throughout history. It has been labeled a disability or illness, as a barrier to higher education for women, as a weakness that justified keeping middle-class women from working outside the home" (2004, 193). Contemporary ideologies heavily influenced by positivistic notions have seemingly come to terms with menstruation, tacitly accepting it as the biological process it is. This acceptance, however, comes at a price, though, for those of us who fail to conform to the "normal" menstrual cycle.

Relatively little has been published by researchers in the social sciences, and I was unable to find any literature relating to PCOS by those in the field of Women's Studies. Feminists have written countless works and critiques on issues like menstruation, infertility, pregnancy, childbirth and abortion, yet the literature on this inherently female disease is startlingly absent. I find this to be particularly troubling because an interdisciplinary approach to PCOS has much to yield in the way the medical community understands PCOS. As a woman who has been living with PCOS for more than half her life, I have often become frustrated with just how little biomedicine understands about the experiences of women dealing with this syndrome. Patients are more than just objects to be examined, diagnosed and sent on their way; they must be seen as subjects with agency who must be evaluated not just as a body, but a whole individual in the context of their lives. If we believe that the social sciences inform the natural sciences, and I include medical science among them, I believe that Women's Studies can make a significant contribution.

A 2005 article published in *Social Science and Medicine* entitled "'The thief of womanhood': women's experience of polycystic ovarian syndrome" is an excellent example of the results research under the auspices of social sciences can produce. Kitzinger and Willmott observe that "Outside medical texts, there has been little public discussion of PCOS, and what rare mentions there are typically serve to reinforce the shame of the conditions as a 'deviation' from proper femininity" (350). The overarching goal of their study was to ascertain "women's qualitative experience of their PCOS, and in the issues they themselves raised in relation to it" (351). Through the use of semi-structured face-to-face interviews, Kitzinger and Willmott documented the stories of 30 female volunteers in the United Kingdom. The women were recruited for the interviews through a mailed flyer initiative sent to members of a national PCOS self-help group, *Verity*. The authors remark that "*Verity* members are largely white, able bodied, heterosexual women, aged 25-34, and the research reflected this with 24 white and six non-white participants, aged between 21 and 42 years old… Interviews were generally conducted in women's own homes and lasted between 45 min and one and a half hours" (350). Considering the common occurrence of discomfort over their appearance, I found the fact that these interviews were conducted in a "safe" setting to be particularly advantageous insofar as it might help women to open up and speak more freely about what is undoubtedly a sensitive issue. In concluding the article, Kitzinger and Willmott argue that "… this research indicates that women with polycystic ovarian syndrome are challenged in their perceptions of themselves as feminine and as women. The women questioned their ability to be defined as 'normal women', two-thirds said that they felt 'different', or 'abnormal' and nine women specifically used the term 'freaks' to describe their experience of themselves" (358). More than just dealing with and treating the symptoms of PCOS, the research done by Kitzinger and Willmott sheds light on the need to not only *hear* the stories of women with PCOS, but to empower them to challenge socially constructed notions of what it means to be a woman.

Goals of Research

As previously mentioned, there has been a lack of research done on PCOS where Women's Studies have been concerned. It is my hope through this research to begin to capitalize on the missed opportunities to explore the experiences of women with this syndrome. Women's Studies, especially through the incorporation of a feminist lens, offers a unique perspective, particularly as it relates to the disciplines focus on intersectionality. This ideology, related to identity politics, stresses the importance of considering an individual at multiple angles. For example, I am not just a woman. To use that term alone indexes a monolithic sense of just what "woman" is. Am I a woman because I have reproductive organs that mark me as such? Because the gametes which came together at my conception resulted in an XY chromosome combination? Instead, I might state that I am a white female, raised in a non-traditional nuclear, middle-class family. In essence, these different locations shape our experiences and, by extension, who we are. By documenting and contemplating the experiences of women, we have the ability to delve into previously unexplored areas of knowledge. As Joan Scott suggests, "Experience is at once always already an interpretation *and* something that needs to be interpreted" (412). Consequently, I believe that the narrative segments of the interviews should provide excellent material for the analysis of commonly recurring themes which will add further support to previous research, such as that done by Kitzinger and Willmott. Moreover, as Weitz argues, "Only by looking at the embodied experience of women, as well as at how those experiences are socially constructed, can we fully understand women's lives, women's position in society, and the possibilities, for resistance against that position" (1998, 10).

Additionally, much of the discussion about PCOS seems to lean towards treatment of infertility. As a woman who does not have designs on motherhood, I am interested in delving into the experiences and stories of women like myself. While more and more women are choosing not to have children or to delay pregnancy until later in life, this trend is a departure from traditional views of what it means to be a woman. Moreover, women dealing with infertility frequently express disappointment with themselves, believing that their inability to conceive is a personal failure. I believe that there are other women like myself who might find the idea of being "freed" from the possibility of pregnancy to be empowering and would like to explore this line of thinking through this research.

