

Too Fat, Too Hairy, Too (In)visible: Polycystic Ovarian Syndrome and Normative Femininity

By Christina Fisanick, Xavier University, USA

Abstract:

It seems that there is much potential at the site of the PCOS body to transgress the boundaries of normative femininity. In many ways, the PCOS body already does just that. In all of its hairy, balding fatness, the PCOS body represents a challenge to what is expected of the female body. The problem is that it lacks visibility. It is hidden within the matrix of cultural expectations, and attempts to make the PCOS body visible are regulated not only by society but by women with PCOS as well. Will future attempts by the PCOSA and other organizations like it ever make the PCOS body a body that matters? Perhaps working in conjunction with NAAFA or other organizations fighting for the acceptance of diversity in body type and kind is one way of doing so, but until then, the PCOS body will remain invisible, a hairy, balding, infertile fat body shuffling along in the dark made visible only when subject to ridicule and regulation.

"You see, your period is like mowing the lawn. All month long, the grass grows up and then, when you bleed, the lawn mower mows it all down. *Your* grass just isn't getting mowed."

—Ob/Gyn explaining PCOS to me at age 25

"[T]he acquisition and maintenance of femininity-female gender identity-requires continuous and unfailing attention to the body as an instrument of self-presentation."

—F.K. Furman, *Facing the Mirror*

1 It is estimated that 6-10% of all women have Polycystic Ovarian Syndrome (PCOS), an endocrine disorder characterized by obesity, male pattern hair growth and loss, irregular menstruation, infertility, and skin abnormalities (skin tags, adult acne, and dark patches of skin under the armpits and between the thighs). Despite its prevalence, PCOS is often not diagnosed or misdiagnosed, leading Dr. Samuel Thatcher to dub it "The Hidden Epidemic." It is difficult not to see the irony (intended or not) in this designation. After all, in our image-obsessed culture, it would be hard to miss a 300 pound balding women with a moustache. Reductive though this characterization is, it nonetheless represents a crucial way of thinking about PCOS and the bodies of women who have the syndrome. Women with PCOS have highly visible bodies, but are coded by normative femininity as invisible.

2 I have chosen the PCOS body as a site for investigation not only because I have PCOS, but because two major sites that construct femininity — body size and body hair — come together in the PCOS body as in no other place. The PCOS body provides an opportunity to explore the ramifications of performing femininity when these characteristic elements are in excess, out of control, beyond normal limits. In this essay, I will explore the

ways in which the normative practices of femininity shape the interpretation of the PCOS body and the quest of women with the syndrome to at once make PCOS visible and keep the PCOS body hidden. In addition, I will explore recent attempts by the Polycystic Ovarian Syndrome Association (PCOSA) to make the PCOS body visible.

On Be(com)ing a Woman: Negotiating Normative Femininity

3 In order to understand the ways in which women with PCOS both subscribe to and resist normative femininity, it is important to reiterate the current conversation surrounding femininity. Femininity is not a descriptor, but an ideological system in which all people participate. As Sandra Bartky writes, "We are born male or female, but not masculine or feminine. Femininity is an artifice, an achievement, 'a mode of enacting and reenacting received gender norms which surface as so many styles of the flesh'" (132). The female body, then, is femininity's site for struggle and its vehicle for expression and for coercion. Although corsets have long left our everyday attire, we are faced with a more binding, more constrictive force than just strings and whale bone; we must struggle each day, each moment within the bounds of an ideology that we can barely render visible let alone easily resist. Femininity relies on a system of negation: no calluses, no bulges, no hair in the wrong places, and also a system of contradiction: produce children, but do not store enough fat to ovulate, have muscle tone, but do not be strong. Coupled with its ability to conceal its own genesis and disguise its disciplinarians, femininity is a project that is doomed to failure.

4 It is in the arenas of negation and contradiction that the PCOS body excels. 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). Is there a possibility, then, in this state of excess, of both hyperfeminine and unfeminine, for women with PCOS and their bodies to subvert the dominant regime of normative femininity?

5 Judith Butler's concept of gender as performative is particularly useful here. Just as gender is constituted through a "stylized repetition of acts," femininity is also performed and "must be understood as the mundane way in which bodily gestures, movements, and enactments of various kinds constitute the illusion" of an enduring femininity (Butler 403). In other words, wearing makeup and high-heeled shoes, dresses, crossing our legs, and dieting are all acts that contribute to the rhetorical illusion of femininity. If, then, 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. Butler acknowledges this prospect by arguing that "the possibilities of gender transformation are to be found in the arbitrary relation between such acts, in the possibility of a different sort of repeating, in the breaking or subversive repetition of that style" (403). But, she is careful to caution, breaking or changing individual acts alone is not enough to evoke this transformation. Rather, what is required is an understanding that all acts are part of a "collective action," a system of acts done with others that follows a script that is always already in existence (Butler 404). Therefore, one could conclude, if transformation or subversion is to occur it must be done collectively; acted out as a group. Of course, this alone is not enough either, because even though the acts may change, if they are still operating within the old system, then they are hardly transformative. For example, hiring a few diverse faculty members is not enough to change a college campus' attitudes towards diversity if the biased system of power remains in place.

6 Likewise, it is not enough for me to show up to class tomorrow having not shaved or plucked or burned off my facial hair. I am sure I would get some stares and maybe even my students would talk about me, but I doubt it would make much of difference. I would simply be the weird woman professor with a mustache. That is not to say that individual acts aren't worthwhile, because they certainly can be self-empowering and even change the way others think, but alone they constitute little more than a red mark or erasure on the heavily encoded script of embodied performance. Therefore, it is necessary to seek out others and attempt to change the system that makes normative acts seem, well, normal. In the following sections, I will attempt to theorize the two most visible aspects of the PCOS body — fat and hair — in the hopes of shedding light on the way these two characteristics are defined by femininity. I chose fat and hair among the other symptoms of PCOS, because they visibly mark the PCOS body and provide a contrast between the visible and invisible. Seen within the matrix of femininity, perhaps, the path to subversion will become clearer.

