

The aesthetic labour of polycystic ovarian syndrome: The strife of heteronormative standards and the possibilities of queering sexualities

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journals.sagepub.com/home/sex**Thea Cacchioni** 

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Abstract

This article contributes to the burgeoning qualitative literature on experiences of Polycystic Ovarian Syndrome (PCOS) by considering PCOS in relation to post-structural theory on gender, sexuality, embodiment, and aesthetic labour. Although to some degree culturally contingent, interview accounts with 30 people diagnosed with PCOS suggest that infertility, hairiness, acne, and/or fatness are a difficult combination with heterosexuality and a source of stigma regardless of identity. This article outlines the aesthetic labour women engaged in to meet heterosexual standards, highlighting structure, and where possible, agency in this work. It also highlights the potential of queer relationships, communities, and perspectives to disrupt heteronormative pressures, considering the promise and limits of bodily acceptance.

Keywords

aesthetic labour, heteronormativity, polycystic ovarian syndrome, queering, stigma

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Introduction

Now a quarter century ago, in my early twenties, I stopped menstruating, rapidly gained 50 pounds, and started to notice hairs on my chin. The brochure my doctor gave me while delivering the diagnosis ‘Polycystic Ovarian Syndrome’ (PCOS) featured a grainy photo of an empty carton of eggs on the cover, suggesting PCOS would be a stark, lonely experience, defined by lack or deficiency. This image and the attending advice from my doctor to lose weight, undergo electrolysis for facial hair removal, and seek fertility counselling, made an emotional and intellectual impression. At the time, as a Masters of Gender Studies student, I was already fascinated by the relationship between science, medicine and the social norms of sex, gender, and sexuality.

Originally coined Stein Leventhal Syndrome by two Chicago based gynecologists (Stein and Leventhal, 1935), PCOS is an endocrine metabolic disorder marked by so-called ‘androgen excess’ in people assigned female at birth. Medical literature mostly quantifies this diagnosis as affecting between 4 to 10% of women globally (El Hayek et al., 2016). PCOS is the result of genetics and epigenetics given that plastics and chemicals in the environment are endocrine disrupting (Palioura and Diamanti-Kandarakis, 2015). The constellation of symptoms that comprise PCOS are varying combinations of anovulation, amenorrhoea, infertility, weight gain, acne, hirsutism, and male patterned baldness (Azziz, 2018).¹ PCOS itself is not necessarily harmful to your health but having PCOS means that you are at higher risk of insulin resistance, type 2 diabetes, heart disease, endometrial cancer, and depression.² Medical treatment protocols for PCOS aim to lower androgen levels, presuming that patients are women who will desire regular ovulation and menstruation, reliable fertility, a low body mass index, clear skin, and relative hairlessness, assumptions drawing on normative ideas of womanhood and femininity. But not all people with PCOS identify as women (Coleman et al., 2012) and not all women wish to conform to social standards of feminine embodiment (Halberstam, 2020).

Despite PCOS being experienced by a variety of people from multiple social locations, existing qualitative literature examining understandings and experiences of PCOS related traits is based almost entirely on the experiences of white, heterosexual, gender conforming women who are devastated by their inability to embody feminine gender norms. Further, similar to medical understandings, explicitly feminist literature often presumes that PCOS patients will have a straightforward, unilateral response to PCOS embodiment. This scholarship lacks in depth theorizing of the complex, nuanced, and evolving relationship one may have to PCOS traits, a relationship that is mediated by gender identity, sexuality, racialization, ethnicity, culture, and class. Feminist discussions of PCOS would benefit from post-structuralist theory when conceptualizing gender, aesthetic labour, and embodiment, as this theoretical orientation resists falsely homogenous, universal, or monolithic interpretations of disciplining or altering the body (Pitts-Taylor, 2009). In the context of these conversations, this article considers the questions: How do gender and sexual identity shape the decision to discipline PCOS embodiment or embrace it? In what ways do understandings and experiences of PCOS embodiment differ across racialization, ethnicity, culture, and class? How can post-

structuralist theories on the aesthetic labour of gender expression guide us as we examine the labour of conforming to heteronormative ideals and/or the decision not to?

Data from this research comes from 30 semi-structured qualitative interviews with people diagnosed with PCOS in Victoria, British Columbia, Canada. I find that experiences of PCOS embodiment vary across axes of identity, albeit with shared experiences of stigma in the broader culture. The interview data is particularly rich for emphasizing the gender and sexuality dimensions of this diagnosis given that half of the participants identified as one of LGBTQ+ or 'queer' to use an umbrella term, including five gender diverse participants (5 = non-binary). This research further demonstrates that the attainment of 'heteronormativity,' an essentialized, socially, and medically produced standard, is often the product of hard work (Cacchioni, 2007, 2015; Cacchioni and Wolkowitz, 2011) in this case aesthetic and bodily labour. However, we can resist evaluating this work in monolithic terms. Indeed, this mainly aesthetic labour may be time consuming, expensive, and unsatisfying due to the array of never-ending possibilities and increasingly elusive standards within capitalist heteropatriarchy. And yet, it may also feel pleasurable, a means of expressing and connecting to feminine gender and identity or community. For those with the privilege of access to aesthetic technologies, using mastery over the body to meet social expectations or dodge the stigma of non-conformity, it may feel productive, agentic, or strategic.