One of the most significant tenets in feminism states that *the personal is political*. When it comes to women's health in general and PCOS in particular, I find this statement to be especially accurate. If we remain frightened and ashamed of our bodies, we run the risk of being silenced. Such personal issues as our health, especially when it relates to aspects of ourselves that are perceived inherently "female," can be difficult at best. It is just this reason, then, that we must find the strength to overcome our fears and speak clearly and boldly about our experiences.

Methods

My initial plan was to conduct only face to face interviews with women who had been diagnosed with PCOS. While I personally know a number of women who fit that description and are local to the Tampa area, I was only able to arrange for interviews with two women. The remainder either did not have time or were not comfortable sharing their experiences in a more public forum. I felt that it was important to collect additional data to have a more meaningful sample, but without the sufficient resources and institutional approval to gather more participants I found the need to explore alternative avenues of possibility. It would be difficult to argue against the fact that the Internet has become a pervasive presence in the lives of many Americans. We frequently utilize it as a source of information that is readily available and easily accessible by those with computers, smartphones and other electronic devices. According to Internet World Stats website, 36.7% of Americans are using the Internet. That equates to nearly 247 million people. There are, however, issues of race, class and socioeconomic status to be considered in relation to sampling in this manner. There is inherent privilege in not only having access to a computer and the Internet, but having the time and skill to afford to use such a medium.

I have been using Internet communities for several years to gather information about medical conditions, including PCOS. The blogging site LiveJournal (http://www.livejournal.com), of which I have been a member of since 2005, has a number of communities that relate specifically to PCOS and more generally to women's health. These groups give individuals the opportunity to connect with others with common interests and provide a forum for questions, concerns and overall support. Other members of the community then have the chance to respond to the original posts, often drawing from their own experiences to provide answers and advice.   I have also been serving as the one of the community moderators for the "pcos" (http://community.livejournal.com/pcos/) community since January. I felt that these communities, especially those focusing on PCOS, had the potential to provide considerable information about women's individual experiences with PCOS. I was not certain, however, how well my inquiry would be received by these women. While the communities, by their very nature, regularly involve the disclosure of personal information, it is provided in the context of finding answers or emotional support from people like themselves. In my tenure as a member of these communities, I do not recall anyone ever asking for participation in a study regarding experiences with PCOS.

I started out with a post on the "pcos" and "pcosupport" (http://community.livejournal.com/pcosupport/) communities, explaining that I had been a member for a number of years and was also a graduate student at the University of South Florida working on my Master's degree in Women's Studies. I also mentioned that I was interested in doing additional research on PCOS and was looking for members of the community who might be willing to participate in the project. I received a total of 26 responses to my post from women who indicated that they were happy to help and excited to make some contribution to my work. I was heartened by their willingness to get involved.

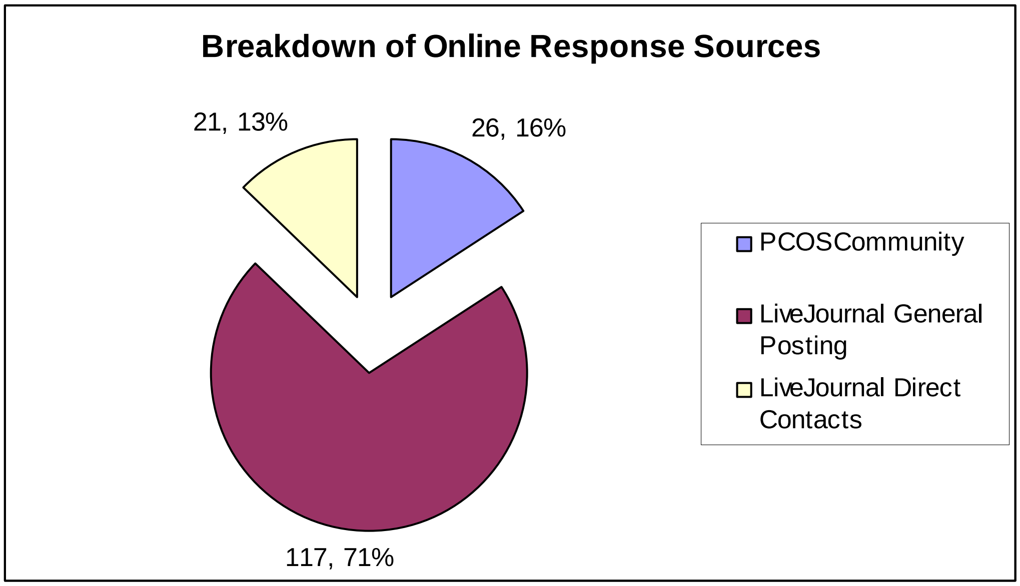
I believed that the most efficient way to collect data while offering the opportunity of anonymity would be conduct an online survey. I subsequently investigated a number of online survey sites. I ultimately decided on a paid account through SurveyMonkey (http://www.surveymonkey.com) as the questionnaires were relatively easy to build and allowed for a useful degree of flexibility in the collection, reporting, and display of results. I utilized the same questions that I had employed in my semi-structured interviews, incorporating the informed consent disclosure into the online version and implementing logic whereby women could only proceed to the personal questions by accepting the terms of the agreement. Those who did not accept the terms stipulated in the informed consent statement were taken to a page that thanked them for taking the time to participate.

