

Bodies in Conflict: Understanding Women's Experiences of Polycystic Ovarian Syndrome

by Samadrita Chowdhuri

Abstract: Polycystic Ovarian Syndrome (PCOS) is a complex medical condition that impacts women's bodies and identities, especially in relation to gendered expectations of health and femininity. Drawing on feminist and social constructionist frameworks, this study uses ideas of "doing gender" and "undoing gender," in connection with the concept of medicalization, to investigate the relationship between self-perception, medical authority, and gender norms. This qualitative study examined the embodied experiences of Indian and Indo-Canadian women living with PCOS in Edmonton, Canada, using semi-structured interviews, focus group discussions, and body mapping as the primary methods of data collection. According to the findings, women establish a hierarchy of symptoms, giving external symptoms like acne and hirsutism precedence over issues about fertility. This hierarchy is a reflection of internalized ideas of feminine appearance and also a rejection of feminine functionality focused on reproductivity. The women's choices of treatment, especially with regard to hormonal contraceptives, reflect a negotiation between defying and adhering to sociocultural and biological standards of womanhood. This study challenges conventional medicalized discourses on PCOS by emphasizing women's narratives, and advances a more comprehensive understanding of gender, health, and embodiment. It emphasizes the necessity of more patient-centered approaches to recognize and validate opportunities for healing that are not based on predetermined and essentialist notions of health and femininity.

Keywords: Polycystic Ovarian Syndrome; healing; femininity; health; gender; body-mapping

Résumé : Le syndrome des ovaires polykystiques (SOPK) est une maladie complexe qui affecte le corps et l'identité des femmes, en particulier en raison des attentes liées au genre en matière de santé et de féminité. S'appuyant sur des cadres théoriques féministes et constructionnistes sociaux, cette étude s'intéresse aux notions de « faire le genre » et de « défaire le genre », en lien avec la médicalisation, afin d'analyser les liens entre la perception de soi, l'autorité médicale et les normes de genre. Cette étude qualitative a examiné les expériences vécues par des femmes indiennes et indo-canadiennes atteintes du SOPK à Edmonton, au Canada, à l'aide d'entrevues semi-structurées, de groupes de discussion et de la cartographie corporelle comme principales méthodes de collecte de données. D'après les résultats, les femmes hiérarchisent les symptômes, privilégiant les manifestations visibles, comme l'acné et l'hirsutisme, plutôt que les problèmes liés à la fertilité. Cette hiérarchie témoigne de représentations intériorisées de l'apparence féminine, ainsi que du rejet d'une féminité définie par sa fonction reproductive. Les choix de traitement des femmes, notamment en ce qui concerne les contraceptifs hormonaux, reflètent une négociation entre la remise en question et l'adhésion aux normes socioculturelles et biologiques de la féminité. Cette étude remet en question les discours médicaux conventionnels sur le SOPK en valorisant les récits des femmes, et contribue à une compréhension plus approfondie du genre, de la santé et de l'expérience vécue. Elle souligne la nécessité d'adopter des approches plus centrées sur les patientes afin de reconnaître et de valider les possibilités de guérison qui ne reposent pas sur des concepts prédéterminés et essentialistes de la santé et de la féminité.

Mots clés : syndrome des ovaires polykystiques; guérison; féminité; santé; genre; cartographie corporelle

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Introduction

Polycystic ovarian syndrome (PCOS) is a complex medical condition that significantly affects women's identities and bodies. This research deploys body mapping, focus groups, and in-depth interviewing to look at how women with PCOS deal with the gendered aspects of living with the disorder. Grounding my work in a feminist and social constructionist theoretical framework, I incorporate theories of both "doing gender" (West and Zimmerman 1987) and "undoing gender" (Butler 2004; Deutsch 2007), while also drawing on Foucault's (1973) conceptualization of "medicalization." Used together, these theoretical viewpoints help to shed light on how women with PCOS navigate their identities and treatment choices by both complying to and defying gender norms.

