
“You Think You’re the Only One”: Comparing Descriptions and Lived Experiences of Polycystic Ovarian Syndrome

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Abstract: This article examines the biomedical diagnosis of polycystic ovarian syndrome (PCOS) from the perspectives of medical anthropology and science and technology studies (STS), addressing two main questions: what does a historical, medical anthropology and STS perspective reveal about how PCOS is described and understood in contemporary North America, and what are the lived experiences of people with this diagnosis? Common descriptions of PCOS are based in normative gendered assumptions. Drawing on interviews with people diagnosed with PCOS and on analysis of historical and contemporary biomedical literature discussing PCOS, I argue that the lived experiences of people with PCOS vary significantly from mainstream (biomedical and popular) descriptions of the diagnosis.

Keywords: polycystic ovarian syndrome, women’s health, endocrinology, metabolic disorder, medicalisation, biopower

Résumé : Dans cet article, j’affirme que les expériences vécues du syndrome des ovaires polykystiques (SOPK) diffèrent considérablement des descriptions courantes (biomédicales et populaires) de la maladie. À partir d’une analyse des sources historiques et contemporaines traitant du SOPK, je soutiens que deux approches du corps, de sa santé et de son fonctionnement, se reflètent dans le diagnostic: l’un centrée sur les hormones et l’autre sur le métabolisme. Sur la base d’entrevues menées avec des personnes ayant reçu un diagnostic de la maladie, j’aborde quatre thèmes majeurs. Premièrement, je montre que la perte de poids est présentée comme un forme de traitement du SOPK et que cela renforce la rhétorique selon laquelle le corps (en particulier celui de la femme) doit être maîtrisé grâce à un régime alimentaire et de l’exercice physique. Deuxièmement, j’affirme que les nombreuses sources qui considèrent que le SOPK a principalement une incidence sur la fécondité contribuent à essentialiser les femmes en tant que mères et négligent les autres préoccupations que peuvent avoir les individus au sujet de la maladie. Troisièmement, je maintiens que la construction du SOPK comme une question de « santé des femmes » et sa description en termes genrés normatifs - comme étant à l’origine de niveaux plus élevés d’hormones « mâles » chez les femmes - exclut les personnes transgenres et non binaires qui peuvent être elles aussi atteintes de cette maladie. Enfin, j’explore les pratiques de prise en charge du corps et les pratiques de soi.

Mots clés : syndrome des ovaires polykystiques, santé des femmes, endocrinologie, déséquilibre métabolique, médicalisation, biopouvoir

Introduction

This article examines the biomedical diagnosis of polycystic ovarian syndrome (PCOS) from the perspectives of medical anthropology and science and technology studies (STS), focusing on the lived experiences of people with this diagnosis and on the historical and social forces shaping the creation of PCOS as a diagnostic category. In online sources (where so many of us find medical information), biomedical literature and everyday conversations, PCOS is commonly described as an endocrine (hormone) and metabolic disorder in which a woman’s body produces higher-than-normal levels of androgens, or “male” hormones, causing a range of “unfeminine” symptoms including irregular periods and infertility, weight gain, facial hair and acne. My primary argument is that lived experiences of PCOS vary significantly from mainstream (biomedical and popular) descriptions of the diagnosis, such as the one I have just given here.

Literature, Methods and Terminology

While there is a wealth of biomedical literature on PCOS (e.g., Azziz et al. 2009; Dewailly et al. 2014; Fauser et al. 2012; Legro et al. 2013), very little research has been done on PCOS from a social scientific point of view, especially taking into account lived experiences of individuals with the diagnosis. Studies that have been done come from the fields of sociology (Kitzinger and Willmott 2002), fat studies (Fisanick 2009), and women’s and gender studies (Ellerman 2012). My work aims to fill this gap by drawing on theoretical perspectives and methodologies from medical anthropology, feminist scholarship, history of science and STS. My analysis is informed by and contributes to several areas of focus

within medical and socio-cultural anthropology, including medicalisation, risk, biopower and critiques of the field of “women’s health.”

Between 2016 and 2017, I conducted semi-structured interviews with six people diagnosed with PCOS: Ruth, a family doctor in her thirties; Donna, a nurse and mother of two in her forties; Logan, a filmmaker and trans man in his twenties; Nadia, a student in her thirties; Erin, a student in her twenties; and Kim, a teacher and mother in her fifties.¹ I also interviewed Annie, a nurse working in a high-risk OB/GYN department in a hospital, whose patients commonly include people with PCOS. As someone diagnosed with PCOS myself, my own experiences also include many informal conversations about PCOS with my own health care providers.

While many medical anthropology studies are based on participant observation in hospital or clinic contexts, there is no dedicated “PCOS clinic” in Toronto (or elsewhere, that I am aware of), as the diagnosis crosses several medical specialities. People with PCOS may be diagnosed by their family doctor or referred to a specialist in endocrinology or gynecology; they may undergo biomedical fertility treatment or seek out alternatives to biomedical frameworks in a naturopathic clinic or acupuncture studio; and so on. I have therefore not focused on any one treatment modality, and instead approached these experiences through interviews with people who have had differing experiences of PCOS. These experiences also include differences on the basis of age, gender, race and whether or not participants have had children. In addition, while I share a diagnosis in common with the people I have interviewed, it is equally important to acknowledge that I am white, cisgender and have not had children, and other aspects of my identity and life experience make my experience of PCOS different from those of the participants in my research. In drawing on my own experiences of biomedicine, I follow the example of several medical anthropologists who have done the same, including [Martin \(2007\)](#), [Rapp \(2000\)](#), [Ginsburg and Rapp \(1999\)](#), and [McCullough \(2013\)](#).

Sources on PCOS generally default to referring to women, a point that I discuss in greater detail below; throughout this article, I instead use the gender-neutral phrase “people (diagnosed) with PCOS,” except where I am in fact writing about women. I use the term *trans* as it is defined by Bauer and colleagues (2009, 348–349): “Trans is an umbrella term that encompasses a diverse group of people whose gender identity or expression diverts from prevailing societal expectations. Trans includes transsexual, transitioned, transgender, and genderqueer people.” *Cisgender*, in contrast, refers to individuals who identify as the sex they were assigned at

birth ([Bauer et al. 2009](#)). Finally, I use the terms *overweight* and *obesity*, not as terms describing appearance but in their context as biomedical terms defining body mass index (BMI) states, and with the recognition that the use of these terms to imply “disease” is inaccurate and harmful ([Jutel 2006](#)), another point I discuss in greater detail below.

Overview

This article addresses two main questions: First, what does a historical, medical anthropology and STS perspective reveal about how PCOS is described and understood in contemporary North American culture? And second, what are the lived experiences of people with this diagnosis?

In addressing the first question, I analysed historical and contemporary biomedical literature discussing PCOS. I argue that two frameworks ([Rosenberg 1992](#)) for thinking about the body and its health and functioning are reflected in these descriptions: one focused on hormones and one on the metabolism. In making this argument, I trace the history of these two frameworks in western biomedical thought and discuss how descriptions of PCOS have changed over time, as well as points that have endured.