I e-mailed the link to the survey to those women who had provided me with their contact information in response to my initial assessment of interest. I then posted the survey along with a second explanation of my intentions to the “pcos” and “pcosupport” groups on LiveJournal, as well another group dealing with women’s issues on the site called “vaginapagina.”

The survey (Appendix A) consisted of 40 questions, 26 of which dealt directly with PCOS. The list of symptoms used throughout the survey was drawn from those specified on Office on Women's Health - U.S. Department of Health and Human Services FAQ on PCOS. Seven questions were open ended and invited participants to share details in a more open format. The remaining questions were used to collect demographic information, to find out if they were interested in receiving a copy of this paper when completed, if I could contact them in the future in preparation for writing my Master’s thesis, and how I might improve the survey. I made an additional post to the general discussion boards on the PCOS Community site (http://pcoscommunity.com/) on the recommendation of one of the community members from LiveJournal.

There is not a specific local agency that deals with women with PCOS. This condition is generally treated by a medical doctors specializing in either endocrinology or obstetrics and gynecology. In retrospect, I might have gone to the local Planned Parenthood office as they offer lower-cost medical care to women; however, I was more interested in finding out how women were getting their information about PCOS. Consequently, I built a question into my survey to obtain that information.

Of the 164 individuals who started the survey, 106 actually went through the entire list of questions. Their ages ranges from 17 – 45 years with an average age of 26. Participants were predominantly from the United States; however, a number of women from Australia, Canada, the Netherlands, Singapore and the United Kingdom also responded.



The vast majority of respondents, both through personal interviews and surveys, indicated their race/ethnicity as white (N=112). The remaining breakdown is as follows: Black or African

American: 4, Hispanic, Latino or Spanish origin: 5, American Indian or Alaska Native: 3, Asian Indian: 1, Chinese: 1, Other/Multi-racial: 14. The majority of respondents were married, followed by single and in a relationship with no plans to marry. I did not collect data on the sexual preference of the survey participants.

The survey sample consisted mostly of women who had had at least some college, including 29 who had completed some graduate work or obtained a terminal degree.

Results and Discussion

I felt it was important to establish a baseline of how these women felt about their health. When asked to categorize their overall health, most answered “average” (N=51) or “good” (N=45). Only 7 indicated that they felt they were in poor health. While the correlation between a family history of PCOS among women with the disease has been proposed, there is no clear evidence to tie the two together. The survey results seemed to follow this. Out of 140 responses, 111 answered no or were unsure. Only 29 indicated that family members had been diagnosed with PCOS. One other consideration is the possibility that many women with PCOS simply go undiagnosed.

The most common complaint that caused women to seek out medical assistance was amenorrhea (N=105), followed by weight gain/obesity (N=86), and hirsutism (N=73). It is important to note that the participants did have the option of selecting multiple symptoms. The absence of a menstrual cycle is generally a cause for concern for women, so it is not surprising that this particular symptom was most frequently reported. This could be correlated with the high number of women (N=86) who expressed a desire to have children, either now or in the future.

That weight gain/obesity was also frequently reported is telling. In the essay “Foucault, Femininity, and the Modernization of the Patriarchal Power,” Sandra Lee Bartky argues that “abundance in a woman’s body is met with distaste” (1998, 28). There is an overwhelming stigma in our society associated with being “fat” or “overweight,” such that eating disorders, diet fads and “get slim quick” schemes run rampant, unchecked and unquestioned by the masses. Those of us who fail to meet those standards are the objects of ridicule or, worse, reduced to invisibility. A number of women shared their feelings about their weight:

> I have a hard time finding clothes that fit, and furniture to fit me. To me I am personally self confident, but it does get hard every once in a while when you see beautiful women have the life of a normal woman and know that you will never have that.
>
> Less of a woman and most every woman with PCOS is going to say the same thing. For the same reasons. Weight gain, not being able to lose the weight, acne, skin tags, facial hair, depression, fertility issues. Having PCOS makes you feel ugly and unworthy. Unworthy of love, unworthy of feeling beautiful, unworthy of children.
>
> I know with PCOS I am not as fertile, and I carry the extra weight associated with it therefore deemed as ugly to society.
>
> I do feel like much less of a woman when it comes to appearances because I'm hairy, I'm fat, and I have acne (because of PCOS), and it makes me feel less feminine, less like a woman because I do not look or feel soft, beautiful, or curvy.