Fighting Fat: When More is Less

7 It is estimated that 75% of all women with PCOS are obese, making this characteristic a prominent one among women with this condition (Thatcher 25). The excess weight, usually centered around the midsection, is caused by the overproduction of estrogen and insulin resistance, a condition that many Americans face today and one that often, if not always, leads to diabetes. It is extremely difficult for women with PCOS to lose weight and even more

challenging for us to keep the weight off, because the body literally fights the weight loss process by altering the uptake of insulin on the cellular level, which causes estrogen levels to increase.

8 In *PCOS: The Hidden Epidemic*, the first comprehensive book on the syndrome written for the lay audience, Dr. Samuel Thatcher points to the "glucotoxic environment" in which Americans live and eat. He argues, as popular culture theorists have as well, that while we live in a world that encourages us to "super size," we are not supposed to be "super-sized" ourselves. Easily accessible foods, such as French fries, cheeseburgers and pizza, contribute to the early onset of diabetes, which could possibly be prevented by better dietary choices. Yet, at the same time, he acknowledges the very difficult task that weight loss presents to women with PCOS when he advises, "Forget about ideal body weight! I know this is heresy, but in PCOS patients, normal weight and the body weight that insurance and American culture has mandated as ideal will never been the same. A goal to reach such a weight is doomed to fail from the start (Thatcher 133). Instead, he encourages women with PCOS to "strive for metabolic fitness. Rather than seeking an 'ideal' weight, a more realistic final expectation is to break and maintain weight under 200 pounds, or to achieve a 20% weight reduction, whichever is the greater loss" (133). Given that the "healthy weight" for women in this country is around 127 pounds, even proposing such a number as 200 as "the goal" is controversial, even though it is much more realistic.¹

9 Abundance. Excess. Glut. All are fearful because they represent things we cannot control. They represent that which cannot be contained, that which has unabashedly broken the rules of modesty and of morality. Nonetheless, our culture encourages and is proud of abundance, of having more than we can use. We are pushed to consume, yet pushed harder to not show signs of that consumption.

10 In *Fat History: Bodies and Beauty in the Modern West*, Peter Stearns directly links our current obsession with slimness to this very contradiction and ties it to American national identity. Americans were and still are known for their excess, for having too much, and for consuming too much. Rockwellian images of Thanksgiving dinner tables packed full of more food than any family could possibly eat instilled pride in Americans who felt as though they had finally made it, that they had succeeded in the pursuit of the American dream. Like the dinner table, healthy and prosperous American bodies were full and abundant. Then, in 1890, for reason that Stearns does not fully articulate, a shift occurred that called for

¹ No more proof is needed of this magical number than an examination of home scales. Of the eight brands found at a local department store, seven of them had display stickers that read the weight of the imaginary (woman) dieter at 127 pounds. The eighth scale read 125 pounds.

Americans to put a stop to their gluttony and to abhor the round female form. (Fat men were not yet victims of these fat attacks.) Stearns argues, "what was happening between the 1880s and 1920 was a moral mobilization against fat among respectable Americans. Habits that had been dismissed or even praised were now condemned" (23-24). He further notes, "World War I provided new opportunities to publicize the attack on that, for healthy eating became part of a patriotic duty" (Stearns 24). Therefore, body size became a national concern.

11 Most interesting about Stearns' approach to fat phobia as a function of national identity is the link he makes between indulgence and control. As Americans became more wealthy and were able to enjoy the finest foods in the largest quantities, guilt about gluttony soon replaced pride in plentifulness. Further, as more and more Americans turned away (or were shut out) from organized religion, the locus of moral control was disrupted, leaving most people adrift in terms of regulating excess. However, it seems that no matter the origin of the current state of fat objection (er, abjection), the public has been set up as the gatekeepers for body size, and if a woman fails to meet the current standards, then there are consequences. Fat women are labeled as being out of bounds, out of control, and out of touch (also read untouchable). Although the fat acceptance movement has gone a long way with the National Association to Advancement Fat Acceptance (NAFAA) and books such as Marilyn Wann's *Fat!so?*, fat is still nowhere near where it's at.

12 The current, early twenty-first century perception of the fat body is complex in that it is constantly being shaped by contradictory rhetorics. Medical science, for example, has taken on a new, stronger authority for most Americans. We are convinced now more than ever before that we can control our bodies, their shape, their size, their well-being. And, we have become an even more consumption-driven culture. Recall the post-9/11 pressure placed on Americans to shop, shop, shop to help our country recover. It is your patriotic duty. Fatness is forbidden, yet the very means that are said to make a person fat are not only promoted, but are expected to be consumed.

13 Susan Bordo picks up on this inner tug-of-war and frames it in the contradictory rhetorics of fulfillment and desire. She argues, "The rules for this construction of femininity (and I speak here in a language both symbolic and literal) require that women learn to feed others, not the self, and to construe any desires for self-nurturance and self-feeding as greedy and excessive" (Bordo 96). Therefore, the "results" of that self-nurturing, a round, fed body, is a physical representation of that greed and excess that cannot be hidden or denied. This outward manifestation of feeding oneself is an affront to ideological system of normative femininity. It challenges the boundaries of this system and invites discipline to those who are

in violation.

14 Cecelia Hartley explores the issue in "Letting Ourselves Go." She argues that fat women represent a challenge to mainstream society, because by "letting themselves go," they physically announce their opposition to dominant gender roles. They are failing to control themselves in a way that is expected of women, that is demanded by the rules of femininity. She writes, "Women who do not maintain rigid control over the boundaries of their bodies, allowing them to grow, to become large and 'unfeminine,' are treated with derision in our society, and that derision is tied inextricably to the personal freedom of women" (Hartley 63). She adds that getting fat, becoming ungainly and therefore, unfeminine, exemplifies the ultimate act of the loss of self-control.