As Marchia and Sommer (2019) note, the term heteronormativity has been defined in numerous ways since it was first coined by Warner and Seidman in *Fear of A Queer Planet* (1993) to capture the pervasive pressure to conform to heterosexual norms. Significantly, this term has been adapted to highlight the inextricability of sex, gender, and sexuality. Sex and gender are quite obviously linked through governance beginning at birth following the declaration of sex. And as Rubin (1993) taught us, 'gender affects the operation of the sexual system, and the sexual system has had gender specific manifestations' (p. 308). Given that experiences of PCOS expose the jumbled overlap of sex, gender, and sexuality, I use heteronormativity in this expansive sense, while still recognizing one can be sexually queer and sex and gender conforming or sexually straight and sex and gender non-conforming.

While none of the participants in the study explicitly spoke of 'queering PCOS,' participants who identified as LGBTQ+ by and large did not seek to alter PCOS traits to the same degree as their heterosexual participants. This was mostly attributed to the refuge from the broader pressures of sex/gender norms they felt in their sexual relationships and peer communities. To discuss my findings that queer participants were more likely to resist heteronormative standards, while acknowledging that this outlook is not strictly attached to sexual identity, I again turn to post-structural theory and use the term 'queering' to signal the ways in which queer participants mostly, but not strictly, resisted heteronormative standards. With origins in AIDS activism and as articulated in queer theory, queering as a verb is different than embracing the queer label as an identity (Halperin, 1995; Jagose, 1996). Queering does not refer to any one set of practices but rather represents evolving and unfixed modes of challenging dominant discourses, practices, and institutions. 'To queer' as a verb is to disrupt, and refuse taken for granted social norms of all kinds.

Existing qualitative research on the lived experiences of PCOS embodiment

There is now a burgeoning body of qualitative literature on lay understandings and experiences of PCOS embodiment. However, as recently noted by several scholars, this body of work could be strengthened by considering how PCOS is understood and experienced across differences in social location.

Whereas biomedical research on PCOS has been published throughout the past century, peer reviewed scholarly works focused on understandings and experiences of PCOS were non-existent until the early 2000s. Willmott (2000) published the first peer reviewed qualitative research that detailed individual experiences of PCOS from a feminist perspective. Consisting of interviews with 30 heterosexual women recruited from a British national self-help organization for women with PCOS, this research was foundational. Reported on by Kitizinger and Willmott (2002), participants in this study used the terms ‘unfeminine,’ ‘abnormal,’ ‘masculine,’ ‘freakish,’ and ‘unnatural’ to describe their PCOS symptoms. They expressed intense frustration with being unable to embody normative female sex characteristics, particularly with respect to hair, menstruation, and fertility. Since then, qualitative research on understandings and experiences of PCOS have similarly focused on white, gender conforming, heterosexual women who report PCOS as an affront to their femininity (for example, McKellar, 2019; Pfister and Rømer, 2017; Snyder, 2006; Thorpe et al., 2019; Tomlinson et al., 2017; Weiss and Bulmer, 2011; Wright et al., 2020).

Distress over specific symptoms of PCOS is likewise well documented in research that is not explicitly focused on PCOS. Scores of research has been published mapping ‘disgust’ (Fahs, 2017a) over hairiness/hirsutism (Eckback et al., 2009; Herzig, 2015; Pfister and Rømer 2017), fatness (Rothblum and Solovay, 2009; Fahs and Swank, 2017), and acne (Prior and Khadaroo, 2015; Lafrance and Carey, 2018). However, given the likeliness that PCOS will bring these stigmatized traits together, having PCOS may compound inner loathing and/outer stigma. As reflected in the title ‘It is always on my mind’ (Eckback et al., 2009), the self-consciousness and self-surveillance that the supposedly abject traits of PCOS often induce can be all-consuming.

There have recently been calls to enrich feminist research on PCOS with further attention to the intersection of gender identity, race, ethnicity, religion, and class. Siva (2023) highlights the underrepresentation of racialized, transgender, and gender non-conforming people in PCOS research, calling for increased diversity and intersectionality in research on people with this diagnosis. When researching qualitative literature on the lived experiences of PCOS, Buddhavarapu (2020) notes the ‘need for queer and trans-inclusive feminist and postcolonial discourse’ (p.414). Indeed, there is only a smattering of feminist research on PCOS that incorporates the lived perspectives of racialized, gender diverse, and sexually queer individuals, thereby adding nuance to the way we understand experiences of PCOS. As noticeable exceptions, Carlin and Kramer (2020) examine the eugenic origins of PCOS discourse which connect testosterone, hairiness, and racialization. Soucie et al.’s (2021) Canadian based study found that symptomology was often ‘rationalized as a “normal” aspect for particular ethnic profiles’ (p. 96), thus potentially compromising medical care. Joanes’ (2023) UK based autoethnographic account of

PCOS recounts the contrast of viewing hair as a ‘gift from God’ as a Sikh woman with being ridiculed by her white classmates for hairiness. [Vleming’s \(2018\)](#) qualitative research on PCOS includes an interview with one trans man. The interview excerpts highlighted focused on his sense of exclusion from the ‘women’s health’ framing of PCOS, but did not tell us about how he felt about PCOS related embodiment itself. Most recently, [Wugalter et al. \(2023\)](#) interviewed 10 gender diverse individuals diagnosed with PCOS (one trans man and seven non-binary folks) and found that while the overall experience of the diagnosis was a ‘burden’ given its heteronormative framing, PCOS was also experienced as an ‘occasion’ to consider and validate non-binary gender identity and as a ‘benefit’ for those who embraced masculinity.