Drawing from Bordo, Crawley, Foley and Shehan suggest that “TV commercials and print advertisements regularly use the notion of ‘control’ as a goal for the presumed female audience, especially the message that control of the body and diet will result in control of the world around them” (92). Carrying around extra weight is perceived as slothful or as having some moral failing, as if an overweight woman simply lacks the drive and motivation to improve herself and conform to those unspoken standards. Unfortunately, for a woman living with PCOS, all the effort and control in the world is sometimes not enough to transform her body into something acceptable by the prevailing discourse. It is, perhaps, not surprising then that when asked what symptom of PCOS women were most frustrated with, 44 out of the 117 women who answered the question indicated weight gain/obesity.

Following closely behind weight gain/obesity, is hirsutism. Elevated levels of testosterone associated with PCOS cause excess hair growth in places that females typically do not have course hair: chin, face, neck and abdomen. Bartky argues that "a woman's skin must be soft, supple, hairless, and smooth" (1998, 31, my emphasis). Returning to Foucauldian notions of discourse, women with PCOS subject their bodies to the practices which dictate "proper" displays of femininity – displays which clearly do not include beards. Even with medication to help correct hormonal imbalances, many women with PCOS still suffer the stigma associated with what is considered unsightly facial hair. We pluck, we wax, and those of us who can afford it may resort to unpleasant and costly option of electrolysis or laser hair removal. Kitzinger and Willmott reported that "Women experienced their body and (especially) facial hair as a betrayal of their identity as women… The act of removing the hair, as much as the hair itself is a continual reminder of their supposed lack of femininity" (2002, 353). Several participants expressed additional sentiments about their hirsutism:

> I feel less of a woman because of the physical symptoms and the fact that it will be harder to have children. As a woman, especially at such a young age, I don't believe I should have to worry so much about things such as growing hair on my face or thinning hair. It may sound silly to some people but I feel like PCOS has robbed me of a normal life, and that is something I have struggled to deal with.
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> My facial hair is embarrassing. I have to wax and tweeze and sometimes shave my chin which no woman should have to do.
>
> I don't think it has made me more or less a woman. Just a very hairy, beardy-type woman.
>
> I feel like less of a woman; especially because of the unnatural hair growth on my face. I know women who are forced to shave just as men do. I have not gotten to that point; however, the hair growth has not slowed down in the least.

> I feel less of a woman, mostly due to the fact that I have a beard! I also have a hairy back, which makes it incredibly difficult for me to feel comfortable naked. I just don't picture a woman as someone with this much dark, coarse hair all over her body.

According to Crawley, Foley and Shehan (2008), we have, in essence, become our own jailers. They argue that “Individuals learn to discipline their bodies to produce these memberships in the group’s ‘true’ or ‘normal’ categories because they are subjected to *panoptical surveillance* – a watchfulness that assesses each individual’s relationship to that which is understood as ‘normal’” (2008, 89). We see images of other women and know that dark facial hair is a very clear signifier of deviation from this accepted norm. Simply dealing with hirsutism can be economically challenging as most insurance companies will not cover specific treatments for this particular symptom. One respondent shared, “Insurance companies should cover prescription drugs used in the treatment of PCOS- such as Vaniqa for hair removal. This is not a cosmetic issue.” Electrolysis and laser hair removal are not only painful but costly procedures that may be out of the reach of many women. Insurance companies generally do not deem the treatment of these symptoms of medically necessary; however, they inevitably impact a woman’s state of well-being if she is constantly fighting hair growth that she cannot control. During the course of one of my two personal interviews, K, a graduate student at USF, shared that while she was fortunate to only have to tweeze the hairs from her chin, her sister was not so lucky. In an effort to rid herself of the facial hair that K referred to as a “beard,” her sister resorted to harsh chemical depilatories which subsequently caused burns and scarring, making her situation that much worse. The pressure to conform is undoubtedly great that women would resort to painful and disfiguring methods to attain this ideal of “normal.”