5 In addition to the cultural consequences of being fat, i.e. verbal abuse, lack of romantic interest from others, being passed up for a promotion, Hartley argues that women see fat as the ultimate punishment for lack of self-control. Noting that many surveys have recorded being fat as a primary fear among women, she states that "Above all, women must control themselves, must be careful, for to relax their vigilance might lead to the worst possible consequence: being fat" (Hartley 64). The object being resisted, then, is the fat female body, which "is suspect, needy, always in danger of erupting into something that will grasp more than is allowed. The end result is that women, fat or thin, often develop an antagonistic relationship with their bodies" (66). Extending Bordo's concept of the self struggling against the self, Hartley now adds an object to the battle, the fat body, that which should be avoided at all costs. In this view, women are no longer just trying to achieve the standards of femininity, but they are also fighting against becoming a fat woman. There is now an object, a target, an image that women can defend themselves against: "The fat body...is a reminder of all that a woman cannot and should not be" (Hartley 67).

16 Le'a Kent, drawing on the work of Julia Kristeva, takes this concept one step further by describing the fat body in terms of abjection. "In the public sphere," she writes, "fat bodies, and fat women's bodies in particular, are represented as a kind of abject: that which must be expelled to make all other bodily representations and functions, even life itself, impossible" (Kent 135). In other words, the fat body is necessary to the existence of the thin female body. Kent argues, "the fat body rings the margins of the good self, haunting them as it helps create them. The fat body must be repeatedly evoked at the margins, drawn in and then expelled, in order to continue taking the weight of corporeality off thin bodies" (136). Therefore, the fat body represents all that is nasty, unsightly, and unspeakable about the body. It represents poor health, disease, and death. It is what allows the thin body to exist as the ideal, because it

assumes the negative qualities that all bodies, in reality, possess.

17 At the same time, Kent argues that "there is no such thing as a fat *person*" (emphasis hers, 135). Using as an example the before and after pictures of dieters found in advertisements for weight loss and exercise products, she explores the notion that a fat person is not a person, but "something encasing a person, something from which a person must escape, something that a person must cast off" (Kent 134). We have all seen ads in which a picture of a fat woman's body is placed over her now-thin body or infomercials in which the new, skinny version of a woman bursts through a blown-up paper image of her old, fat self. This very scenario, Cecilia Hartley adds, "both consigns the fat body to an eternal past and makes it bear the full horror of embodiment, situating it as that which must be cast aside for the self to truly come into being" (145).

18 Of course, what these ads and the ideologies behind them imply is the prevailing and unquestioned belief that all fat people want to be thin. It is impossible for most people to believe that anyone would prefer to remain fat. In *Women's Health: Psychological and Social Perspectives*, Christina Lee argues that these expectations are the result of the concept of "normative discontent," which she describes as "the notion that it is normal for Western women to be unhappy with their bodies, [which] has been accepted as a natural facet of femaleness; in fact, not being concerned about one's body shape is seen as unfeminine and somewhat odd" (136). It is the rare exception that anyone, including other overweight people, would think that a fat person could possibly love their own round bottoms, rolled tummies, and thick thighs. If you love your fat body, you are said to be, as Kent writes about herself, "impossible, I am living in a state of denial, and I must sooner or later come to my senses and resume loathing my body, if only for my 'health'" (131). It is interesting that self-help gurus like Oprah and Dr. Phil want you to love your body, but they only want you to love it so that you can make it thin. After all, if you truly love and respect your body, you will lose weight, eat right, and exercise. "Body love" has now become the new means of control. In our PC, reverse-psychology world, it has replaced verbal abuse as the way of getting fatties to get down the pounds, because, if you don't love yourself, then you can't possibly love anyone else. And what more evidence do you need than a fat, lazy, sloppy body to prove to the world that you don't love yourself?

19 Despite its obvious visibility, the fat body remains invisible, an absent presence lumbering through life only to be ignored or shunned. It represents and is represented, yet has no representation. Kathleen LeBesco discusses the "presence" of fat female bodies in her essay, "Queering Fat Bodies/Politics." She deconstructs women's magazines that feature both

dieting and high-fat, high-calorie food articles right on the cover. One might conclude, she notes, that the object or audience for these magazines are fat women, yet these women are nowhere to be found, a state that Braziel has called "the corporeal mark of absence" (LeBesco 78). In this case, her absence is the result of a number of issues. Obviously, it would be difficult to profit from a magazine selling diet tips and recipes with a fat woman on the cover. Again, no one wants to be fat and her presence would imply that the diet did not work and the foods made her fat. In addition, no one wants to see, to be confronted with, the fat body. It is an object of ridicule and disgust. To see the fat body requires an acknowledgement by the looker that he or she does not desire or even respect the fat body. It is better to simply avoid this messy encounter altogether and leave the fat body out of the picture in the first place. Therefore, as Jana Evans Braziel notes, "the fat female body. . . constitutes that which should not be seen, perhaps that which should not *be* at all" (emphasis hers, 237).

20 These cultural attitudes about the fat female body have greatly impacted the way in which women with PCOS have been treated by the medical profession. Although obesity was part of the original diagnostic criteria for PCOS established by Drs. Stein and Leventhal in the 1940s,² it remained the only one of the four classic symptoms to go untreated until the 1990s. Despite (or in spite of) the prevalence of obesity among women with PCOS, doctors and researchers failed to address the issue scientifically. Enough research existed on the dangers of obesity for doctors to conclude that obesity exacerbated the other aspects of PCOS, therefore, making weight loss the first line of treatment for women with PCOS, but the treatment was placed entirely in the hands of the patients. If they did not lose weight, then they were only hurting themselves and making their PCOS symptoms worse.