While the above research deepens our understanding of the experiences of PCOS across differences of social location, existing feminist research on PCOS has yet to theoretically unpack the decision people with PCOS are often met with: disciplining the PCOS body toward heteronormative ideals or accepting or celebrating the PCOS body as is, or landing somewhere in between. The section below sets the stage for the theoretical framework which informs the interpretation of the empirical findings.

Theorizing the aesthetic labour of heteronormativity

Research on the aesthetic labour of heteronormativity has followed the pendulum of ‘structure versus agency’ debates in feminist theory. Now, moving past structure versus agency, feminist thought tends to view this labour as both oppressive and potentially agentic, to some extent, depending on context, identity, and location.

Beginning in the 1970s, Marxist feminists and radical feminists positioned women’s labour in service of bodily discipline toward feminine beauty standards as the result of capitalist patriarchy (for example, [Rowbotham, 1973](#); [Dworkin 1974](#)), with Black feminists highlighting their scaffolding in white supremacy ([Davis, 1981](#)). A through line of thinking was that women were victims of broader social structures. A shift is evident in the early 21st Century when feminist theorists, especially those guided by post-structuralism, attempted to make space for greater agency in these processes. For instance, a burgeoning body of feminist scholarship on cosmetic surgery was attuned to multiple readings of the labour involved in these processes, including agentic ones ([Davis, 1997](#); [Heyes, 2003](#); [Pitts Taylor, 2007](#)). These theorists were influenced by the work of [Foucault \(1995\)](#) who noted the productive and repressive aspects of disciplinary power. Similarly, theoretical work on trans embodiment ([Spade, 2006](#)), rooted in post-structuralism, provided a nuanced account of the ‘technologies of gender’ that aid in the expression of gender identity. In this vein, [Sullivan’s \(2006, 2009\)](#) work on ‘somatechnics’ was key. Inspired by a speech given by trans scholar Susan Stryker in 2003, somatechnics troubles the binary of trans embodiments as technologically mediated and cis embodiment as ‘natural.’ In fact, as pointed out decades prior by [Haraway \(1985\)](#), all gender expression involves technological intervention and mediation. In her in her groundbreaking essay ‘The Cyborg Manifesto,’ she proclaimed, ‘we are all chimeras, theorized and fabricated hybrids of machine and organism’ (p. 435).

The spirit of nuance is clear in the more recently coined field of Critical Femininity Studies which ‘examines femininity through a nuanced, multidimensional framework, moving beyond femininity as a patriarchal tool, to instead consider the historical, ideological, and intersectional underpinnings of femininity, particularly those that contribute to femmephobia’ (Hoskin and Blair, 2022: p.1). And it has long been evident in Black feminist scholarship on Black women’s relationships to beauty culture, acknowledging the possibilities of community and subcultural identity building in adherence to specific aesthetic cultures, alongside the recognition of ongoing racism and white supremacy in hegemonic beauty culture and professional standards (Byrd and Tharps, 2001; Dabiri, 2023; Hobson, 2018; Pough, 2007).

With all of that said, contemporary theorists recognize the limits of aesthetic body projects *and* individual self-acceptance when stigma continues to shape social structures, privilege, and oppression (Tsaousi, 2017). While embracing the postmodern spirit of ‘technologies of gender,’ the trans of colour critique have been particularly firm in this emphasis. Although Featherstone and Hepworth (1991) once proclaimed, through the ‘aestheticization of everyday life,’ the body has become ‘plastic,’ Gill-Peterson (2018) more recently clarified, ‘plasticity’ is coded in whiteness.

Data, methods, and methodology: A researcher with PCOS researching PCOS

This article draws on 30 qualitative, in-depth, semi-structured interviews in Victoria, British Columbia, Canada. Participation required that they were over 19 years old or older, English speaking, and had at some point received a medical diagnosis of PCOS. With University of Victoria ethics approval, recruitment occurred primarily through social media and posters at the university and Island Sexual Health, a local community sexual health clinic with no connection to the university, as well as through minimal snowballing sampling. I took a ‘slow’ (Bagelman and Bagelman, 2016) research approach and allowed these interviews to trickle in over a 5-year span from 2017 to 2022. Before the Covid-19 pandemic, interviews took place in my office on campus or at people’s homes. However, with pandemic related restrictions, interviews switched to Zoom, which in hindsight, allowed for greater convenience for the participants who were generously donating their time to discuss sensitive subject matter. Overall, interviews ranged from 35 minutes to 2 hours with an average length of 55 minutes. The interview script focused on participant experiences of PCOS symptoms and their attempts, if any, to alter them. Interviews were accompanied by a short questionnaire collecting demographic information and background details of their diagnostic and treatment process.