Out of 107 participants that responded when asked how PCOS had affected their body image, 67 of them chose “definite change for the worse,” and 25 indicated “some change for the worse." Similarly, when queried about the impact PCOS has had on their self confidence, 50 and 38 participants rated themselves in the "definite change for the worse" and "some change for the worse" categories respectively. These numbers, especially when correlated with the personal narratives, are a clear commentary on just how devastating the effects of PCOS can be on a woman. Most women felt that PCOS made them feel like less of a woman, primarily due to the symptoms related to condition. One woman explained:

> PCOS has made me feel like less of a woman. I'm still a woman in all the aspects that are the most important such as being strong, sensitive and nurturing like women are. However, I do feel like much less of a woman when it comes to appearances because I'm hairy, I'm fat, and I have acne (because of PCOS), and it makes me feel less feminine, less like a woman because I do not look or feel soft, beautiful, or curvy.

There were a small number of responses, however, from women who replied that PCOS either had no change on the way they felt about themselves or that it actually made them feel more like a woman. For one participant, PCOS seems to have been a site of personal empowerment: "[I feel like] more of a woman in the sense that I have had to come into my own in a lot of ways. I have had to assume more responsibilities for myself and my health/ Learn to have a voice, make sure I'm heard and really demanding more from my doctors and treatment methods."

The reported age at which women were formally diagnosed with PCOS ranged from 12 – 40 years with the most common ages being 23 (N=14), 22 (N=11), and 24 (N=8). The onset of symptoms, however, was markedly younger with the majority. 36 women reported that their symptoms surfaced between the ages of 14 and 16, 32 aged 13 and under, and 30 between the ages of 17 and 20. In her documentary *Scrambled*, Randi Cecchine mentions that the average woman sees 4.5 doctors before her PCOS is finally diagnosed (2003). The results observed through my own research indicate that 83 out of 118 respondents saw between one and three doctors before being diagnosed, while 26 saw between 4 and 6 doctors before receiving the diagnosis of PCOS.

“Some patterns of doctor-patient interaction are clearly shaped by the gender of the patient,” argues Ratcliff, “Doctors are more dismissive of women and more likely to doubt the authenticity of their health complaints” (2002, 34). In her essay, “Sexism in Women’s Medical Care,” Halas suggests that “sexism in the medical care system poses particular problems for women. Many physicians see women’s complaints as trivial, neurotic disorders best treated with placebos or symptomatic therapy” (2004, 4).

> I have never had regular periods and went to the doctor several times about it and was constantly told it was my age. I was put on the pill and then told all my problems where from being on or coming off the pill. I started getting a sharp pain in my right side, I was sent for a scan and when they found a large cyst on my ovary they started to listen to me. 1 year later I was diagnosed with PCOS and put on metformin.
>
> My first symptom was high blood pressure but it was border line so that doctor didn't do anything. Over the next five years I added complaints of excess facial hair, acne, dandruff to the point that my entire scalp would peel off in one big layer, irregular periods and gained over 100 pounds (even though I exercised regularly). The doctors I saw always only focused on one symptom and never put all of them together. At one point when I went in for a physical, the doctor asked me to list all of my complaints. When I started listing everything, she asked if I was depressed! She did absolutely nothing for me! I finally got a doctor who recognized that something was wrong with me. She put me on blood pressure medication then started looking for a cause. She said someone as young as me with blood pressure as high as mine was had to have an underlying cause. I spent almost the next two years undergoing every possible test. They all came back normal. She said she had one last test to run and if that came back negative she was out of ideas. She sent me for an ultrasound of my ovaries and I knew the next day it was PCOS.
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> My endo decided to call my PCOS Type II Diabetes. I spent days denying that I was a diabetic and actually became angry. I insisted on seeing another doctor in the same practice who told me I did have PCOS, it was just easier for the other doctor to tell me I had Diabetes rather than explain. I was furious. I knew there was something wrong with me for so many years. Diabetes was and still is not one of my health issues. I am glad to finally have a name and some form of treatment. I slowly feel more like myself day by day.
>
> I always knew there was something wrong. I was 13 when put on BCP because of irregular periods, and nothing else was done to look into what was causing it. The doctor

> just said "she's young, it happens" and sent me home with BCP. I took the pill until my husband and I got married in June, 08. I got off it with this gut feeling that it was going to be a process getting pregnant. Funny how your gut feelings are usually right. I called my doctor in August to make a appt since I hadn't had my period and I knew not wait any longer than 3 months without having it. I went in talked to her about all my symptoms. I think she knew what was going on right away but didn't want to scare me so she was hoping that a rx of progesterone to induce a period would be enough to jump start my cycle and it would go back to normal. I did get my period with the progesterone, but then not again after that. So back up to the doctors I went, and we did the progesterone thing again. This time she ran blood test also, and told me to make an appt to come back in couple weeks to go over the results. She told me then she was pretty sure it was PCOS. Two weeks later when I went back it was confirmed.