21 When the connection between PCOS and obesity began to be explored around 1992, women with PCOS were treated like any other obese patient who was urged to follow the diet and exercise programs popular at the time. Unfortunately, women with PCOS had a great deal of trouble losing weight on low fat, high carbohydrate diets. As a result they were subject to criticism by their health care providers and some were even verbally abused for their inability to lose weight.

22 Of course, not all doctors treat their obese patients with disdain, but many doctors have little respect for their obese patients who to them seem out of control and lazy. Roberta Pollack Seid discusses this attitude in *Never Too Thin: Why Women Are at War with Their Bodies*: "Doctors treat their overweight patients in patronizing and often cruel ways, regarding them as recalcitrant patients who won't follow orders" (23). Further support that fat phobia is

a problem in the medical community is the large number of medical-based Web sites that offer listings of fat-friendly doctors.

23 By the late 1980s and early 1990s, a condition known as insulin resistance attracted the attention of PCOS researchers. The debate about the relationship between insulin resistance and obesity gained more interest in the mid to late 1990s as several studies demonstrated that obesity, at least in women with PCOS, is independent of insulin resistance. It was determined that women with PCOS are, as a group, insulin resistant. Even so, many doctors still believed that obesity caused insulin resistance and continued to treat their obese patients by urging them to lose weight. Other health care providers, however, seriously examined the condition of insulin resistance and began experimenting with insulin resistant treatments, such as drug therapy normally prescribed for diabetic patients. Not all doctors have accepted the insulin resistance theory and even those who have are reluctant to treat it. Whether the reluctance of the medical community to treat insulin resistance with such drugs is the result of a wait-and-see attitude in which doctors give new theories time to be thoroughly analyzed before they try them or as the result of the still strongly-held belief that obesity is the result of high fat, high calorie diets and lack of willpower, most doctors are still treating PCOS in much the same way as they did in the 1980s with birth control pills that simply mask, or make invisible, many of the secondary symptoms of PCOS.

"Diabète des Femme a Barbe," or Bearded Lady Diabetic

24 The title of this section refers to a 1921 article by two French physicians, Achard and Thiers, who studied the prevalence of diabetes in women with excess facial hair. Of course, it is hard to miss the association with the bearded lady of freak shows and circus tents. Women with beards do not go unnoticed and are often the object of ridicule. Although advances in hair removal options, such as electrolysis and home depilatory products, have made it easier for today's bearded ladies to disguise their five o'clock shadows, the intense scrutiny placed on the female body makes even previously "normal" hair growth abnormal.

25 Although Achard and Thiers did not mention PCOS directly, many researchers point to their study one of the earliest appearances of PCOS in medical literature. It is somewhat ironic to think that even at this early date a connection was made between excessive hair growth in women and abnormal glucose levels, yet it would take PCOS researchers more than 60 years to make this connection a valued site of research and treatment for the woman who suffers with PCOS. According to Geoffrey Redmond, a leading PCOS researcher and physician, "the most common underlying condition causing increased hair growth is PCOS."

High male hormone levels are responsible for over 90% of all excess hair growth in women, and women with PCOS generally exhibit high levels of testosterone due to elevated insulin levels. In short, high insulin levels affect the ovaries, which causes an overproduction of testosterone; therefore, women with PCOS have difficulty controlling their weight, getting pregnant, maintaining regular periods, and exhibit excess hair growth, among other symptoms. Given this relationship, it is not surprising that Achard and Thiers were compelled to write about the excessive hair growth of their female diabetic patients, yet there are still many questions surrounding the actual "diagnosis" of abnormal hair growth and determining the proper course of treatment.

26 Hirsutism, the medical term used to describe a *woman* with excessive body hair, is itself gendered in that it "refers to increased hair in the so-called 'sexual distribution.' Sexual distribution simply means skin areas on which men and women have different amounts of hair" (Redmond). While hirsutism is often treated as a medical condition, only 1% of all cases of hirsutism in which women seek medical attention are due to an endocrinologic disorder (Redmond). Health care providers typically do not classify excess hair growth as a disease or even a problem that requires their attention, rather it is women who seek treatment on their own. According to Merran Toerien, whose study on attitudes about body hair I will turn to in the next few paragraphs, "the decision by some physicians to define hirsutism as any hair growth that embarrasses the woman in question, highlights the strongly social element involved in the presumption of female hairlessness." What she makes clear here is further reinforced by Samuel Thatcher who writes matter-of-factly, "Generally, an excess of hair growth is overestimated by the concerned woman and underestimated by her physician" (104). In other words, hirsutism is not a condition that requires medical care, but it *is* a condition that women, influenced by the social meanings of excess hair on their bodies, demand to have remedied. Women simply cannot be hairy!

27 Hair removal and the imperative toward it is, just as we have seen with obesity, irregular menstruation, and infertility, part of the larger system of femininity. The process of hair removal is naturalized, remaining hairless (or very closely cropped) is normalized, and the cultural meaning of a hairless female body is problematically sexualized. Toerien, whose research examines attitudes about body hair in English women, concludes:

female body hair removal is constructed as so obviously necessary as to require no explanation. In this way, the socio-cultural construction of the practice as necessary and normative is obscured; hair removal just is. Particularly indicative of this assumption is the repeated tendency for women who do not shave to be called to account for this 'failure,' rather than for women who do shave to be questioned about their practice.

28 In other words, hair removal has become naturalized. Few women question why they are embarrassed to be seen in shorts if they haven't shaved their legs in a few days. Even fewer question why they find "the hippie girl's hairy pits" to be offensive. Women who do not shave their publicly visible body hair are sometimes called bohemian, dirty, lazy, or lesbian. The practice of hair removal has been going on for so long in many Western countries that to not do it is seen as wrong, as breaking the rules of femininity and good hygiene.