The participants I interviewed were in some ways diverse, and in other respects homogenous. Participants had a range of PCOS symptoms in various combinations and with varying levels of continuity. It would be impossible to quantify the symptoms given that some may ebb and flow and some may be contained through various management strategies. Collectively, the most common physical symptoms of PCOS were irregular ovulation and menstruation; infertility; hairiness or hirsutism (on face and body); thinning hair on head; bloating, weight gain, fatness, and/or a high BMI,

and cystic acne or acne. Ages spanned from 22 to 57 with average age of 29. Victoria, British Columbia is known as proportionality the most sexual and gender diverse city in Canada (Census, 2021) and the University of Victoria and Island Sexual Health are especially known for their LGBTQ+ inclusivity. This may have shaped the fact that ½ of participants ($n = 15$) were LGBTQ+ identified, 1/3 of whom were non-binary ($n = 5$). Victoria is also a predominantly white, middle-class, educated city. And so, it was not surprising that 25/30 participants identified as white with 2/3 either in the process of earning or having already achieved a college or university degree. The overall middle-classness of the participants means that they were more likely to have the energy, resources, and access to seek advice and treatment for PCOS, spanning the medical, holistic, and aesthetic sectors. Therefore, the theorizations I offer on the labour of managing PCOS should be taken as plausible within the privileged socio-economic context of having the security of one's basic needs met, which is not to suggest that money was not a factor in their accounts.

Interviews were transcribed verbatim and manually coded by the author, again using the 'slow' method of highlighting themes in various coloured felt markers. While maintaining the confidentiality of participant accounts, I chose not to use pseudonyms but rather refer to participants by numbers. Next, I analyzed the interview transcripts using grounded theory, an approach that 'explicitly assumes that any theoretical rendering offers an *interpretive* portrayal of the studied world, not an exact picture of it' (Charmaz, 2006: p. 10). Moreover, grounded theory is an inductive approach to data that allows the researcher to analyze the research according to themes that emerge from the data itself. Themes of heterosexual failure, stigma, queering, and the complexity of bodily discipline versus resistance were striking across all 30 interviews and resonated with me personally as well.

As hooks (2015) argues, 'the politics of location necessarily calls those of us who would participate in the formation of counter hegemonic cultural practice to identify spaces where we might begin the process of re-vision' (p. 15). My relationship to my own embodiment and my desire to discipline it in certain ways, alongside my journey to self-acceptance has likely shaped the way I interpreted the interview data. My perception of my PCOS symptoms has shifted over time, as influenced by my own sense of a fairly feminine gender identity and my exposure to range of theoretical perspectives on beauty standards and body modification as outlined above. Initially, my PCOS related traits were straightforwardly distressing. And yet, I believed that my feminist beliefs should shield me from a negative body image. However, as years have passed in my career in Gender Studies, I have made greater peace my body and with this disconnect. Theories that resist over-simplified understandings of body image, bodily discipline, and body modification, have helped me better understand the disappointment I initially felt for not being a 'better feminist.' I am now more forgiving of my will to modify the PCOS traits that I feel at odds with. I recognize there are a jumble of motivations for doing so. At the same time, I am aware of the uneven playing field of access to body projects and care, and I recognize that my privilege of access is shaped by my privilege as a white, middle-class professional educated in research. I also understand and believe that narrow definitions of feminine corporeality offer a limited understanding of

attractive and healthy embodiment. For these reasons, I have also challenged myself to be more accepting of my body, likely the influence of my immersion in the body positive or at least neutral feminist and queer world of Gender Studies.

Findings

PCOS as heteronormative failure

Across the interviews, all participants revealed how PCOS makes achieving heteronormative standards difficult, but those difficulties differ depending on cultural context and type of PCOS symptom and the weight of these difficulties differ across axes of gender and sexuality. In line with insights from other qualitative research on PCOS, heterosexual women in this study were highly aware that they were unable to meet heteronormative standards of female biological sex, gender, and sexuality. As P 14, a white 35-year-old woman reflected, ‘that’s what our society values. We see women as hairless, perfect skinned people that are thin and all of that kind of stuff, and petite, and so it impacts your thoughts on that because you don’t fit that mold anymore.’ Similarly, as P 10, a Japanese woman in her 50s bluntly stated, ‘chubby girls with mustaches are not who society celebrates.’

Infertility was a factor in making successful heterosexuality feel out of reach. P 25, a 21-year-old Chinese woman emphasized, ‘you’re expected to have a kid.’ P 7, a white, woman in her 20s confided, ‘I’m stressed about it. Also, I feel bad, guilty, I feel like it’s my fault that we can’t have a family, haven’t been able to yet [...] I know that it’s disappointing to him [her husband].’ Like several others who experienced infertility, she blamed herself reflecting, ‘I think it’s mostly me coming to the table and feeling bad, feeling guilty, and again, like I’m letting him down.’ Highlighting the omnipresence of this guilt, she elaborated, ‘you’re never really present when you’re feeling guilty all of the time.’