> My Primary Care Physician refused to diagnose me because, although I had *every other symptom*, I don't have cysts on my ovaries. My OB/GYN at the time tried to get him to make the diagnosis so I could receive treatment through my insurance, but he refused. Three years after my initial concerns, I changed doctors because of a move, and my new OB/GYN diagnosed me and medicated me immediately.

According to Ratcliff, “A doctor’s power also means that any prejudices he has, whatever lack of empathy he may have for particular kinds of people, may be consequential for his patients” (2002, 35). Women with PCOS frequently seem to fall victim to this particular brand of mistreatment, especially those who are battling with their weight.

> Initially, the doctors were insisting that it was just problem eating, hence my weight gain. But I was suffering from pains, regular bleeding but for extended periods of time. Each cycle could last for an average of 20 days each. That was when the doctor did a scan, which reflected the many cysts present in the ovaries. On top of that, my symptoms were consistent with PCOS and I also had a weight gain of 30kgs within a span of 10 months.

> I was sent to an endocrinologist because I was heavy, he actually treated my very badly because I had a hard time losing weight. He did blood tests etc and told me he would give me birth control for my acne. He never once mentioned PCOS. Later I made an appointment to see an OBGYN after having a two week long period. She did an ultrasound and diagnosed me.

The prevalent attitudes about overweight women in America seem to blind doctors who seem more interested in blaming patients for some failing than in making the effort to see beyond their own preconceptions. It is much easier, apparently, to find the cause of excess weight within the (lack of) control of the patient than to attribute it to a chronic health condition.

The culture of Western biomedicine socializes women to trust their doctors implicitly, yet the level of frustration experienced by women with PCOS makes that difficult. PCOS is a complex condition, yet the fact that it is so commonly occurring might make one believe that medical professionals, especially those dealing with women's health issues, would be relatively well informed about it. Based on the example provided above, however, there seems to be a lack of confidence in the ability of these professionals to treat this syndrome. When asked to rate how well health professionals understand PCOS, the 118 respondents indicated that there was "some lack of understanding" (N=46) or a "widespread lack of understanding" (N=44). Even so, most women are still seeking treatment from doctors, specifically, an endocrinologist, OB/GYN or primary care physician. 86 out of the 118 women who answered the question reported that they are currently seeing a health professional. The remainder were either choosing to self-treat, could not afford to see a doctor due to a lack of health insurance or were seeking other treatment options outside of the biomedical system.

In light of my own experiences with PCOS, I believe that women dealing with the condition and who are turning to resources outside of medical professionals are better informed about PCOS. Along this line of thinking, I decided to query the participants as to recommendations they might make to improve the quality of care with regards to PCOS. 71 women offered suggestions, including:

> The biggest thing is I think we need to educate doctors to get over their general fat-phobia so that when women come to them exhibiting all the symptoms, they're not just told to lose weight and you'll get better. Yes, weight loss can help improve PCOS symptoms, but some PCOS symptoms (IR, no cycles) need to be treated BEFORE that weight loss is even possible. So many women spend their lives just thinking they're fat and lazy, despite healthy diets and exercise.
>
> Health professionals should learn to take the symptoms seriously and test for PCOS, especially when there is more than one symptom. I could have been diagnosed several years ago if my doctors had not dismissed my symptoms as "normal." Also, it would help

if doctors were more sensitive to their patients when diagnosing it. PCOS may not seem like a big deal to people who do not have it, but it is huge to someone who actually has it. I felt like my allopathic doctor did not care about me because she told me nothing could be done about the PCOS or losing my hair and that I should just take metformin and see what happens. I felt like I was doomed. I am going to be seeing a natural doctor soon who specializes in PCOS. I am hoping she will provide more advice on how to treat all of my symptoms.

I would say that male doctors need to stop equating PCOS as being a solely cosmetic disease. The physical symptoms are miserable, and the hair is the least of it.

It is not all about being infertile and does need to be treated even if you are not having kids. Waiting until someone is 400 pounds and has full blown diabetes is not okay. Blood tests do not tell the whole story. If a woman says something is wrong please listen to her.

If there was one thing I could suggest to improve things for women with PCOS is for doctors to making women feel uncomfortable for expressing concerns about their bodies. A lot of times, I feel like my concerns about my health have gone unnoticed and written off as me being "paranoid." People know their own bodies better than someone else does, but unfortunately most often we're told we're paranoid when we think something is wrong (and it actually is!)