In addressing the second question, I conducted interviews with people diagnosed with PCOS, as described above. Several themes emerged from these interviews. First, I look at the way in which weight loss is presented as a treatment for PCOS and argue that this reinforces a biopolitical rhetoric that the body (especially the female body) ought to be brought under control through diet and exercise. Second, I argue that while many sources frame PCOS as primarily affecting fertility, this narrative contributes to the essentialisation of women as mothers and overlooks other concerns people may have about their diagnosis. Third, I discuss how the framing of PCOS as a “women’s health” issue and its description in normative gendered terms, as causing higher levels of “male” hormones in women, excludes trans and gender nonbinary people who can also have this diagnosis. Finally, while I argue that PCOS diagnosis and treatment can be productively analysed using the theoretical framework of Foucauldian biopower, in the final section of this article, I argue that this framework may not adequately account for all experiences of people with PCOS, and I consider practices of caring for the body and self as another important area of focus.

Before addressing the two questions in full, I first describe PCOS in greater detail than the brief description already given, focusing on how it is diagnosed and how this diagnosis does, and does not, represent medicalisation.

Diagnosis and Medicalisation

Medicalisation describes “the processes through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems” (Clarke et al. 2003, 161). Numerous feminist authors have argued that women’s bodies and bodily processes have been especially subject to medicalisation, citing as examples menstruation, menopause, pregnancy and childbirth (e.g., Boston Women’s Health Book Collective 1973; Ehrenreich and English 1978; Lock 1995; Martin 1987). In addition, critique of and resistance to medicalisation have been of great importance to LGBTQ activism (in refuting the designation of homosexuality as a disease) and disability activism (in arguing for social and political models of disability as opposed to medical models), to name just two examples (Conrad and Stults 2008, 331; Kafer 2013). At the same time, critiques of medicalisation may sit uneasily alongside the desires of some people for greater medical recognition of their experiences, as in the case of what are sometimes called *contested diagnoses*, such as chronic fatigue syndrome and multiple chemical sensitivity (Conrad and Stults 2008; Dumit 2006; Murphy 2006, 151–178). I consider PCOS in light of both these views of medicalisation in this paper.

Diagnosis of PCOS (also sometimes referred to as polycystic ovarian disease, or PCOD) is based on a combination of two out of three key symptoms: (1) irregular or absent periods; (2) polycystic ovaries visible on an ultrasound; and (3) outward signs of “excess” androgens, namely, “male-pattern” hair growth on the body and face and hair loss on the head, acne and weight gain, particularly around the abdomen (a pattern that is also associated with insulin resistance) (Women’s College Hospital n.d.). Because only two of these three symptoms are necessary for a diagnosis, it is possible to have polycystic ovarian *syndrome* without having polycystic ovaries (and vice versa), making the name somewhat misleading. PCOS is associated with greater risks for diabetes and heart disease having to do with the insulin resistance facet of the diagnosis, but the exact relationship between these factors (i.e., whether insulin resistance is the cause or the result of the hormone imbalance and cystic ovaries, or simply correlated) is not known (Women’s College Hospital 2014).

The visible physical traits that are looked for in diagnosing PCOS – “excess” facial and body hair, acne and weight gain – are also experienced by women who do not have PCOS. All women have androgens (the so-called “male” hormones, including testosterone), and there is no set threshold above which PCOS is automatically

diagnosed. Even the designation of “irregular periods” may reflect the medicalisation of women’s bodies; Trevathan (2010, 52), a biological anthropologist, notes that “while a ‘normal’ menstrual cycle is about 28–30 days, . . . there is much variation from woman to woman and for the same woman from month to month . . . The actual range of variation is far greater and a lot of that range is still healthy.” Finally, PCOS varies widely in its presentation, as people experience different symptoms to different degrees. All of this means that there is a great deal of room for medicalisation in the diagnosis of PCOS: At what point are a woman’s weight, or the amount of facial hair she has, for example, “abnormal” enough to be considered “symptoms”? These are also highly gendered traits, and so the medicalisation of PCOS reinforces contemporary western conceptions of the “ideal” feminine body as thin, hairless, fertile and so on (Fisanick 2009). As Jutel (2011, 3) writes, biomedical “diagnosis provides a cultural expression of what a given culture is prepared to accept as normal and what it thinks should be treated.”

Another note on terminology is relevant here: some authors, including Trevathan (2010, 63), have argued that an appropriate response to the medicalisation of PCOS would be to refer “to the condition as simply PCO . . . rather than PCOS or PCOD, both of which explicitly emphasize the defect concept.” However, while I agree that the framing of PCOS as a defect or disease is problematic, I continue to use the acronym PCOS both because polycystic ovaries (which the moniker PCO seems to emphasise) were not the primary concern of most of the people I interviewed, and because I am interested in the way in which PCOS is constructed *as* a syndrome, something that involves multiple associated symptoms.

Finally, it is helpful to know a bit about how PCOS is treated. PCOS is a chronic condition for which there is no cure, so biomedical treatment options are geared toward managing the symptoms of most concern for each individual. These options can include hormonal birth control to prompt regular menstrual bleeding and reduce facial hair and acne; fertility treatment if trying to conceive; and treatments for insulin resistance (such as metformin, a medication also used in the management of diabetes). Patients may be referred by their family doctor to specialists (e.g., in endocrinology, gynecology or dermatology) for some of these treatments. Finally, “lifestyle changes” – that is, changes to diet and exercise – are almost always recommended, as weight loss is said to help manage symptoms and reduce future risks (Women’s College Hospital n.d.).

Historical and Present Descriptions of PCOS

Polycystic ovarian syndrome was first described by gynecologists [Irving Stein and Michael Leventhal](#), in a paper published in the *American Journal of Obstetrics and Gynecology* in 1935. They reported on seven patients, each of whom had all of what are now known as the three key symptoms of PCOS: polycystic ovaries, androgen excess (referred to by Stein and Leventhal as “masculinizing changes” [181]) and irregular or absent periods (182).

Prior to Stein and Leventhal’s report, polycystic ovaries were described as early as the seventeenth century in autopsy findings, though not always referred to by the term “polycystic.” For example, [Azziz and Adashi \(2016, 250\)](#) cite a report by the physician Antonio Vallisneri, who describes an infertile woman with “larger-than-normal ovaries, both smooth and shiny.” Similarly, there existed descriptions of women with “masculine” features, especially facial hair. However, these previous studies tended to present isolated cases as “medical oddities” and exotifying stories of “bearded ladies” ([Azziz and Adashi 2016, 251](#)). Stein and Leventhal, in contrast, were the first to report on a group of patients and to describe the symptoms occurring together, speculating about a common cause. What has changed since the first description of these symptoms as a diagnosis approximately 80 years ago? In this section, I trace changes in two main areas, describing how a diagnosis that initially centred on the ovaries came to be understood as based in and affecting the metabolic and endocrine systems of the body.