This qualitative research aims to get a more nuanced knowledge of the experiences of Indian and Indo-Canadian women with PCOS living in Edmonton by examining how women identify their bodies in response to living with a gendered disease. In this study, I explored illness experience with regards to symptoms but also illuminated treatment approaches and perspectives to understand the reasons why women go through treatments, whether and why they prefer certain forms of treatments, or if they are challenging conventional forms of the same. Building on previous research done on PCOS that has focused on experiences of women, this study explored how "health" is connected to the construction of a "normative female body." The research questions were as follows:

1. What are the treatments Indo-Canadian women prefer with regards to PCOS?
2. How do these preferences arise from their lived experience of PCOS?

My research found that the narratives of the 18 women in this study established a hierarchy of symptoms, giving visible symptoms precedence over less visible issues with reproductive function. This prioritization of symptoms highlights a complex dynamic between internalized ideas of womanhood and external gendered expectations. Furthermore, the treatment decisions made by these women, especially with relation to hormonal contraceptives, suggests a conflict between defying and fitting into different ideals of femininity. Women accept or reject hormonal treatment (referred to as birth control) based on whether their physical/visible symptoms get better and they prioritize these symptoms over reproductivity.

By elevating the perspectives of women, this research challenges traditional narratives about the female body and advances a more comprehensive understanding of the intersections of gender, health, and embodiment in the lived realities of people with PCOS. My positionality as an Indian immigrant woman with PCOS helped me approach this study with both empathy and a critical eye because of my lived experience which acknowledges how intersecting medical, cultural, and social influences affect the experience of PCOS. In this article, I argue that my participants are enmeshed in prevailing webs of medicalized and gendered discourses while I also highlight their resilience and places of resistance.

Polycystic Ovarian Syndrome

Polycystic Ovarian Syndrome or PCOS is a condition characterized by different symptoms of menstrual abnormalities, weight gain and obesity, acne, hair loss, and hirsutism (male hair growth pattern) based on the key feature of an increase in androgen synthesis by the ovaries. It has been stated that this condition is incurable and treatments are mostly directed at masking the symptoms and regulating hormonal functionality (Vrbikova 2012). PCOS is the most frequent endocrinopathy among premenopausal women, the major cause of infertility, and is the most widespread endocrine disorder affecting women (Vrbikova 2012). The diagnosis of androgen excess, which centers on clinical indicators of “increased” male hormones, suggests a problem with PCOS patients’ bodies since they depart from normal gender embodiment.

Oral contraceptive pills, insulin stimulation medicine, and antiandrogens are the most commonly used treatments (Witchel et al. 2019). The first-line treatment options for the clinical signs of PCOS are combined hormonal contraceptives (CHCs). CHCs are believed to help regulate the clinical symptoms of hyperandrogenism and menstrual cycles because they include both an oestrogen and a progestogen component (de Melo et al. 2017). The side effects of routine intake of birth control include mental health problems, high blood pressure, and hypertension (Lucidi 2016). These medicines and lines of treatments are mainly focused on masking symptoms that manifest the dominance of male hormones, which makes this syndrome even more complex. These gendered aspects of treatment suggest that the pathologization and construction of this syndrome is another example of the perpetuation of essentialized ideals of femininity within established medicalized frameworks. Thus, it is important to consider women’s narratives of this condition and their expectations with regards to treatment.

In recent years, PCOS has become a very common “disease” among Indian women (Pruthi 2019) but it is still a condition most people are not aware of and it has been under-explored in research initiatives (Ellerman 2012).. The high incidence of PCOS among Indian women was one of the primary reasons this exploratory research was focused on their experiences.

Research on PCOS

This study explicitly builds on previous research that concentrates on women’s voices to understand what living with PCOS looks like, with an emphasis on studies that have explored how femininity has played out in those experiences.

Studies that focus on how physical symptoms of PCOS affect women’s ideas of femininity mostly observed that participants were concerned about their appearance as a woman. Research on experiences associated with hirsutism highlighted that body and facial hair led to social isolation and rejection by intimate partners and people around the participants (Kitzinger and Willmott 2002; Meyer and Zerksen 1960). Studies that focused on hirsutism highlighted that women were preoccupied with restoring a feminine (hair-free) appearance. For instance, women in Pfister and Rømer’s (2017, 180) study expressed that they feel more feminine when they remove their body hair, as they perceive the hairless body as a symbol of “proper” femininity.