29 In her study, Toerien surveyed 682 women as to their conceptions of female body hair. Julie, a respondent with PCOS, discusses what she feels is the illusion of choice when it comes to body hair removal. As Toerien comments, "[I]n a culture where female hair removal is normative, the options 'to remove or not remove' do not carry the same weight." Many other respondents supported Julie's position about which Toerien concludes, "Described in terms that presume it to be a 'given,' female hair removal is constructed not as a choice, but as a need."

30 Clearly, hair removal among women is culturally laden and is, as Toerien argues, "symbolically linked to 'appropriate' femininity." Women not willing to participate in this act, must face social consequences. And like women who fear becoming fat because of obesity's cultural currency, women also fear that others will be able to see their hair, to discover their secret. Toerien points to a 1993 study conducted by Barth, Catalan, and Day which found that 68% of so-called hirsute women avoided social situations in which they felt their hair "problem" would be exposed.

31 In as much as the hairy female body is marked in our culture, the hairless body, specifically the hairless vulva, is also heavily encoded. A quick trip down the pornographic section of an adult bookstore or a flip through an adult movie catalogue reveals a decidedly large interest in women with hairless vulvas. Although it is easy to argue (and to agree) that hairless vulvas allow for better close ups during filming and photographing x-rated sex scenes, the interest in keeping vulvas shaved and smooth extends beyond the realm of pornography. It is not unusual for a lover to be asked to shave her vagina, nor is it odd for a woman to just do it because she wants to do so. My goal here is not to argue that women can't or shouldn't gain pleasure-aesthetic and/or sexual-from removing her pubic hair, what I am suggesting is that this seemingly extreme interest in mainstream pornographic materials of hairless vulvas is partially due to the vulnerability that it produces in women.

32 In a culture where hair removal has become as common as the daily shower, the hairy and the hairless are at opposite ends of the spectrum. Within the rhetoric of femininity, hirsute women are not acceptably performing femininity. Women with excess or non sex-specific

quantities and/or qualities of hair growth not only defy societal norms, but also call into question their own sexuality and sexual desirability. Yet, the practice of hair removal is very rarely questioned, even among feminists, whose campaign in the early 1970s to equalize the hairy and hairless has never come to fruition.

Subverting the System?: Revealing the PCOS Body

33 I began this essay with a discussion of femininity in the context of Judith Butler's concept of performativity with the possibility of that it might lead to insight into particular ways in which the cultural system of normative femininity can be disrupted. The PCOS body, obese, irregular, infertile, and hairy, attempts to do so, but the body alone is not enough to alter the oppressive system of normative femininity, especially when the body is a "full-figured phantom,"³ invisible in all ways that matter. Rather, it takes an actor to affect change in the way the acts are read and repeated.

34 Many theorists have written about the power of the fat female body as a site of conflicting ideologies. In *Fat is a Feminist Issue*, Susie Orbach argues that being fat itself is a powerful form of resistance. "Getting fat," she insists, can be "a definite and purposeful act; it is a directed, conscious or unconscious, challenge to sex-role stereotyping and culturally defined experience of womanhood" (Orbach 40). Catrina Brown echoes this conclusion by noting that being fat "is an ultimate form of female covert power" (60). In other words, despite its obvious visibility, corpulence, for the female, can become a powerful form of transcendence in that she takes up space and doesn't play by the rules set up for "ladies." Cecilia Hartley adds, "[being fat] allows a woman to nurture herself, to reject sexually-stereotyped roles, to deny society's demand that she be the perfect woman, and to stake a claim on the world, taking up space without having to demand it" (70). Hartley takes this one step further by noting the deliberateness of such an act as becoming or staying fat: "Just as we have come to realize that the thin ideal is not an innocent construction, so we can no longer afford to dismiss the fat body as making no particular response to the society that would construct it otherwise" (70).

35 While there is no doubt that the fat female body and other so-called unfeminine bodies (hairy, disabled, disfigured) resist the norms of femininity by their very existence, I do not think that this alone is enough to make a real difference in terms of the larger project of demystifying and dismantling normative femininity. If it was as easy as simply getting fat, then, according to recent statistics, the problem of femininity would already be defeated,

³ W. Charisse Goodman, *The Invisible Woman: Confronting Weight Prejudice in America* (Carlsbad, CA: Gurze Books, 1995), 1.

given that millions of American women are considered to be overweight. Therefore, destructing femininity must require much more than simply not looking the part. As LeBesco notes, "We need some way of discerning which actions are truly disruptive of so-called normalcy, and which in fact help to maintain the status quo...What performance in what context will help to destabilize naturalized identity categories?" (77). A look at the recent activities of the Polycystic Ovarian Syndrome Association (PCOSA) might reveal the distinction between which acts are actually transgressive and which acts simply appear to be so.

36 It has been a long-term goal of the Polycystic Ovarian Syndrome Association (PCOSA) to make PCOS visible.⁴ A national non-profit organization created to support and educate the public, including patients, friends, and health care providers, about PCOS, the PCOSA has long realized the importance of making others aware of the syndrome. From its genesis as Internet-based support group in 1995, the PCOSA's aims were to make others aware of the prevalence of the syndrome and its long-term health risks, including heart disease and diabetes. As the organization has grown in membership and status, its efforts to increase awareness of PCOS have shifted as well. From yearly conferences to an Oprah campaign to adopting a spokeswoman, the PCOSA has attempted to educate the world about PCOS. Unfortunately, not all of their projects have been successful, and in fact, some of their more recent ventures have led to further abjection of the PCOS body.

37 One of the most effective events organized by the PCOSA is the international conference this it has held every year since 1998. These conferences are held with the purpose of bringing together women with PCOS and doctors who treat the syndrome. Physicians and other health practitioners have presented topics ranging from diet to infertility to hair growth to alternative therapies, such as Tai Chi and acupuncture. While these conferences have been useful in disseminating information about the syndrome, especially the latest developments in treatments, the most useful aspect of these conferences has been visibility. For perhaps the first time outside of their family situation, the women who attend these conferences are in the same room with more than 200 other women who look like them.⁵ I remember my own reaction to walking into the conference hall in 2001. For the first time in my life, I felt

⁴ The PCOSA's website is located at <http://www.pcosupport.org>.