Ovarian Dysfunction

Stein and Leventhal identified the polycystic ovaries of their patients through surgery, carrying out ovarian wedge resection (removing a wedge of each ovary) “not only for diagnostic purposes but also as therapy” ([Azziz and Adashi 2016, 249](#)). In doing so, they were joining a significant history of surgical procedures performed on women’s ovaries: “As abdominal surgery rapidly developed,” wrote [Dastur and Tank \(2010, 121\)](#), “the ovary fell easy prey to the intrepid and enterprising gynecologist, who explored, biopsied, needled, resected, transected, excised, suspended and transplanted the organ for all sorts of indications.” In fact, Stein and Leventhal’s wedge resection procedure represented a much more conservative approach to surgery than was performed in the century preceding their work. This history is significant because it demonstrates an enduring biological essentialisation of women in medical thought concerning the role of the

ovaries in the body, as [Laqueur \(1992\)](#) argues. Laqueur quotes the French physician Achille Chereau, who wrote in 1844, “*propter solum ovarium mulier est id quod est*” (it is only because of the ovary that woman is what she is)” – though in fact it would be “forty years before there would be any evidence for the real importance of the organ in a woman’s life” (175). Over the course of these forty years, doctors performed ovariectomies – the surgical removal of ovaries – on a massive scale, on the assumption that the ovaries were the root cause of a wide variety of ills affecting women. Rather than the surgery being performed with a thorough understanding of its effects, [Laqueur \(1992, 176\)](#) argues, knowledge of the function of the ovary was produced by observing the effects of its removal:

The large role of the ovary in the biological lives of women – though certainly not making woman “what she is” – was finally established in the late nineteenth century by assuming that which was yet to be proven and using it as justification for the surgical removal of histologically normal ovaries . . . Removing healthy ovaries in the hope of curing so-called failures of femininity went a long way toward producing the data from which the organ’s function could be understood.

Today, ovarian surgery is seen as a last resort treatment for PCOS (when it is performed, a less invasive laparoscopic treatment is used much more often than the wedge resection practiced by Stein and Leventhal) (Women’s College Hospital n.d.). Polycystic ovaries are now identified using ultrasound, a technology that was “originally developed during World War I for detecting enemy submarines” and was first used for medical applications in the early 1950s ([Rapp 2000, 28–29](#)).² In the case of PCOS, while it is now diagnosed and treated without surgery, a trace of nineteenth-century surgeons’ assumption that the ovaries are what make women, women is evident in some descriptions of the diagnosis, which suggest that polycystic ovaries, and the syndrome named for them, are responsible for the “masculine” traits associated with the diagnosis.³ [Ellerman \(2012, 3–4\)](#) argues that the naming and categorisation of PCOS places “blame” on the ovaries, and obscures the fact that PCOS is more accurately understood as affecting multiple systems in the body.

Endocrinology

While the ovaries were the focus of Stein and Leventhal’s analysis, they remained unsure as to why or how the “masculinizing changes” they observed in their patients were related to “the ovarian and ovulatory pathology on which they were so focused” ([Azziz and Adashi 2016,](#)

251). At the time of Stein and Leventhal's writing, the field of sex endocrinology was just beginning to emerge and was bringing with it a shifting understanding of sex and gender – specifically, of where sex and gender were thought to be physically located in the body. Testosterone was isolated and named in 1935, the same year as Stein and Leventhal's publication (Azziz and Adashi 2016, 252). As well, “in 1935 the ovaries in the non-tumorous state were not supposed to produce [what were then called] male-like substances,” an assumption reflective of the history described above, in which the ovaries were thought of as the quintessential female organ; “it was not until 1960 that the ovary was clearly documented to produce androgens, including testosterone. Thus, Drs Stein and Leventhal can hardly be blamed for not considering the hyperandrogenism of their patients as the result of their ovarian dysfunction” (Azziz and Adashi 2016, 252). Today, however, PCOS is firmly understood as a disorder of the balance of “male” and “female” hormones in the body, and thus, in this section, I explore the history of this line of thought.

Oudshoorn (1990, 185) argues that “cultural assumptions about sex,” in particular, the assumption of duality or binary sex difference, have had a clear influence on the field of sex endocrinology from its start. Researchers in the early decades of the 1900s hypothesized that there would be one hormone, produced by the ovaries, that made women, women, and one hormone produced by the testes that made men, men – and they were surprised to find what they thought of as the “female essence” in males, and vice versa. Oudshoorn (1990, 1994) argues that this gradually led to a shift in the understanding of sex as being located in the organs to one of sex being based on the relative amounts of these hormones in the body; nevertheless, the notion that these hormones were essentially either masculine or feminine persisted. Ostertag (2016, 163) illustrates how this idea shapes the way in which we still describe the effects of hormones both synthetic and naturally occurring: he points out that synthetic testosterone causes muscle mass to increase but also causes testicles to shrivel, and he argues that if one begins from the assumption that testosterone is inherently masculine, then the muscle mass is what is expected, and the effect on the testicles is a surprising side effect. If one does not start from that assumption, however, and instead conceptualises hormones simply as chemicals that have various effects in the body, then there is no need to explain away a “surprising side effect” (163).⁴

Contemporary ways of thinking about hormones continue to reinforce this dualistic or binary-gendered framework. “Masculine” traits supposedly caused by testosterone include aggression, sexuality and athletic

performance (Hoberman 2006). The association of testosterone with athleticism is one that could potentially frame high testosterone levels in women as advantageous; instead, this is often responded to as a threat, with anxiety and policing. In a highly-publicised example, South African Olympic runner Caster Semenya has been subject to invasive “gender tests” and accusations that her hyperandrogenism gives her an unfair advantage on par with cheating.⁵ As Eastmond (2016) argues, these accusations have hinged more on framing Semenya as “a freak” rather than on concrete evidence, since “it’s hardly true that her condition eliminates the need to train hard and practice in order to build on her natural sporting abilities,” just as any other athlete.

Circulating in news stories and everyday conversations, these associations of hormones and normative gender are also present in discussions of PCOS. In our interview, Kim mentioned that when she was diagnosed with PCOS in her twenties, she was given blood test results that indicated “male” and “female” hormone levels, and she said, “I remember the humiliation of looking at that and thinking, ‘oh my god, my *male* hormones are too high.’” This was also a common theme in interviews with women with PCOS conducted by sociologists Kitzinger and Willmott (2002). They write that the word “freak” came up frequently in their interviews, and that it was “evident from women [they interviewed] that the way their condition had been explained to them by medical practitioners (e.g. in terms of ‘male’ hormones) contributed significantly to their feelings of freakishness” (359).

Synthetic hormones have played a central role in the history of endocrinology and, while not always central to PCOS, deserve a brief discussion here. Oudshoorn (1990, 1994), Ostertag (2016), Gaudillière (2004) and Lock (1995) have all traced how pharmaceutical companies were instrumental in the development of this new field in the early twentieth century. Oudshoorn (1994, 167) writes that “pharmaceutical companies, gynecologists, and laboratory scientists created networks in which research was focused on the chemical identification and isolation of sex hormones in order to make possible their industrial production.” Much important work in women’s health has been on the topic of synthetic hormones, which have been prescribed to women in the form of hormonal birth control; DES (diethylstilbestrol), a synthetic estrogen that was prescribed to pregnant women until it was documented to have carcinogenic effects on children exposed to it in utero; and HRT (hormone replacement therapy) in menopause, as just a few examples (Haraway 2012; Lock 1995; Watkins 2007, 2012).