Along with physical appearance, internal functionality was also an important factor for women in various studies. Kitzinger and Willmott conducted interviews with women in the UK and concluded that they were “challenged in their perceptions of themselves as feminine and as women” because of issues with hirsutism, irregular menstruation, and infertility (Kitzinger and Willmott 2002, 358). They also noted that women were also extremely concerned if there were menstrual problems. They either felt different from other women or were worried that their present issues with menstruation may affect their fertility in the future, since regular menstruation is one of the essential definitive elements of a female body (Hennegan et al. 2019). Snyder (2006) investigated experiences of American women with PCOS and discovered that her interviewees believed their PCOS symptoms made them different from other women. The participants said that they had always yearned to be

“normal” which they defined as having a regular menstrual cycle and seeming more feminine. In their study, Meyer and Zerssen (1960) claimed that women with polycystic ovaries had a deep-seated uneasiness about a feminine sex role. In the Kitzinger and Willmott (2002) study, the majority of women discussed not feeling normal and expressed a sense of social separation brought on by irregular or non-existent periods.

Across these various studies, participants prioritized concerns related to their gendered identity, with limited emphasis placed on health as the primary focus. Inspired by these findings, my research explored the common themes that came up, especially feminine appearance, fertility, and treatment. I examined how these themes were viewed by my participants to understand the complexities of femininity for women experiencing a health condition like PCOS.

Theoretical Framework

The theoretical structure in this study was influenced by a social constructionist lens. It utilized a feminist framework to understand gender and bodies. I primarily used theories of “doing” (West and Zimmerman 1987) and “(un)doing gender” (Deutsch 2007; Butler 2004) to understand how women negotiate their gender identities and navigate the treatment process with regards to femininity norms. West and Zimmerman (1987) argue that the social construction of gender is continuous, taking into account “normative conceptions” of men and women (Deutsch 2007, 106). Deutsch (2007) states that people act in certain ways knowing that they will be evaluated based on standards that are applied to their sex category, which dictate what is considered proper for either gender. Deutsch argues that, according to West and Zimmerman, both conforming to and resisting gender norms are examples of doing gender since, by definition, doing gender means behaving “at risk” of being evaluated in accordance with those standards (Deutsch 2007, 109). According to this notion, resistance is rendered invisible by highlighting the definitional similarity of compliance and resistance, where the focus is on the maintenance of the gender order.

Deutsch (2007) questions the application of West and Zimmerman’s theory since it ignores situations when gender is being undone, such as when people’s identities and behaviours undermine gender hierarchies and binaries. The concept of “doing gender” suggests that gender is created through ubiquitous social interactions, but it may also be dismantled and deconstructed (Pecis 2016). As noted by Deutsch (2007), an ethnomethodological approach to gender also entails comprehending the resistance to gendering activities: “It is time to put the spotlight squarely on the social processes that underlie resistance against conventional gender relations and on how successful change in the power dynamics and inequities between men and women can be accomplished” (Deutsch 2007, 107).

Building on Deutsch’s need to recognize the subversive potential of doing gender, this research was also influenced by Butler’s framework of “undoing gender” which contextualizes the complexity of embodied experiences (Butler 2004). In her book *Undoing Gender*, Butler poses a question, or more specifically calls it “a question for ethics,” when one considers not only what makes their own life bearable but also what makes the lives of others bearable. This question illustrates how, for Butler, bodies are not entirely our own and also belong to the social sphere (Butler 2004, 17). The body becomes a social reality which is not only a medium that is used to adapt to the current socio-political and economic conditions but also is used to maintain medicalized and essentialist ideas of female bodies. However, Butler also asserts that while gender serves as the locus for the formation and normalization of the normative binary of masculine and feminine, it can also function as a site for the dismantling and deconstruction of these constructions. In this study, I adopt Butler’s framing of “doing gender” to understand the experiences and decisions of women with PCOS and how they are following and/or rejecting specific ideals of femininity.

To understand the complexity of women’s conformity and resistance to the gendered nature of PCOS, I used Foucault’s concept of medicalization as a guiding framework to understand the construction of the disease and

how medical discourses impact women's decisions (Foucault 1973). Through instruments of femininity and medical management, women with PCOS are persistently forced into surveillance and management of their bodies. Foucault argued extensively that knowledge emanating from social relationships and interaction implicitly promotes behaviours, relationships, and beliefs that lead to creation of discourses in society. These discourses are enhanced by various forms of regulatory processes that ensure that people conform (Frank 2020).