Noticeable amounts of hair on the face and body also led to a sense of heterosexual failure. P 14, a white 35-year-old explained, ‘It makes you feel less feminine when you’re growing hair out of your face, it’s not really a feminine quality, in terms of feeling pretty.’ She further stated, ‘I think it’s cultural, that’s what our society values.’ Indeed, several participants were directly bullied for having facial and body hair. As P 8, a straight, 31-year-old woman recounted, ‘as a teenager I was called “hairy beast.”’ Some participants associated hirsutism with their ethnicity, normalizing hairiness to some degree, and yet not enough to mitigate the stigma they felt. P 21 stated matter-of-factly, ‘I’m half Middle Eastern and half Lebanese Armenian. So, I’ve been dealing with it [being ‘very hairy’] since I was 8.’ Some white, cis heterosexual women framed hairlessness as part of whiteness. P 22, a white 21-year-old stated, ‘I know Indian women have dark hair and that’s normal for them to have long sideburns and stuff, but like the white woman with light hair, it’s not something I’ve ever considered.’

Fatness similarly made navigating and achieving heterosexuality difficult, even for those who consciously attempted to adopt a body positive mindset and politics. P 10, a Japanese Canadian woman mused, ‘Would you rather be in out in public treated as a thin

woman? Or as an extremely overweight woman? Well obviously, you want your life to be easier.’ She later reflected, ‘It’s a really shame because I am the same person whatever my weight.’ P 16, a white woman in her early 20s explained, ‘Carrying around this gut goes right back to my identity because people look at you and think, she eats poorly, she’s disgusting.’” She later explained, ‘You can “accept it” but every day you still think about it. It’s great to be body positive but it’s not so cut and dry.’ P 8, a white woman in her early 30s who was bullied in high school for being fat reflected, ‘Sometimes I just wish that they would follow me for a day. Cause they just assume you’re fat, you must be lazy, you must not do anything.’

However, P 2, a Black woman with roots in East Africa positioned fatphobia as a cultural construct. She recalled, ‘when I went to visit my family and stuff in East Africa for the first time, I was like, “Wow.” You know? And “I feel feminine,” and “I feel like a woman,” and “I feel desired.” Super weird. The fat here doesn’t matter!’ And I was like, “I’m going to come back to Victoria with the mentality that everything is very subjective.”” This quote invokes the possibility that one can consciously bring the mentality of one’s specific culture into the hegemonic colonial culture. And yet, at another point in the interview she stated, ‘I’ve been on a diet since I was 9 years old,’ highlighting the power of European heteropatriarchal feminine ideals.

Acne was associated with equal parts shame and stigma, and this extended to cisgender participants as well. As P 3, a white, heterosexual, 25-year-old woman most forcibly stated, ‘I used to tear myself up about it. I hated it looking at myself in the mirror just because I felt like I was just this little pizza face, you know? I absolutely had no self-esteem for years; it was really hard on me.’ And further stated, ‘It [the acne] made me feel less beautiful, it made me feel less strong really. I didn’t think that such a physical trait could really tear someone down that much, but, um, it definitely did.’

A sense of heteronormative failure was often so profound that participants would limit, halt, or avoid sexual encounters with men. The above participant rued, ‘It was so bad. My mental health was in the toilet. My self-esteem was gone. It [acne] completely affected my ability to develop a healthy relationship (with men) because I was ashamed of my body.’ P 22, a white woman in her early twenties stated, ‘It [hair growth] has been very frustrating to me because it really affects my confidence.’ She continued, ‘I have a lot of confidence issues, like I don’t really date. That’s probably related to that [hair growth].’ P 16 likewise reflected, ‘I definitely have some pretty strong barriers to romantic relationships [...] I would never mention PCOS because then he would think, okay, “she’s not the typical kind of girl I want to go for.” It definitely changes the perception of your sexual identity because you don’t feel sexy and therefore sexual.’ P 18, a heterosexual identified Chinese woman in her early 40s had never dated for these reasons.

Several participants referred to ongoing worries about ‘passing’ as the cisgender identity that they identified with. P 8, a straight white woman similarly stated, ‘I’m still being told, “Oh sorry sir. I mean oh sorry ma’am.” It’s definitely a sore point being referred to as a man simply because I have these very male traits I can’t help.’ She later commented, ‘someone with PCOS can converse very easily with a trans woman, because we take a lot of the same medication.’ She finally confided, ‘I will never be a girly girl but it would be nice to not have my body fighting with me [...] I just want to be recognized as

a woman.’ P 16, a white woman in her early 20s similarly reflected, ‘women are supposed to be small and cute and not have facial hair, and it very much puts you at odds with the gender binary.’ As P 3, a white 25-year-old woman stated, ‘I sometimes heard in the sort of transgender community this concept of people talking about [...] like people trying to “pass.” [...] Yeah, I didn’t realize until very recently that I lived with this constant sense of having to work very hard to “pass” for a like a real girl or woman.’ As well, some participants discussed the difficulty of being ‘trapped in the wrong body,’ a common narrative required by medical keepers of transgender affirming care. Despite the body positivity that P2 felt when she visited Africa, she reflected, ‘Yeah, it’s very hard. It’s a super big disconnect from what I feel on the inside, what I want to portray.’