Industrially produced hormones and their by-products now permeate our environment. The effects

of these chemicals have garnered a great deal of media attention, much of it concerned with effects on human sex and sexuality, and characterised by [Ah-King and Hayward \(2014, 4–5\)](#) as “a transex panic,” a discourse in which “human sex . . . is described as under siege, endangered, and threatened,” and in which stories about animals “changing sex” or young boys developing breasts receive greater attention than other serious health risks. Endocrine disruption came up only once in my interviews, when Donna mentioned that she wondered whether the well water in the place where she grew up (near Hamilton, an Ontario city known for its industrial history) may have had something to do with her developing PCOS. Indeed, some biomedical research does suggest a causal link between endocrine disruption and PCOS (see [Palioura, Kandaraki and Diamanti-Kandarakis 2014](#)). While it was not a prominent theme in my interviews, endocrine disruption is nevertheless a significant part of contemporary public conversations about hormones and sex/gender.

Drawing on Oudshoorn’s work, [Hasson \(2016, 963\)](#) writes that “ideologies of gender work through technologies to shape bodies and subjectivities . . . [and] individuals use technologies to perform gender . . . Attention to technology is a necessary component of theorizing how individuals do gender and how bodies materialize sex/gender.” In the preceding two sections, I have examined how technologies such as synthetic hormones (marketed in the early twentieth century for enhancement and later developed for contraceptive and therapeutic uses) and ultrasound used to image the interior of the female body have contributed to the contemporary understanding of polycystic ovarian syndrome as a disorder of gendered, hormonal bodies, and briefly explored some other areas where hormones appear in everyday conversations. As [Roberts \(2006, 55\)](#) notes, “rather than remaining within the technical realms of biomedicine and technoscience, hormonal bodies are increasingly becoming something that citizens and patients are asked to do something about, in order to ‘help themselves.’” The understanding of PCOS as based in the ovaries and in gendered hormones also contributes to an essentialised understanding of the diagnosis as a women’s health condition, a point which I discuss in greater detail below. In the following section, I turn to the way in which PCOS is also understood as affecting metabolic bodies.

Metabolic Disorder

In the past, it was thought that PCOS was caused entirely by the excess production of androgens . . . More recent research has shown that insulin resistance and high levels of insulin (hyperinsulinemia),

which appear to cause the overproduction of androgens, play a key role in PCOS . . . Both insulin resistance and high levels of androgens lead to disturbances in the productions of the female hormones . . . that control a woman’s menstrual cycle and drive ovulation. All of these factors, in turn, contribute to the irregular menstrual cycles and the pattern of missed ovulation of women with PCOS. (Women’s College Hospital n.d.)

In their 1935 publication, Stein and Leventhal explicitly cite infertility and menstrual irregularity as the most “significant” symptoms of their newly identified syndrome (189). More recently, biomedical attention has shifted to the metabolic implications of the diagnosis, within the context of broader concerns about metabolic disorder and obesity. Rather than a complete shift occurring in the understanding of PCOS as an endocrine disorder to a metabolic one, the metabolic conceptualisation of the diagnosis is added to the hormonal one, and these systems are seen as interacting in complex ways, as the above quote from the Women’s College Hospital indicates. As [McNaughton \(2013, 73\)](#) writes, “in recent years . . . the idea that fatness is the central cause” of diabetes and other so-called lifestyle diseases “has become increasingly prominent and thoroughly naturalised in the media, popular discourse, academic research, and public health campaigns . . . [and these diagnoses are] increasingly framed as self-inflicted: the result of wholly changeable and highly risky lifestyle factors such as overnutrition and physical inactivity.” This idea reinforces a moralisation of weight that has harmful, stigmatising effects, which I discuss in greater detail below. First, however, I focus on the emergence of metabolic disorder as a conceptual category into which PCOS is slotted.

[Landecker \(2013, 496\)](#) argues that “a culturally and historically distinctive form of reasoning about how food and the body interact in and through metabolism is emerging today” in North America, and specifically within the context of North American concerns about obesity and overweight. This currently emerging understanding is new compared with nineteenth-century models, which saw the metabolism as “a factory whose main job is to make bodily building blocks and create energy for movement” (511) – an understanding that drew heavily on factory imagery and metaphors appropriate to its industrial-era context (495). In contrast, in Landecker’s characterisation of twentieth- and twenty-first-century metabolism, food is no longer seen simply as fuel but increasingly in terms of its “molecular components – amino acids, vitamins, minerals, lipids and carbohydrates” ([Landecker 2011, 173](#)). A second difference is that “whereas nutrition

science emerged in an era of scarcity and grew in legitimacy and scope through the investigation of deficiency diseases and the body's ability to generate and store energy from food, today metabolic science is characterised by its drive to understand the biology of excess, of hyperphagia, of overload" (2013, 515). Landecker refers to the models that are the outcome of this metabolic research as "*fat knowledge* – the knowledge effects of obesity" (511; original emphasis). It is not simply that people are fatter today and that metabolic scientists are studying this; rather, by focusing on fat knowledge, scientists are helping to create this model of the world and the metabolism, similar to the way in which endocrinologists reflected the world as they saw it in creating their models of sex/gender and hormones. As an example of what this looks like in practice, Landecker asks, "Why are researchers culturing cells in a nutrient medium of excess glucose? Because they believe it to be an experimental image of humans in the contemporary world" (502). This current scientific model of metabolism underlies descriptions of PCOS as a metabolic disorder, as well as the instructions given to people with PCOS to measure and watch their weight and the components of their diet, such as carbohydrates.

Another example of "*fat knowledge*" in the contemporary world is the increasing attention paid to weight measures and the expectation that individuals should monitor and manage their weight. Solomon (2016, 36) argues that "historically, the domestication of the scale from public venues into homes was essential for mainstreaming the measurement of body weight. Without the technology of measurement, the moralities affixed to body weight simply couldn't adhere." Like the weight scale, body mass index (BMI) is another (imperfect) technology facilitating moralisation and categorisation. Another historical note is important here: BMI was initially conceptualised as a population-level estimate of "normal" or average body size, not as a "useful individual diagnostic because it ignored any variable other than weight and height" (36) – though it is now routinely applied to individual bodies and used to define states of overweight and obesity.

Summing up this section, we now see PCOS not as a disorder of a particular organ (the ovary) but of complexly interacting metabolic and hormonal systems in the body. These systems are also seen as dynamic and changeable. Solomon (2016, 228) writes that "the constant rescripting of what counts as metabolic illness creates a broad spectrum of possible meanings for clinicians and persons experiencing obesity and diabetes to work with . . . this dynamic has profound implications for people who experience a moving target of expert knowledge that informs bodily intervention."

I argue that the combined understanding of PCOS as a metabolic and endocrine disorder are foundational to approaches to treating PCOS that frame the diagnosis as a "lifestyle disease" that can be treated through bodily intervention – namely, changes to diet and exercise. In the following section, I focus on the way in which these approaches can be productively analysed using the theoretical framework of Foucauldian biopower.