⁵ It should be noted that not all women with PCOS are overweight. A small percentage of women with the syndrome are thin. These women in some ways have a more difficult time dealing with PCOS, because it typically takes them longer to get diagnosed. The syndrome is not expected in a thin body. Also, because they are in a minority, it is more difficult for thin women with PCOS to relate to other women with the syndrome. According to Mary, a thin woman with PCOS that I interviewed a few years ago, "It's like [fat women with PCOS] don't believe that I have it too. They can't understand how I got so lucky. I try to explain to them that I have the other symptoms. I can't get pregnant. I have hairy face. But, that doesn't seem to matter."

average, unbelievably average. I didn't feel like the chairs would be too small or that everyone would stare at me as I walked down the center aisle to take my seat. At my table sat four other women, all over 250 pounds. I saw myself in them. I saw thinning hair, acne, stubbly mustaches, and double chins. I felt liberated and powerful knowing that there were other women on this planet that were like me. Yet, I know that my own willingness to identify with these undesirable, abject bodies is not necessarily the most common reaction of other participants. After all, identifying and being empowered by the fat, hairy, PCOS body is admitting to doing femininity wrong. It is rejoicing in, reveling in a socially objectionable body. Fat, hairy women are not supposed to like being fat and hairy-that's just unfeminine.

38 A conversation held on a PCOSA message board illustrates this type of resistance. Soon after *Shrek II* came out in the theaters, I advanced the idea on one of the PCOSA's message boards that perhaps Fiona should become the spokesperson for PCOS. Fiona is an ogre, like Shrek, who, we learn in the first movie, had been cursed as a child to take one form by day (beautiful princess) and one form by night (ogre) taking her true form with true love's first kiss. As you may have guessed, Shrek's kiss at the end of the first movie prompted Fiona to take her true form as an ogre. When we meet her in the second movie, she and Shrek are on their way to a party hosted by her royal family. We see Fiona in this movie in her true form. We see her belching, shaving, and eating as much as and what she wants. To me, it is a liberating, though conflicting view of alternative femininity. In one respect, it is perhaps troubling to see a fat "woman" engaged in what society might think are disgusting acts: eating fried field rats, belching and farting. In another respect, however, we see a fat woman being herself, enjoying her life, and being loved.⁶

39 When I saw the movie, I thought that Fiona would make a wonderful spokeswoman. She has a round body, and she even shaves her face each morning! Although some women thought my idea was terrific, many women grew angry at the mere suggestion. One woman wrote, "Who wants a smelly, stinking, green ogre representing us!" Another woman wrote, "I don't want people thinking that I am like Fiona. I try hard to get people to see me as normal." As these comments illustrate, some women with PCOS certainly do not want to be identified with any figure that is abnormal or thought to be disgusting. And, honestly, I cannot blame these women. After all, the consequences of doing femininity *that wrong* are severe.

40 Nonetheless, the PCOSA's conferences remain potential sites of agency establishment for women with PCOS. Being able to see other women who look like you with their partners and children and friends is a powerful way of substantiating the PCOSA's motto, "You are not

⁶ There are many troubling aspects of this movie that space does not allow me to expand upon.

alone." Women who attend these conferences often return to their home chapters and begin new educational programs to bring what they have learned back to their chapter members, including regional health care providers. In addition, many women leave these conferences feeling empowered for perhaps the first time to demand better health care, to educate others about the syndrome, and, as I did after the 2001 conference, to go swimming without a cover up for the very first time. Therefore, the PCOSA's annual conferences do provide opportunities for subversion, because they not only encourage women with PCOS to perform alternative acts, such as modeling plus-size fashions and taking the stage to the presentations, but to also make changes in the way in which people across the world think about the PCOS body by encouraging them to educate others and hold their own events in their areas of the world.

41 One of the major methods by which the PCOSA educates the public is by press releases and encouraging women all over the world to tell their stories to their local news outlets. Over the past several years, articles about PCOS have appeared in publications ranging from the *Washington Post* to *Self* magazine to *Woman's Day*. PCOS has also been featured on the *Today Show* and on various regional television programs. In 1999, Heather Lubinsky, a PCOSA volunteer, went on *Jenny Jones* to talk about PCOS as part of a show focusing on women's health issues. It was a liberating segment in many ways, because Lubinsky did not attempt to hide or otherwise mask the effects of PCOS on her body. Instead, she attempted to fully articulate the toll the syndrome has taken on her body. She pointed to her thinning hair, the hair growth on her face, and to the fact that she has been unable to conceive. She even related stories about her difficulty in the workplace with having excess facial hair. The success of the show, in terms of raising awareness about the syndrome, was quickly noticed by the large volume of hits on the PCOSA website immediately following the show. Unfortunately, however, not all media provide such a positive outlet to discuss PCOS or fat bodies.