Heteronormativity, labour, and discipline

Given their awareness of the standards of hegemonic femininity, it is not surprising that most of the heterosexual participants in the study sought treatment from numerous sources spanning medical (GPs, gynecologists, endocrinologists), holistic (naturopaths, acupuncturists, reflexologists, social media influencers and authors), aesthetic (aestheticians, laser hair removal), dietary (dieticians, authors, and influencers), and athletic (fitness instructors and trainers). They took oral contraceptives, hormonal IUDs, anti-androgen drugs, drugs for insulin resistance, acne medication, supplements, and used razors, wax, and lasers. They did weight training, aerobics, Pilates, and yoga. They tried calorie restricted diets, low carb diets, and low-fat diets. A few participants described what was clearly disordered eating as a strategy for managing PCOS.

This process was viewed as costly, time-consuming work, often with few results and rewards. Many heterosexual participants referred to the ‘thousands’ or ‘tens of thousands’ of dollars they had spent on managing PCOS traits deemed abject. As P 18, a 42-year-old, Chinese woman stated, ‘It definitely is so much work, so much brain power thinking about it, and money, and time.’ P3, a white 25-year-old woman highlighted the fine balance of this work wherein one must strive to live a ‘perfect life,’ stating, ‘You could be on a perfect diet and you could be doing your perfect amount of insulin sensitizing exercise, but if your work life is making you lose sleep, that can just as easily throw the axis off. So, it’s hard, and it’s not really fun to live like that.’ P 16, a white woman in her early twenties similarly explained how much effort it takes to lose weight with PCOS, ‘If I was a normal person with normal hormones and normal metabolic health and I worked out and ate as clean as I do, I would not look like this.’

Doing this work within the context of heterosexual relationships brought specific challenges. Some participants discussed the labour of hiding this work from their partners due to embarrassment. P 8 was in a long-term relationship with a man but hid her hair growth. She explained, ‘I don’t want him to hear the razor going when I’m shaving. I have at-home laser hair removal, and I don’t let him see that.’ By contrast, P 12 discussed the labour of sharing the PCOS experience with her male partner, educating him along the way. She explained the importance of medical validation when navigating her partner’s response to her PCOS symptoms reflecting, ‘in his head, he was thinking “I need to lose weight.” As opposed to thinking that “my illness is showing up.”’ She elaborated, ‘when

the diagnosis was finally delivered, it was a key for him to hook into. It was something he could hang his hat on. I didn't have to keep advocating for myself as a fat woman. I was a woman with PCOS. And so that shifted things for him.' She further mused, 'It's taken him a long time to really believe me, and it's taken him a long time to work on his own biases and concern, around the weight piece in particular.'

While most expressed frustration with the labour of regaining femininity, some were positive about this form of bodily discipline. Some spoke about becoming skilled in this labour using the language of empowerment: P. 20, a white, heterosexual 43-year-old reflected, 'Going through aesthetic school and learning how to wax my own chin, [laughter], really empowered me to feel more beautiful and more feminine.' Others discussed this labour as part of culture and self-care. P 21, an Arabic Armenian in her 40s reflected on how feminine beauty rituals connected her to her culture and the women in the family. 'It's a form of self-care that is important for women.' She elaborated, 'I grew up with my mom and my aunties always discussing hair care and skin care. They would bring me into these conversations, and it felt like they were passing down important knowledge to me. It's part of my culture. We don't see it in a negative light. It's creative, relaxing, and makes you feel good.'

Queering PCOS

LGBTQ + identified participants in this study were far more likely to embrace self-acceptance over disciplining their bodies into the norms of sex, gender, and sexuality. P 12, a white, queer woman exemplified the more carefree relationship to PCOS symptoms as told by queer participants when she stated, 'My youngest always says, "Mmm, you have a beard." And I'm like, "yup, sure do! Women have beards sometimes."'

Several participants explicitly attributed being queer to their sense of body positivity or neutrality. P 5, a white, 22-year-old queer woman simply stated, 'I do think it [being queer] offers different understandings,' adding, 'I also don't find my possible infertility would matter that much. I don't see that as being a red flag in a relationship with a queer person, especially if it's not a cis guy, whereas if I'm with cis straight dudes, there's more of that attached to it.' Similarly, P 11, a white, 35-year-old lesbian woman, explained, 'Yeah. And I guess in society there's these kind of social views of "woman" and a lot of it is wrapped up in fertility and that kind of thing which already I think queer people have a different relationship with that, not necessarily having that same heteronormative path to reproduction if that's what you're interested in.' P 17, a queer woman in her 30s explained, 'a lot of people who are in my bubble are looking at gender and being critical of the gender binary. I think it makes it easier to cope with not fitting into that cookie cutter gender mould.' She further stated, 'it's easier just in the sense that as a queer woman, I have the option of being with female partners who will understand the complexities and challenges of PCOS.' P 23 recalled, 'I guess it has helped me to connect a little more with female partners' and 'my self-esteem doesn't rely on physical appearance anymore.' P 1, a white non-binary person in their early 20s likewise reflected on their experience of queer community, 'So I think finding my identity as a queer person and finding community in that helped a lot.' They elaborated, 'exposing myself to [...] people who don't conform to

these gender norms and didn't conform to how society told them their bodies should look was really a key resource for me' in 'finding peace in my body and being able to accept these traits that the patriarchy tells you are repulsive.'