Lived Experiences of PCOS

One of the ways that biopower exercises power over life is through normalising discourses about the body (Foucault 1984). Harris (2005, 514), drawing on Foucault, notes the way in which "standards of normalcy are established . . . which influence how one works on the self"; this work on the self becomes not only an issue of normativity but also of morality, as "the disciplining of morality . . . exercises control by adhering the labels of 'normal' and 'abnormal' to bodies and behaviors" (514), a labelling that is facilitated especially by biomedicine. Also building on Foucault, Novas and Rose (2000, 491) have coined the term "somatic individuality" to describe the way in which "recent developments in the life sciences, biomedicine and biotechnology are associated with a general 'somaticization' of personhood in an array of practices and styles of thought." They write that "individuals are increasingly obligated to formulate life strategies, to seek to maximize their life chances, to take actions or refrain from actions in order to increase the quality of their lives, and to act prudently in relation to themselves and others" (487).

In this section, working from the theoretical concepts of biopower and somatic individuality, I argue that discourses about PCOS focused on controlling symptoms through "lifestyle changes" suggest that the PCOS body is abnormal and flawed – too fat, too hairy, too masculine (Fisanick 2005) – but that the body can be brought under control through such changes and thereby made to fit expectations of normative femininity. Femininity becomes conflated in these messages with health and, by extension, responsibility: not only can the body be brought under control, but it should be, in order to avoid potential future repercussions.

These future repercussions constitute a risk discourse that is a common theme in much publicly available information on PCOS. For example, an article titled "PCOS Is More Than a Reproductive Condition" quotes an endocrinologist who says that women with PCOS "should think of themselves as higher risk, and their physicians should think of them as higher risk" for diabetes (Women's College Hospital 2014). Besides type 2 diabetes, other potential issues are "gestational diabetes, high blood pressure, high cholesterol and possibly

heart disease” (Women’s College Hospital n.d.). Many of these health risks are also associated with overweight and obesity; as Landecker (2013, 516) notes, the “fat knowledge” that is produced by biomedical work focused on the metabolism “might be understood as the biology of risk society, in this case focused on metabolic risks.”

A commonly cited recommendation is that losing “just” 5 to 10 percent of body weight can help reduce PCOS symptoms and avoid future health risks (or, as Donna put it in our interview, “the big thing [I was told by doctors] was weight management”). What these sources seldom acknowledge is that not only is it difficult to make the recommended “lifestyle changes,” but these changes are also not guaranteed to be successful: there is no medical consensus on strategies to lose weight (with or without PCOS); on the contrary, there is a great deal of evidence that healthy, sustained weight loss is quite rare and that treating patients in stigmatising ways (e.g., by suggesting that weight gain is a failure of the will) itself negatively affects health (Gaesser 2009; Greenhalgh 2016). Further, from my own experience, as well as from interviews, I know that it can be not only confusing and frustrating but also, in some cases, outright harmful to be told to lose weight in order to treat a condition in which weight gain is one of its symptoms.

“The Best Thing You Can Do for Yourself Is Lose Weight”: PCOS and Disordered Eating

Writing about the United States (though it is equally applicable to Canada), Greenhalgh (2016) argues that the “war on fat” has been unsuccessful in its purported public health goals and has fuelled an increase in disordered eating/eating disorders, particularly among young women. Her use of the term *disordered eating/eating disorders* is meant to highlight the way these may be experienced on a spectrum: “I was struck by the difficulty of differentiating between the subjects with [diagnosable] eating disorders and those who showed ‘merely’ severely disordered diet, exercise, and thought patterns . . . the difference appeared to be in degree rather than in kind” (551).

In two of my interviews, women described experiencing disordered eating/eating disorders after being diagnosed with PCOS and told by their doctors to lose weight:

I went to see an endocrinologist when I was diagnosed . . . and she said, you know, “Yes, you do have PCOS, and the best thing you can do for yourself is to lose weight.” And, um, at the time I was heavier than I am now, but I think I took that to heart . . . I was really, like, “this is the best way to prevent diabetes, to deal with all this stuff,” and so I embarked on a weight-loss journey that ended up

being quite unhealthy . . . [I was] like, “well, I mean, I’m not doing this for [vanity], I’m doing this ‘cause I have to,” and it, at least for me, it allowed me to sink into it in a way that was unhealthy behind the guise of being healthy. (Ruth)

I was actually bulimic . . . for like three years, because I would end up feeling so bad, like, I starved myself for two weeks eating chopped celery and carrots and whatever, like, grilled chicken breast . . . and then I would gain weight on the scale [anyway], so then I would go out and eat all the things that I’d wanna eat and then I would throw it up. But that didn’t last for very long, fortunately. (Nadia)

Both Ruth and Nadia considered themselves to be recovered from their eating disorders/disordered eating at the time I spoke with them, but only after having worked for years to rebuild healthy relationships with their bodies. Recent quantitative research suggests that their experiences are not isolated: “In the largest cross-sectional study to date to evaluate the prevalence of disordered eating in women with PCOS, [these authors] demonstrated that women with PCOS have over four times the risk of reporting disordered eating behaviors than controls” (Lee et al. 2017, 798).

The paper by Lee and colleagues (2017) suggests that disordered eating is a risk of PCOS itself (in a sense adding it to the list of risks already associated with the diagnosis), but the authors do not consider how broader cultural messages (what Greenhalgh identifies as the “war on fat”) as well as messages specifically about PCOS (the emphasis by doctors on weight loss as a first-line treatment for the diagnosis) contribute to this risk. Neither Nadia nor Ruth attributed their experiences solely to their PCOS diagnosis – they also mentioned factors such as stressful life experiences, social pressures and media messages – but it was clear that concerns about PCOS added significantly to these factors. While Greenhalgh argues that young women generally are at risk for disordered eating in a culture that so thoroughly stigmatises fatness, this is even more the case for individuals diagnosed with PCOS. The medicalisation of weight in the context of PCOS diagnosis gives weight loss a gloss of “health” and a moral dimension, even imperative: as Ruth put it, losing weight for her was not just about “vanity” but was something she “had to do” for her health.

“Should Obese Women with [PCOS] Receive Treatment for Infertility?”

A series of editorials published in the *British Medical Journal* is indicative of the way in which weight stigma affects the treatment of people diagnosed with PCOS.

The first editorial is titled, “Should Obese Women with Polycystic Ovarian Syndrome Receive Treatment for Infertility?” (Balén et al. 2006). The authors present a laundry list of risks that are associated with pregnancy and childbirth for obese people, including “increased rates of congenital anomalies (neural tube and cardiac defects), miscarriage, gestational diabetes, hypertension, and problems during delivery” (434). They conclude that “given the risks” that obese people with PCOS and infertility would likely face in pregnancy, “they should lose weight first” (434) – that is, they should be denied fertility treatment until they do. This is not a marginal opinion; the lead author, Adam Balén, is a specialist who currently chairs an expert working group on PCOS for the World Health Organization’s global taskforce on infertility.