42 An episode of *Oprah* from January 2001 is one such example.⁷ Before Dr. Phil McGraw got his own show, he was regularly "unleashed" on *Oprah's* audience every Tuesday. A psychologist known for his hard hitting, tell-it-like-it-is rhetoric, Dr. Phil is not afraid to make the guests angry, and he does not hold back his thoughts on the questions at hand. During this episode, Dr. Phil told weeping woman after weeping woman that they were overweight because they wanted to be. That fat women choose to be fat and that they can only

⁷ Parts of this section on Phil McGraw were presented at the Conference on College Composition and Communication in Chicago, Illinois in March 2001 under the title "Women's Bodies, Oprah, and the Power of an Online Community."

become thin if they "wake up." At one point, an audience member asked if there were any true medical reasons for obesity. According to Dr. Phil, there is no medical reason for obesity. Obesity is always the result of emotional trauma, and it is possible to be thin only if the emotional trauma is resolved. He told the tearing woman, "You choose to be overweight. Accept that your lifestyle is contributing to your obesity." I was shocked, not only because he was hurting so many women, but because he had just misled the hundreds of thousands of viewers that watch Oprah's show each day. There are many diseases that promote obesity in those who suffer from them, such as Crohn's disease, Graves disease, thyroid disease, and Polycystic Ovarian Syndrome (PCOS). Not to mention the fact that he clearly dismissed the many women who choose to be obese and do not see their weight as a problem or a cause for concern. Like so many other Americans, Dr. Phil obviously finds it hard to believe that fat women can be content with being fat. I nearly turned off the TV, but then the camera panned to Oprah, who was nodding her head in agreement with everything Dr. Phil was saying, which made me wonder how a woman who has suffered, publicly and privately, with weight issues for so many years could agree with such false statements. And, I wondered how a woman who knows that her show is seen by 21 million viewers a week and is shown in 21 countries around the world can allow such harmful words to be stated as fact and then agree with those statements (Push).

43 By the time the closing credits began to roll, I was online, hoping that the women on the PCOS Main List (PCOSM-L), an e-mail-based discussion list for women who suffer from the syndrome, had seen the show, too. By the time I got there, a rush of e-mails had already been sent. They wondered, as I did, why Oprah would allow Dr. Phil to say such things? We wondered why Dr. Phil felt he was qualified to make such statements? And, we wondered how the hundreds of thousands of women all over the world who might have PCOS or another disease that was linked to obesity must be feeling? Did they feel bad about their bodies all over again (or even more so)? It wasn't enough that these women were chastised about their weight from their health care providers, families and others, but now, on national television they were being told once again that they were fat because they were lazy emotional victims, not because their illnesses prevented them from losing weight or because they chose to be fat.

44 Before midnight that night, the list was abuzz with deciding what sort of action should take place to let Oprah and Dr. Phil know that what they had done was wrong. Soon women were sending copies of e-mails that they intended to send to Oprah, Dr. Phil, and Harpo Entertainment Group, Oprah's production company. They were asking for critiques of their

messages, making sure that what they were saying was on the right track and offering to read other messages to get them ready to send. Within twenty-four hours of the airing of that show, hundreds of messages were sent letting Dr. Phil, Oprah and others know that there are medical reasons for obesity and that it is not all "in the heads" of the women who were overweight.

45 Then, someone suggested that we turn to the message boards on Oprah's website and spread the message not only about obesity possibly having endocrinologic and metabolic causes, but also to let other women know about PCOS. It is well known that an untold number of women not only have no idea that they have PCOS. Several of us posted messages about the erroneous message of Dr. Phil and explained that there were real medical conditions that contributed to uncontrollable weight loss. We talked about PCOS, left our e-mail addresses, and the PCOSA's website address for more information. Many of us received e-mails from women who visited the message boards at www.oprah.com. Not all of them were positive. Some of the responders felt that we should not have posted our "anti-Phil" and "anti-Oprah" messages. Others felt that we disrupted the conversation that was taking place on those boards. But, most of the messages that we received were positive and asked for more information about PCOS. As an online community, we discussed the responses that we received, feeling that if we had done nothing other than get one more woman diagnosed then we had accomplished something vital.

46 The CEO of the PCOSA had been reading about our struggles with Dr. Phil's message. To help us in our efforts, she decided that the PCOSA should write a formal letter to Oprah to let her know of our frustrations and to ask her help in educating the public about PCOS. Once drafted, the letter, addressed from the PCOSA officers and its members, was posted on the PCOSA's website for member critique. The final draft was very powerful. Basically, we stated that what Dr. Phil had said was wrong and dangerous to the women in Oprah's viewing audience. We firmly stated:

Overweight women have suffered enough mistreatment and misunderstanding. Propagating false information, as Dr. Phil has, is not only irresponsible, but in this case serves to perpetuate the notion of blaming the victim. Is this really a message that Oprah wants to send the millions of viewers who tune in daily and who are trying to be the best that they can be? ("Letter")

Just explaining the problem was not enough. We demanded that, "[Oprah's] show take responsibility for this misinformation and correct it. Wouldn't it be better to let women know they may have this disorder? [...] Blanket statements that are medically erroneous are dangerous to the millions of women who have PCOS and don't yet know it" ("Letter").

47 Included in our package, now called "Project Oprah," was a statement from Dr.

Samuel Thatcher, the medical director of the PCOSA. In "With Extreme Prejudice: A Perspective on Weight and Weight Loss," he took a much stronger approach against Dr. Phil's statements than we did on the PCOS site and allowed his credibility as a well-respected physician to make his case that "obesity is not a psychiatric diagnosis [...] weight and its control are much more than either self-will or emotion can explain or direct." He asserts that diets composed of processed carbohydrates and not enough protein and vegetables coupled with a lack of necessarily daily activity is partly responsible for the crisis that is obesity. He goes on to say that "Obesity should be considered a legitimate, chronic, lifelong medical disorder and approached as such" (Thatcher, "With Prejudice"). He closes by arguing that "Many PCOS patients have a lifelong battle to maintain weight that many still would consider 'fat.' The ignorance of Dr. McGraw's statements just sent another arrow flying and another wound as been inflicted on these women" (Thatcher, "With Prejudice").