To treat PCOS itself and not just manage the symptoms - to realize I’m worthy of good treatment even if I am not trying to conceive at this time – at least listen to the ladies who have PCOS because my experience has been that I, myself, as well as many woman I’ve spoken with online who have PCOS may be more knowledgeable about the disease/syndrome than the doctor themselves. - appreciate the value or research of homeopathic remedies in regards to PCOS -honesty if they are not knowledgeable and readiness and insistence that we see specialists in regards to these specific issues. Encouraging us to be open about the issues we are facing, anxiety or depression or other symptoms - Also I think one of the most frustrating things about having PCOS is tied in with the insulin resistance. I SWEAR on my life, it seems every doctor aside from those who have diagnosed me with PCOS just assume I have diabetes. I have even sat there and explained to them I have PCOS and as a result have insulin resistance which is why I take metformin...they still don’t believe me, insist I should be checking my sugar levels and have often just done it myself...all despite that my primary care physician insists it unnecessary.

Ask the patient what symptoms they experience and ask how it makes them feel and affects their life. Ask what they would like to be different, and offer treatment based on what the patient wants to change about themselves. Do research for them. Realize it is not their fault they have this disease. Explain WHY they are on certain medications and how it's affecting their bodies. Keep up to date on the research of PCOS.

These narratives share a common theme: doctors not hearing their patients. These women are not looking for miracle cures or even expecting that their physicians will have all the answers. More than anything, these women want to have their concerns validated. Medical professionals cannot hold undisputed claims to knowledge about the body. As subjects inhabiting our bodies, we alone possess a unique awareness about ourselves. It is vital that this information be taken into account and that positivist notions which place credence in symptoms that can be observed and quantified be tempered accordingly.

Another problematic aspect in the treatment of PCOS is the view that it is strictly an issue of reproduction and infertility. I count myself among the women that do not plan on having children now or at any point in the near future. Women are more than vessels to produce the next generation, and consequently, some women with PCOS are not particularly burdened by the fact that they may have issues with fertility. One respondent explained:

> Women have a lot to deal with in life when it comes to things like hormones and fertility usually. If PCOS is having a big effect on a woman's fertility to me that does not mean she is any less of a woman. Having a child is not the top goal in womanhood for me, and I think there is too much focus on that. People tend to think there is something wrong with you if you have not had a child by a certain age.

A woman who is otherwise fertile but chooses not to have children might be cast in a negative light as if she were somehow shirking her responsibilities as a woman. A state of infertility was painful for many women who participated in my research; however, for women who did not have intentions of conceiving, it is a release from the stigma associated with the choice *not* to be a mother.

While some women mentioned that they would like to have had the choice as to whether or not they would become pregnant, there is also the potential to be relieved of the worry of becoming pregnant. Realizing that the practice of safe sex is still vital but also that there is a difference between “perfect use effectiveness” and “typical use effectiveness” when it comes to contraception, I asked women if being at a greatly reduced risk for pregnancy resulted in greater enjoyment and freedom in intimate relations.

> Yes, in a way. I can have casual sex without worrying about getting pregnant - I still use a condom, but getting pregnant is one less thing I have to worry about when going into an intimate relationship. During the times I have been in committed relationships and did not use a condom, the freedom of knowing that I would probably not get pregnant was liberating. However, it was also always in the back of my head that if I ever wanted to get pregnant someday that I would probably have a hell of a time doing so. I still consider myself "too young" to have children, so I am lucky that I have time to think about everything and "fix" myself before it's time to do that.
>
> Yes. It was a great freedom once I got past my pride. When my current boyfriend and I learned that I was infertile we were relieved and were more open with not being so safe about getting pregnant, we have never wanted children and still don’t. It definitely saves money in contraceptives.

The ability to enjoy one’s sexual life is key to a state of overall good health. Though, as previously discussed, many women with PCOS have issues with their own body image, being released from pregnancy can have the potential to improve a women’s comfort when engaging in heterosexual relationships. Being able to break with stereotypical expectations of womanhood can be a healthy way to deal with PCOS. In it, women may well find an increased sense of agency and greater reproductive choice.

Recommendations

The suggestions made by survey participants encompass many of my own sentiments about improving the way that we deal with PCOS. I have experienced the same frustrations in my attempts to deal with my condition, and continue to struggle each time I see a new doctor. On a recent visit to a new cardiologist, I found myself entering into the same, tired discussion as we went over my list of medications. Though the insulin sensitizing drug metformin is taking primarily by diabetics, it is commonly prescribed to women with PCOS who are dealing with insulin resistance. "I see you're taking a number of drugs for diabetes," the doctor remarked. I answered, "Yes, I am, but I am not diabetic. I have PCOS. My blood sugar is normal. I'm just insulin resistant." He gave me a confused look and asked, "Then why are you taking those medications?" This scenario is far from unusual, and I inevitably find myself plunged back into it every time I see a new doctor. One of my survey participants with whom I communicated further outside of the survey itself shared our common experiences on that topic. Such interactions are far too common as women with PCOS navigate the often treacherous terrain of our own healthcare.