Responding in the same journal, Lord and Norman (2006, 609) take this risk discourse even further, speculating about the possible risks to hypothetical future children:

An additional concern not mentioned in the editorial [by Balén and colleagues] is fetal programming. If evidence were found to support the hypothesis that insulin resistance in the mother could ‘programme’ the fetus to become obese in later life, then failing to treat insulin resistance in women seeking fertility treatment now may be creating problems for future generations.

In other words, the (unproven!) risk of future children becoming obese is so unquestioned as to justify curtailing the reproductive choice of women in the present. A similar point is made in a second response in the same journal by Laredo (2006, 609), who writes that “to suggest . . . that obese women defer treatment until they achieve a particular BMI is equivalent to refusing most of these women reproductive care” and “will only add to their sense of stigmatization.”

Aside from Laredo’s comment on stigmatisation, largely absent from these authors’ editorials is a consideration of the experiences of people who might be told they need to lose weight before getting pregnant. Writing about her own experience being told by a doctor that she was “‘too fat’ to have a baby” (McCullough 2013, 217), anthropologist McCullough writes that “treating obese women as weak and blameworthy will not improve health statistics. If the concern is the relationship between maternal fat and birth outcomes, perhaps the medical establishment should also be concerned about the correlation between stigmatizing treatment of obese pregnant women and birth outcomes” (230). She also notes how the rhetoric that describes obese pregnant people as “endangering” their children follows a broader, also risk-focused discourse stigmatising mothers, “such

as those who smoke or use drugs and alcohol” (220). It should be noted that McCullough does not mention having a diagnosis of PCOS or asking her doctor about fertility treatment; nevertheless, the experience of stigmatisation she describes is likely reflective of what someone with obesity and PCOS could experience in seeking fertility treatment. The elements of moral imperative and risk discourse present in her exchange with her doctor echo those I have discussed above.

Essentialisations and Exclusions of “Women’s Health”

Referring to PCOS as a “women’s health” concern places it within a particular context of feminist critique. Health has been a major focus of feminist movements, both challenging the medicalisation of women’s bodies and drawing attention to the health disparities faced by women. As just one example among many, researchers have shown that higher rates of mortality for women with heart attacks can be partly explained by the fact that most biomedical research on heart disease has focused on men; women are more likely to present with “non-standard” symptoms that are misdiagnosed or dismissed, yet these symptoms are only non-standard because research has excluded women (Dusenbery 2015). At the same time, “women’s health” projects and feminism generally have sometimes tended to reify the category of “women” and reinforce the essentialisation of women on the basis of biology and reproduction (assuming that a woman’s most essential characteristic is her ability to bear children; Inhorn 2006, 350). Butler (1990, 2) notes that academic feminist projects have often assumed a cis-gender, heterosexual subject. Murphy (2012, 41) expands on this idea in her history of the North American women’s health movement; she traces the genealogy of “women’s health” within related feminist projects, coining the phrase “unraced feminisms” to describe those “feminist projects practiced by predominantly white women that did not explicitly hold themselves accountable to addressing race” and instead “identified their politics under the generalized unraced category of women.” And Feldberg (2011, 260) notes that “reproduction has defined and dominated North American interest in women’s health for almost a century. A review of articles on women’s health reveals that, even at the turn of the twenty-first century, most women’s health research continues to focus ‘navel to knees’ – that is, on our reproductive systems.”⁶ In sum, while academic as well as activist efforts to draw attention to women’s health have provided a necessary and important corrective to the dismissal of women’s experiences and health concerns, they nevertheless may

reinforce a hetero- and cisnormative, “unraced” image of “women.” Increasingly, however, feminist projects have taken into account critiques along these lines and drawn greater attention to, for example, the experiences and health care needs of trans and gender nonconforming people (e.g., [Butler 2004](#); [Heyes 2003](#); [Murphy 2012](#); [Scott-Dixon 2006](#)).

Several of the people I interviewed expressed frustration that their doctors did not seem to see PCOS as an issue to be treated unless and until they were trying to conceive. Nadia described the endocrinologist who diagnosed her with PCOS as having

the worst bedside manner of any doctor I’ve ever met . . . He told me, after doing the blood test confirming that it was PCOS, and not a thyroid problem, he told me that I would likely suffer from infertility, should consider freezing my eggs at a young age, um, that I *would* get diabetes, and would have higher risks for certain female cancers, so that was terrifying, when you’re 18, especially too because I was always one of those girls who wanted to have babies, so that was the first thing that was most jarring to me.

While the mention of diabetes and cancer risks were certainly part of what made her doctor’s remarks “terrifying” (and are also an example of the sort of risk discourse discussed above), Nadia suggested that what stuck with her most was the pronouncement of infertility; when she did decide to attempt fertility treatment years later, she said, “you go in for your initial assessment, and I expected to be told that I was completely, like, barren.”

While her endocrinologist’s focus on infertility was upsetting to Nadia because she did want children, for others, the same focus may be alienating, as it tends to reinforce normative assumptions regarding reproduction. Logan said that “regardless of PCOS, I find those narratives [about infertility] difficult because, especially as an adopted person, I see that stuff all the time . . . they don’t want to adopt, they need that biological kid . . . I mean maybe it’s that big a deal [to some people], but to me that always felt kind of funny.” This perspective is also reflected in feminist scholarship on reproductive technologies; as Thompson (2002, 52) notes, “contemporary infertility and its treatment are conceptualized and structured on a strongly coupled, ultraheterosexual, consumer-oriented, normative nuclear family scenario.”

Of course, this critical perspective is not meant to disparage those who do choose to go the route of fertility treatment, as a majority of participants in my research did (at the time of our interviews, Nadia and Ruth were both undergoing fertility treatment; Donna and Kim both had children using fertility treatment).

These participants tended to speak about the emotional experience of undergoing demanding and sometimes invasive treatment regimens. These types of experiences have been discussed in the large body of existing anthropological literature on infertility and reproductive technologies (e.g., [Inhorn and van Balen 2002](#); [Thompson 2007](#)). One participant, however, suggested that there may be an additional emotional hurdle associated with fertility treatment for women with PCOS: undergoing fertility treatment often means discontinuing medication, such as hormonal birth control, that may be used to treat symptoms such as acne and facial hair. Ruth summed this up with the statement: “You kind of have to live in this place where you have to . . . hand over your body for the purposes of something else.” Similarly, Donna said that “you start fertility drugs and put your body into stress,” and she felt that her PCOS symptoms, particularly her weight, had gotten much worse after her fertility treatment and pregnancy. Thus, while many sources on PCOS emphasise infertility, and by extension see “achieving” pregnancy as the primary goal of treatment, all the problems associated with PCOS are not “solved” when one becomes pregnant.