48 Neither Oprah nor Dr. Phil nor her production company responded to these letters or our individual e-mails. We wondered as a group how she could just ignore the cries of so many women. All we wanted was for her and Dr. Phil to set the record straight so that the thousands or perhaps millions of women watching could understand that they, too, could be suffering from a real medical condition that needs treatment. In the case of PCOS, not getting treatment can lead to reproductive cancers, diabetes, and heart disease.⁸

49 Although our efforts ultimately failed, "Project Oprah" provides an example of the willingness of the PCOSA to publicly display the PCOS body. Many of the letters from women with PCOS were about daily living with the syndrome and even included tweezers and hair removal creams and special hair growth shampoos along with other "tricks of the trade." There was no effort to suppress or to regulate the ways in which the PCOS body was displayed. In fact, women were encouraged be as demonstrative as possible in the hopes of convincing Oprah that PCOS is an issue that is in need to attention.

50 I have to wonder, then, if this refused acknowledgement is what led the PCOSA to focus many of their recent efforts on finding a well-known, but acceptably feminine, spokeswoman to represent the organization. The quest for a celebrity spokeswoman went on for quite some time. It is believed that someone in the public eye would be most effective in calling attention to PCOS. After all, many non-profit organizations have celebrity spokespersons who are essential in raising awareness and funding for their causes. The

⁸ For an argument about the possible reasons that Oprah refused to educate her viewing audience about PCOS, see my article, "One thing I know for sure: Oprah is Fat Phobic," in the Spring 2005 issue of *Feminist Media Studies*. In it, I closely examine an episode of *Oprah* that focuses on fat women and conclude that Oprah is fat phobic as evidenced by treatment of fat guests.

trouble was in finding a famous woman who has PCOS. It is not a syndrome that women talk about in private let alone in public. When chef Jamie Oliver's wife, Jools, began discussing PCOS publicly because they were having trouble conceiving a child, many members of the PCOSA thought she would make a great spokeswoman. It is not known if the PCOSA's officers contacted her or not, but the search for a spokeswoman continued.

51 In 2004, the PCOSA announced that they had found their spokeswoman.⁹ Tulin Reid, well-known plus-size fashion model, accepted the title and intends "to travel throughout the United States to promote PCOSA and its mission to support the millions of women and girls worldwide with Polycystic Ovary Syndrome" ("Tulin Reid"). Reid is a beautiful woman who, despite weighing around 160 pounds, conforms to many of the standards of femininity. She has full, shiny hair, no facial hair, smooth, clear skin, and well-proportioned hips and thighs. Although she "plans to speak very openly about her struggle, symptoms and avenues she has taken to live a healthier life with the syndrome," it is obvious that the woman that she was before "dealing with" the syndrome, when her "hair was falling out in hand fulls, I had acne and my weight exploded from a fit 160 pounds to 250+ pounds in less than two months," and after, "a workout and eating plan," clearly represents the before and after pictures that fat women are all too familiar with ("Tulin Reid"). In her "after" mode, Reid is not dangerous or disturbing or transgressive. She is a beautiful woman talking about the way she looked "before," when she was "unfit." In Kent's words about this "before and after" phenomenon, the fat person in this scenario does not exist. In essence, by choosing Tulin Reid as the spokeswoman for PCOS, the PCOSA has effectively made the PCOS body invisible, erased it out of existence. This is not to say that Reid or the PCOSA have deliberately negated the PCOS body, but what I am saying is that by making her spokeswoman, they have obeyed the rules of femininity.

52 I am not attempting to reduce or demean Reid or the PCOSA, but rather, I am trying to illuminate the distinction between choosing a publicly acceptable body as opposed to an unacceptable one to represent women who have a syndrome that makes their bodies unfeminine in so many ways. Reid represents the "after" picture; the possibilities of what you can look like if you beat the syndrome, which far too few women manage to do. At once we have a woman telling the world about her struggles with a syndrome that defeminizes women, and yet, who does not have an unfeminine body. Perhaps some women, like those who objected to Fiona as spokeswoman, might find Reid inspiring, but to others she may simply represent all that they wish, but will never be. I am not trying to essentialize the PCOS body,

⁹ In April 2005, Reid stepped down from her PCOSA spokesperson position to devote her time to promoting her website, www.PCOSLiving.com.

because it certainly can take many forms, including thin, clear skinned, and thick haired, but I am saying that the PCOSA's choice of spokeswoman is not a representative with which most women with PCOS will clearly identify.

53 Many questions arise from the PCOSA's endeavors to make PCOS visible. Certainly, they desire to spread the word about PCOS and make the medical community and the general public aware of the syndrome, but at the same time, there is a real desire for the body that represents the PCOS body to be acceptable, to try as much as possible to conform to the standards of normative femininity. Is it to make the PCOSA and PCOS seem as credible as possible? After all, American culture sees fat women as silly, sloppy, lazy, dishonest, among other negative qualities. And, to have a hairy woman as a representative? Unseemly.

54 Then again, if these are truly the cultural interpretations of the PCOS body, could displaying such a body be transgressive? If the PCOSA chose to use the body of an everyday woman with PCOS (and really, who would that be? What would she look like?), as its representative, then wouldn't it be easy for her to be ignored, disregarded, not taken seriously because of the way her body is marked? Or, could her very presence as a representative of a syndrome give her form credibility, and thereby give credibility to the bodies of other women who have the syndrome? Could challenging the idea that obesity is always a condition of laziness and sloppiness and may in fact be the result of a real medical condition transform the way in which we think of fat women?

55 It seems that there is much potential at the site of the PCOS body to transgress the boundaries of normative femininity. In many ways, the PCOS body already does just that. In all of its hairy, balding fatness, the PCOS body represents a challenge to what is expected of the female body. The problem is that it lacks visibility. It is hidden within the matrix of cultural expectations, and attempts to make the PCOS body visible are regulated not only by society but by women with PCOS as well. Will future attempts by the PCOSA and other organizations like it ever make the PCOS body a body that matters? Perhaps working in conjunction with NAAFA or other organizations fighting for the acceptance of diversity in body type and kind is one way of doing so, but until then, the PCOS body will remain invisible, a hairy, balding, infertile fat body shuffling along in the dark made visible only when subject to ridicule and regulation.

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