Non-binary participants felt not only acceptance but often happiness in their PCOS traits. As P 1, a non-binary person in their early 20s stated, 'I love not getting my period and obviously that is good for me gender wise.' P 29, a white non-binary person in their early 20s stated, 'I just I like being masculine.' They later mused, 'I'm at a point in my life where I'm actually considering potentially going on a small dose of testosterone, so like, any testosterone I can get naturally, I'm cool with it.' P 30, a Turkish non-binary person in their 20s boasted about how high levels of testosterone can help with athleticism due to their natural muscularity. They proudly proclaimed, 'I can do pushups and I don't work out.' At the same time, P 30 was clear that as a non-binary person, they do not always want to shine their masculinity. They clarified, sometimes they 'fit more masculine' with 'really short hair' and masculine dress but other times they identify more with femininity and therefore, shave their beard every couple of days. Gender diverse participants also attributed their ability to embrace their masculinity in terms of the support of queer and trans + community. P 28, another Turkish non-binary person argued that 'non-binary people already have this questioning about gender roles, gender, biological functioning' which has aided in the PCOS process.

Some gender diverse participants related to PCOS as a form of physical confirmation for their desire to have a masculine gender identity. For instance, P 30, a non-binary participant from Turkey, described their early awareness of PCOS symptoms as, 'I'm not really saying it caused something, but it really increased some of the feelings I have.' P 29 mused, 'And so then getting my PCOS diagnosis, I feel like was just another thing amongst a bunch of other stuff that sort of made me realize that I wasn't going to like tick all the boxes of what I expected myself to be.' They elaborated, 'And in some ways maybe it allowed me further to be like, this is another way that I don't fit into what is expected of a woman.' Similarly, P 30, stated, 'I have thought to myself that some of my gender experience is due to my hormone balance because ever since I was small, I was always a tomboy, kind of a boy child. But when I knew I had PCOS I questioned whether it was due to my masculine hormones.' However, they later explained this viewpoint has evolved stating, 'I really don't want to think about it [being non-binary] like that, because I am who I am. I don't want to give gender to hormones.'

Complexity and nuance within heterosexual and queer experiences

With the above said, it would be overly simplistic and counter to this article's theoretical framework rooted in resisting universal truths to suggest a strict binary between straight and queer participants' experiences of PCOS. Firstly, many queer and gender diverse participants had once identified as and/or lived as cisgender and/or straight. During the interviews, they often reflected on their perspectives and experiences before understanding and embracing being queer. For instance, P 1, a non-binary person in their 20s who had come to love their facial hair, recalled, 'I remember it [hair growth] kind of

coinciding with how far I was willing to go with someone. I was like, okay “what are we doing tonight? What do I need to remove my hair from? You know?”

Secondly, while I have argued for Rubin’s reading of heteronormativity as potentially influencing the triumvirate of sex, gender, and sexuality, we must not overshadow the reality of gender non-conforming straight people and femme queer women. As a white intersex, sexually queer woman, P 24 had a complicated relationship to PCOS. She felt secure in sexual relationships. As she states, ‘Um, well as a gay woman, I’ve never even given it [PCOS] a second thought. It hasn’t influenced anything to do with my sexuality. I don’t feel less of a gay woman.’ Nevertheless, PCOS was tough for her personally in terms of her gender identity. She reflected, ‘It’s just disheartening some days and you’re like, “I don’t really look like a woman.”’ On the background information questionnaire filled out at the time of the interview, and throughout most of the interview, she identified as she/her, but at one point stated, ‘I really identify with being a female, like, that is what I am most comfortable and confident in. And I, you know, I love being a feminine woman, but there are days when I’m kind of like, “okay, I feel like a they/them.”’ She elaborated, ‘It’s disheartening to identify as a woman and then come to look at yourself in the mirror and be like, okay, so my mustache is coming in.’ Moreover, much like myself, she felt politically guilty for feeling bad about herself as a woman stating, ‘I think having this diagnosis and being a feminist, it’s almost like you’re feeling sort of doubly let down, because if you have a negative reaction to these traits you have this feminist guilt of, ‘I shouldn’t care, and I know where it all comes from, but I’m feeling it anyways.’’ She later stated, ‘It’s a double edge sword where you’re like, I shouldn’t feel bad, but I also do feel bad, because I want to be a lady kind of thing [...] Like logically, academically [...] I know society is pushing these norms on me, but it also makes me feel good.’ And yet, P 24 was aware that there are key structural privileges with PCOS as opposed to gender affirming healthcare for trans people, particularly those who are marginalized in relation to racialization or socio-economic status. As she stated, ‘I feel as though if I were a trans person of colour, like female to male, it would have been an extremely different situation.’

Finally, there were some heterosexual women in the study whose perspectives were shaped by queer community and allyship. As P 3, a white heterosexual 25-year-old woman stated, ‘I had friends that were gay, women that were lesbians, [...] and physically the way they expressed themselves, whether they allow a mustache to grow, a beard to grow, and all that, that really opened up my heart and my mind is the only way I can describe it. I actually came to accept myself more.’ And yet, allyship with queer community was not a panacea. As P 18, a 42-year-old Chinese Canadian woman recalled, ‘I’ve met so many people who perhaps fall outside those gender norms and I love them and they’re great, they’re wonderful people. But that doesn’t apply to me somehow.’ Comparably, after reflecting on the positive influence of fat activism, P 14, white, straight woman stated, ‘I meet these wonderful people and they don’t care, it’s not a big deal, but there’s still a lot of baggage in certain things.’