Whether focused on fertility or not, sources on PCOS almost always address women, failing to acknowledge that the diagnosis can also affect people who do not identify as women – namely, transgender men and gender nonbinary individuals. This is most evident in popular online sources that aim to provide information and support to people with the diagnosis, which tend to be stereotypically “feminine.” For example, two of the largest such sites are Soul Cysters ([soulcysters.net](#)) and PCOS Diva ([pcosdiva.com](#)); I have not found any similar website that discusses PCOS with gender-neutral or trans-inclusive language, except in places where the diagnosis is mentioned (usually briefly) on sites focused on trans health in general.⁷

In biomedical literature, research on the prevalence of PCOS among trans people is inconclusive. A report published by the Center for Excellence for Trans Health states that “several studies have suggested an increased prevalence of PCOS in transgender men prior to testosterone therapy” ([Wesp 2016](#), 115–116). Of the studies cited, however, one concludes that “PCOS was not significantly increased in [transgender men] in comparison with controls” ([Mueller et al. 2008](#), 1408). A second concludes that PCOS is “common” in trans patients, but it does not acknowledge that it is also common in cisgender women; further, the study reflects outdated, stigmatising and othering assumptions about trans people, speculating about “the possible role of polycystic ovaries . . . in the pathogenesis of female-to-male

transsexualism” and comparing the trans patients involved in this study to women with PCOS who “have a normal female gender identity” (Balén et al. 1993, 328). On the other hand, even if it is not any more common in trans and gender nonbinary individuals than in cisgender women, it is clear that PCOS is not an uncommon experience for this population, leading Deutsch (2016) to note that some of the symptoms associated with the diagnosis, such as facial hair and absent periods, “may be welcomed by transgender men” – a fact that troubles their designation as symptoms. And importantly, whether or not there is any correlation between PCOS and trans identity, it should be recognised that not everyone diagnosed with PCOS (or other “women’s health” conditions) identifies as a woman.

What, then, are the experiences of trans individuals with such diagnoses? Research conducted in the US (and, ironically, published in the *Journal of Midwifery and Women’s Health*) elicited the experiences of transgender men seeking reproductive health care, concluding that “all participants had a general dislike of receiving gynecologic care, but each expressed an interest in maintaining their physical health despite the emotional challenges to receiving care” (Dutton, Koenig and Fennie 2008, 334). These themes were echoed in my conversation with Logan, a trans man who had been diagnosed with PCOS following hormone testing at the start of his medical transition.

Logan was quick to point out that most of his health care providers were respectful and competent when it came to dealing with his transition. Where he experienced more discomfort was when it came to accessing “women’s health” care. He described, for example, being the only man in a waiting room, or getting a “double take” from doctors:

“Women’s health” is a really tough one, yeah, because it’s awkward . . . these are spaces where there’s all women . . . I just kinda pretended that it’s not a big deal and I don’t let it, you know, bother me, um, or if people are looking at me I’m just like, well, whatever.

There’s a little bit of fear there, right, because they [doctors] see you, male everything, and then they look at what [procedure] you’re getting, and there’s this weird moment where they’re like, what?

Logan also mentioned the pink forms at an OB/GYN office, echoing another point made by Dutton, Koenig and Fennie (2008, 336):

While the literature and the news tend to focus on larger health care barriers [for trans people], such as lack of health insurance, it is equally important to acknowledge the smaller barriers like using the

patient’s chosen name. Barriers such as intake forms and name and pronoun usage are easily corrected, but they require the assistance of the entire practice, not just the health care provider. It is critical to remember that a single health care provider is only as sensitive and competent as the rest of the practice.

Even addressing these basic competencies, however, would not change the fact that so much of the western biomedical system is structured on the assumption of binary sex difference, and that health care of the “female” reproductive system – that is, the uterus, ovaries, vagina and so on – is considered “women’s” health care.

Reconsidering Biopower: Practices of Care

In the final section of this article, I return to the themes of biopower and somatic individuality discussed above. In her analysis of somatic individuality, Roberts (2006, 56) suggests that “it is, at best, unevenly distributed across different people and fields and, at worst, open to co-option by capitalist biomedical discourses in the pursuit of compliant consumer populations.” The danger of somatic individuality, unevenly distributed as it is across gendered (as well as raced, classed and otherwise marked) bodies (Murphy 2012, 41), is that “instead of providing a wider range of options or establishing new practices of bodily self-management,” it may “work to produce willing and compliant consumers for medical services and/or pharmaceutical products” (Roberts 2006, 69) and for products marketing themselves as alternatives to biomedicine. I have demonstrated above how “lifestyle” approaches to treating PCOS reflect this. In addition, while I have not analysed these in this article, a number of companies sell diet programs and supplements for the treatment of PCOS, which exemplify Roberts’ argument. These are often marketed as alternatives to biomedicine, but they echo the most frustrating aspects of the biomedical approach that tells patients, especially women, that their bodies should be brought under control in order to fit a definition of “health” that conflates it with normative femininity.

At the same time, I think that the popularity of these products reflects a real demand: people who take up forms of somatic individuality and endeavour to normalise their bodies through various practices, including purchasing products they believe will help them to do so, are responding to very powerful messages about morality, risk and health. In this section, I wish to interrogate whether these practices can be viewed through another lens, one that focuses on caring for the body. Like Heyes (2006) in her analysis of US commercial weight-loss programs, and like Yates-Doerr (2012) in

her analysis of Guatemalan dieting clinics, I have found Foucauldian biopower to be a useful analytic for examining how people with metabolic disorders are told to lose weight, but one that does not account fully for how people respond to these injunctions. Yates-Doerr writes, “when patients around me sought the help of their nutritionists, expressing a desire for more and not fewer nutritional services, this was not because they were being duped by medical power, but because something meaningful happened for them in the clinic” (153). Several of my interviewees expressed to me that they wished their doctors would be more attentive to their experiences or that there were more options for biomedical treatment of PCOS. For example, Erin relayed that her doctor had not shared any information about the metabolic implications of her diagnosis: “I think she made an assumption [based on my appearance] that I know how to manage weight.” She expressed to me that she would have appreciated guidance from her doctor as to whether she should be worried about future risks to her health and ways to avoid these. Kitzinger and Willmott (2002) also observed this in their interviews with women with PCOS: “Many participants talked about the frustration and anger they felt about delays in diagnosis, the lack of information provided by health professionals, and what they experienced as a general unwillingness of health professionals to take their symptoms seriously” (353). In addition, as someone who shares this diagnosis, I have sometimes struggled to articulate a critique of biopolitical forms of control alongside an acknowledgement of my own desire to take care of my health (which has, at times, indeed meant attempting to change my diet or exercise more).

A recent, large-scale international quantitative study adds statistical weight to the experiences described in Kitzinger and Willmott’s interviews and my own: of 1,385 participants, one-third of women reported seeing at least three health professionals over a period of two or more years before being diagnosed with PCOS, and “few were satisfied with their diagnosis experience or with the information they received” (Gibson-Helm et al. 2017, 604). While the category of women’s health is problematic for the reasons I have discussed above, an important insight of the women’s health movement has been that women’s experiences are often dismissed or minimised by biomedicine, and this undoubtedly shapes the experiences of people who feel their concerns about PCOS are not taken seriously.