The compartmentalization of our bodies needs to be brought to an end. Especially in light of the multi-morbidities mentioned earlier, women with PCOS need healthcare professionals with are competent in the treatment of the condition. A March 2007 article in *The Journal for Nurse Practitioners* sums up a bit of advice that I all health professionals should be made aware of:

> NPs [nurse practitioners] who manage women with PCOS must remember that this syndrome can have devastatingly negative psychological consequences for these women. By sharing one's clinical reasoning with the client, she becomes a collaborator with the NP in the effort to produce positive health outcomes. Clients should be treated with respect and should be praised for achievements but never criticized when their efforts do not product the desired results. Women should be given the opportunity to express their frustrations. Appropriate and supportive management of both the physical and psychological aspects of this life-long syndrome can improve the overall quality and longevity of a woman's life. [DuRant and Leslie 2007, 185]

Their comments accurately sum up the way I want to be treated as a woman living with PCOS.

It is difficult to express just how important it is that a woman be considered an equal and active partner in the treatment of her condition. It is the difference between being a victim of PCOS and learning to live with and accept it. Breaking down the barriers to knowledge is absolutely essential. Women must be encouraged to become their own advocates. We must be active participants in the fight for our own health. I believe that resources like the LiveJournal communities and credible web sites on PCOS mentioned are crucial tools in helping women manage their condition. By providing sites of public pedagogy whereby women can share not only their experiences but their knowledge, we have the opportunity to empower ourselves. These women are engaged in a very political act by the very nature of their willingness to speak openly and honestly about their condition.

Women have the ability to arm themselves with information that will give them ability to question medical authority. In the essay, “How to Tell Your Doctor a Thing or Two,” Hunt argues that “there is growing evidence nowadays that the ‘bad’ patient is a better one, in terms of medical results, than the ‘good’ patient. According to a number of recent research studies, the passive, uncomplaining, unquestioning patient is less likely to get well quickly” (2002, 24). An effort needs to be undertaken in earnest whereby women are educated on just how to deal with medical professionals. We need encouragement to move past the shame and discomfiture we feel as a result of our perceived failures to measure up to societal norms and expectations. Women must find the confidence within themselves to break free from the role of submissive patient and take the risk involved in becoming the “bad” patient who demands control over her own body.

Feminist perspectives are part and parcel to such methodologies. In *No Longer Patient*, Sherwin argues that

> The current health care system is organized around the central ideal of pursuing a “cure” in the face of illness, wherein “cure” is interpreted with most of the requisite agency belonging to the health care providers. A feminist alternative would recommend that the health care system be principally concerned with empowering consumers in their own health by providing them with relevant information and the means necessary to bring about the changes that would contribute to their health. (1992, 239)

Until policy changes and activism can bring such changes about, women must exercise their own agency to seek out useful resources and to share them with others. Trailblazing initiatives like *Our Bodies, Ourselves*, a groundbreaking and ongoing project by the Boston Women's Health Collective, should serve as models for the means by which information and knowledge can have a transformative and powerful impact on health. For the first time in its history, this germinal work has included information PCOS (2005, 632-634). More importantly, however, the book provides women with practical advice on how to take a more active role in the health and well-being of their bodies. Such information needs to be incorporated in materials not only for women dealing with PCOS, but for women and girls of all ages.

Conclusion

Polycystic ovarian syndrome is more than an endocrine disorder or a cause of infertility. It is more than just a thread in the overall fabric of my life or the life of any other woman who has had to face the challenge it presents. It is symbolic of the greater crisis that women face in regard to their own health. It is our need to be nurtured; to feel whole and complete as we are, no matter what the predominant view is. It embodies our desire to be in control of the vessels which we have been given in this life, to not only be heard but understood. That understanding will require the effort of more than just an individual woman, but all the women who deal with PCOS, as well as those on whom we depend for medical treatment. The personal is indeed political. In speaking out and increasing awareness of PCOS, personal narratives become political statements about the state of women's health care. Kitzinger and Willmott point out that "despite a far-reaching concern with women's issues in general, feminist awareness of, or activism in relation to, PCOS, is very limited" (2002, 350). Now more than ever, we must raise our voices and the awareness of PCOS so that a large group of women do not find themselves left behind as we move towards improved health care for all women. We may not menstruate each month. We might have more testosterone floating around our bodies than what one might see in a “normal” woman. We might not embody that which is popularly seen as feminine, but we are indeed women nonetheless.

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