Discussion and conclusions

I offer the findings of these interviews with 30 people with PCOS, as well as my own experiences, as a small but telling, and to some extent intersectional, contribution to the

burgeoning body of qualitative research in this area. This research was most illuminating in relation to the ways in which PCOS may be experienced differently across gender and sexual axes of identity. Like existing heterosexually focused research on this topic, heterosexual interview participants highlighted the difficulty of achieving normative heterosexuality. Because sex, gender, and sexuality are linked in heteronormative standards, several participants struggled to 'pass' as the cisgender people they identified as and/or felt 'trapped in the wrong body.' These women portrayed PCOS symptoms such as infertility, hairiness, acne, and fatness as highly stigmatized and at odds with their sex, gender, and sexual identities. Unfortunately, navigating PCOS embodiment made approaching heterosexual relationships stressful, arduous, and sometimes impossible. Given that heterosexuality and PCOS were experienced as a distressing combination, it is not surprising that heterosexual women in the study sought to reduce their PCOS symptoms through various means from medical to holistic to aesthetic to diet and fitness, sometimes with a sense of empowerment, self-care, or cultural belonging, but also at a high cost of time, energy, and resources.

Drawing on post-structural theory on bodily discipline and aestheticization, we can look at this labour through a nuanced lens. On the one hand, particularly the heterosexual women in this study who could not live up to heteronormative ideals experienced undeniable pain and self-loathing as well documented in the siloed areas of Critical Fat and Critical Hair Studies. On the other hand, using technologies of gender to express femininity could possibly be seen in positive terms as gender affirming or at least neutral terms by recognizing that we are all technologically mediated. Nonetheless, it is important to note that some people have more agency than others in how their bodies and technology meet. Cisgender women with PCOS do not face the same kinds of medical gatekeeping as trans people when seeking hormone therapy. Socio-economic status, racialization, and ability are also key factors shaping access and the standards that shape the ideals of femininity.

With half the participants identifying as queer sexually, five of whom were non-binary, this research may inform a greater understanding of queer and gender diverse experiences of PCOS, typically left out of feminist analyses. In line with the findings of [Wugalter et al. \(2023\)](#), gender diverse participants who identified with masculinity were in harmony with the masculine traits that are attributed to PCOS, at times pointing to PCOS as validation of their inherent masculinity. Interview accounts reveal the potential of sexually queer relationships, community, and perspectives for disrupting the hegemonic pressures of femininity, and the potential, as well as the limits, of bodily acceptance as an alternative to disciplinary labour. By and large, queer identified participants were more accepting of what are often seen as socially abject bodily traits for those assigned female at birth and engaged in less PCOS related labour. And yet, whatever gender or sexual identity, nobody was entirely immune to the stigma attached to somehow not meeting the binary sex/gender codes entrenched in hegemonic culture, nor the internalized insecurities that often accompanied this awareness. To suggest that queer acceptance of traits deemed abject in the broader culture is a straightforwardly pain free experience is overly simplistic. Many participants in this study described their childhood and youth as rife with bullying, had experienced the pressures of heterosexual relationships,

and navigated adult life with an awareness of hegemonic norms, despite whatever refuge they felt within their queer relationships or community.

There is not nearly enough PCOS research highlighting the experiences of racialized people assigned female at birth and this study was also limited in this capacity. A key limit of this study is that it did not include the perspectives of Indigenous women and two spirit folks who are disparately impacted by PCOS (Boyle and Teede, 2012; Patrie, 2023). With that said, in the case of this study, some accounts by racialized women offered windows into cultural norms that diverged from Eurocentric notions of beauty and some participants discussed participation in feminine beauty culture in culturally meaningful terms. Also reflecting the social construction of race, white women discussed their PCOS symptoms as counter to the norms of whiteness, suggesting the ongoing currency of theories of hairiness as part and parcel of racialization. However, more research is needed to unpack the myriads of ways that PCOS may be understood and experienced across a multitude of diverse locations, socially, geographically, and politically.

Ultimately, the findings of this research are not intended to romanticize queer sexuality and demonize heterosex, a much-critiqued tendency of radical feminism, but rather to offer inspiration to those who, for any reason, are seeking alternative perspectives on sex, gender, embodiment, health, and beauty. The data suggests that straight participation in queer community and feminist social justice-based communities may be influential in and of itself and that participation in the labour of feminine aesthetic ideals can be examined with a mind toward complexity. All the above speak to my own experiences and perspectives on PCOS embodiment, marked by nuance, contradiction, and flux.

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Notes

1. The most widely used Rotterdam Criteria requires two out of three of the following diagnostic criteria: 1) Hyperandrogenism 2) Menstrual Irregularity and 3) Polycystic Ovaries on ultrasound.

Given that the presence of ovarian cysts is not a required symptom for current diagnostic frameworks, PCOS is frequently a misnomer. In fact, there is movement afoot to rename the diagnosis ‘Androgen Excess Disorder’.

2. It not clear whether the risk of depression is physiological or psycho-social given that PCOS associated traits are highly stigmatized (El Hayek et al., 2016; Deeks, 2010).

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