In many cases, this leads people to seek alternatives to biomedicine. Of my research participants, Ruth and Nadia had both used acupuncture treatment, Nadia and Kim had both seen naturopathic practitioners, Nadia had tried Ayurvedic medicine and Kim had used supplements

in treating PCOS. In a systematic review of publications concerning the use of complementary and alternative medicine (CAM) by women with breast cancer, Wanchai, Armer, and Stewart (2010, 48–50) list a broad range of reasons identified by women for using such approaches: CAM was said to “enhance overall quality of life . . . and reduce stress”; “[address] their dissatisfaction with traditional medical care, and [help] them gain a sense of control”; “increase hope and optimism”; and, finally, “patients sought an active role in their treatment, and had a wish to leave nothing untried.” While PCOS is of course very different from breast cancer, similar feelings of a lack of control and dissatisfaction with biomedicine are expressed by people seeking alternative treatments for PCOS.

Returning to the interviews with Ruth and Nadia, both women mentioned ways they strove to care for themselves in their disordered eating recovery and everyday lives. Ruth, for example, spoke about shifting her perspective on food and dieting away from a restrictive one: “I’ve become super fascinated . . . about diet. And I don’t mean diet in the sense of, like, ‘being on a diet,’ but, how do we fuel our bodies, to find the weight that best suits you?” After being diagnosed with PCOS by an endocrinologist with “the worst bedside manner of any doctor [she had] ever met,” and being unsatisfied with the treatment options offered by biomedicine, Nadia turned to alternative medicine and did her own research on PCOS to manage her symptoms: “I gave up on western medicine helping me with PCOS; I did a lot of reading, a lot of acupuncture and Chinese medicine, a lot of Indian Ayurvedic medicine, and I found out of everything, those were the best avenues for me.” She, like Ruth, spoke about the diet she tries to stick to now, not in the context of restriction but as something she does because it makes her feel her best: “Eating clean, eating hormone free, eating paleo, not smoking, which was something I did in my early twenties . . . not drinking.” She also mentioned, here and at other points in our conversation, keeping stress in her life to a minimum. “But,” she said, “this is nothing that any doctor told me. This is all stuff that I researched myself.” While these practices certainly fall into the category of biopolitical “techniques of the self,” they are experientially very different from the disordered eating patterns and repressive weight-loss practices described above.

Heyes (2006, 127) argues that the tendency of feminists to focus “on Foucault’s account of disciplinary practices” in analysing dieting “might usefully be supplanted by Foucault’s own concern, toward the end of his career, that he had emphasized technologies of power at the expense of technologies of the self.” She argues that commercial diet programs such as Weight Watchers work

through “not only the desire to produce an appropriate [docile] body . . . but also the sense of self-development, mastery, expertise, and skill that dieting can offer” (137).

A more radical critique is that made by Lorde in her writing about her cancer diagnosis and treatment, which includes the line, “caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare” (quoted in [Ahmed 2014](#)). An essay by [Ahmed \(2014\)](#) explores the significant meaning of this short line: she writes,

Audre Lorde . . . gave us a strong critique of neo-liberalism, even if she did not use that term. Her work is full of insight into how structural inequalities are deflected by being made the responsibility of individuals . . . And yet . . . she defends self-care as not about self-indulgence, but self-preservation . . . Neo-liberalism [as a mode of critique] sweeps up too much when all forms of self-care become synonymous with neo-liberalism.

This is reminiscent of Mol’s (2008, 113, fn. 5) response to biopower, which I have also found very useful:

While ‘biopolitics’ seeks to encompass everything that individuals might do ‘in the name of individual and collective health,’ the term evokes a strategy that comes from elsewhere, and a power that subjects us as it turns us into subjects. In contrast with this, in articulating the logic of care, I have sought terms that do not presume us to be either free or subjected, or both, but rather terms that try to avoid this dichotomy.

Mol’s book *The Logic of Care* is especially relevant here for the fact that she focuses on the self-care practices of people with diabetes – a metabolic disorder that requires, in most cases, even more intensive day-to-day management (such as measuring blood sugar and modifying one’s diet in response) than PCOS. Her “logic of care” is summed up nicely in this line: “Yes, health care meddles with every detail of our daily lives. And indeed, it tries to normalize our bodies. But it does not despise them. Care has little to do with repressing and all the more with cherishing our bodies” (37). However, in outlining her general “logic of care,” Mol does little to address relevant differences (of race, class, gender, ability and so on) that Ahmed, through Lorde, reminds us of. I want to advocate greater acceptance of, and challenge the medicalisation of, the physical traits characterising PCOS. But I also recognise that to simply tell people (especially women) with PCOS to “accept themselves” would be to ignore the very real reasons why people might find these traits uncomfortable, frustrating or unattractive, as well as the power structures shaping these feelings ([Fisanick 2009](#)).

Conclusion

This article contributes to medical anthropology by applying theoretical insights from medical anthropology, as well as history of science, feminist science and technology studies, and gender studies, to a biomedical diagnosis that has as yet been understudied by medical anthropology and related disciplines. PCOS is almost always described as affecting women and causing “masculine” (and therefore undesirable) traits. A historical science studies perspective allows us to see the cultural underpinnings of the idea that hormones and the traits they produce are either “masculine” or “feminine.” A queer and gender studies perspective allows us to trouble the idea that “masculine” traits are always undesirable outside of men and to recognise that “women’s health” conditions such as PCOS can and do affect people who do not identify as women. Additionally, theoretical insights concerning biopower and resistance to biopower help to contextualise the experiences of people with this diagnosis.

Finally, the quote that I use as the title of this paper was from Donna, but in fact, every person that I interviewed made a comment similar to hers and expressed that hearing stories of people who had had similar experiences of PCOS was meaningful to them. It is my hope that drawing attention to the lived experiences of people with PCOS, especially those whose experiences tend not to be represented in mainstream descriptions of the diagnosis, contributes to challenging and eventually changing these dominant discourses around PCOS.

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Notes

- 1 Pseudonyms are used for all research participants in this article. Quotes from formal interviews are directly transcribed from recordings, and other quotes have been paraphrased to the best of my memory. Formal interviews were semi-structured, and each lasted about an hour, with

follow-up interviews of half an hour to one hour each conducted with Erin and Kim.

- 2 A great deal of attention has been paid to the routinisation of ultrasound use during pregnancy since the 1960s, with some feminist authors arguing that the technology has the potential to privilege images of the fetus over the subjective experience of the pregnant woman (Bordo 2003; Petchesky 1987).
- 3 It is also of note that PCOS is listed in the International Statistical Classification of Diseases and Related Health Problems (10th Revision) as Code E.28.8, falling under category E28 – Ovarian Dysfunction (World Health Organization 2015).
- 4 The fact that testosterone produces what we think of as “masculine” traits and estrogen “feminine” traits is what allows trans individuals wishing to undergo medical transition to employ hormone therapy to do so, a dynamic Ostertag (2016) discusses in his book. In pointing out that our conceptualisations of hormones and gender are socially constructed, I do not mean to suggest in any way that this makes the experiences of trans people any less real, nor that their choices to use available medical technologies are any less valid.
- 5 *Hyperandrogenism* simply means high testosterone levels and is not only associated with PCOS.
- 6 Inhorn (2006, 351) notes that medical anthropologists studying women’s health have tended to do the same.
- 7 Logan also mentioned getting information on PCOS from other trans individuals he interacted with in support groups and through related resources, which, being in a large city with a robust LGBTQ community, he had access to.

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