According to Foucault (1973), the normalizing gaze is always at work in an ongoing assessment of one's conformity to these regulatory factors, whether it comes from other people or from one's own self-normalization. McNay (2013) emphasizes that Foucault's concept of disciplinary power helps explain how individuals internalize and enact their own subjugation by embodying social norms. The effectiveness of the normalizing gaze lies in its subtlety; it operates without the need for an external observer, as individuals take on the role of monitoring and regulating themselves. Women with PCOS are often exposed to this normalizing gaze. On one hand they are stigmatized because of visible symptoms or the diagnosis and on the other hand they self-regulate their bodies through different cosmetic or medical solutions.

PCOS bodies are exposed to regulation wherein the conventional treatment consists of inducing artificial hormones into the body. In the study presented here, the notion that the female body is not merely a biological fact but a socially constructed condition shaped by medical interpretations of womanhood serves as a critical framework for examining the treatment-seeking behaviours of women. At the same time, I ask not only on how women are internalizing medicalized and essentialist notions but also whether and how they challenge or resist them.

Methods and Methodology

This qualitative study was informed by a narrative research approach combined with aspects of feminist methodology. By giving voice to women's bodily experience, it served as a platform for feminist research techniques and, in the process, produced experiential knowledge that might broaden this particular area of study. I studied how identity conflicts and treatment choices are created as distinctive parts of the PCOS experience with a focus on personal narratives and perceptions obtained through interviews and focus group discussions (Jarvis 2021). In its most basic form, narrative inquiry starts "with experience as expressed in lived and told stories" and employs narrative as a research methodological tool (Clandinin and Connelly 2000, 40).

As part of my data collection instruments, I conducted in-depth face-to-face semi-structured individual interviews (both in person and virtual) that lasted for an hour. These were followed by a virtual focus group session (comprising six participants) that lasted for ninety minutes, with women who were not part of the interviews. In-depth interviewing helps "to gain insight into how people interpret and order the world" (Milena et al. 2008, 1279). The focus group was useful in "providing in-depth information in a relatively short period of time" (Gundumogula 2020, 299). For both, I used semi-structured questionnaires that focused extensively on women's experiences regarding symptoms, treatments, and relationships. I also used a supplementary method of data collection through a short body mapping exercise which sought to understand participants' experiences of their bodies and lives as well as the significance they attach to these experiences (Lys et al. 2018). At the end of the interviews and the focus group, a body outline was given to the participants, and they were informed that they had complete freedom to add to or draw on it. Participants were asked to associate any kind of feelings, thoughts, or memories they have with their bodies in terms of their PCOS journeys. For virtual interviews and the focus group, the outline was shared through a whiteboard on Zoom.

The sample included a total of 18 Indian and Indo-Canadian women living in Canada within the age category of 20-30 years. The sample focused on women who have been diagnosed with PCOS within the last ten years, to control for the diagnosis time period. Recruitment was done through posters at the campus of University of Alberta to reach out to women who have been diagnosed with PCOS. In addition, social media platforms,

Facebook and Instagram were used for recruitment. Most women identified as immigrant Indians from various parts of the world (India, USA, UAE, and Kenya) however, five women identified as Indo-Canadians who were either born in Canada or have been living in Canada for most of their life and also identified as Canadian citizens.

I used thematic analysis to structure my findings, which allowed me to methodically examine narrative content in order to identify underlying themes that arise from people's stories (Creswell and Poth 2018). All recorded interviews and the focus group discussion were transcribed. Data from the interviews were analyzed first to shape the focus group discussion. Based on the transcripts and the body maps, I extracted themes from the data, which included both open and axial coding. This helped me form categories based on emerging patterns in the data which eventually led to higher-level themes.

Owing to ethical considerations, informed consent was obtained from all the participants after they were given a thorough explanation of the study (Government of Canada 2022). For the focus group, participants signed a confidentiality agreement. The participants were given the opportunity to review the interview transcripts for clarification and to ensure fair representation. I have used pseudonyms to present their narratives to ensure that confidentiality and anonymity of participants was strictly maintained (Government of Canada 2022). All the participants were also informed about the positionality of the researcher and my connection to the research topic. The study was approved by Research Ethics Board 1 at the University of Alberta (ID: Pro 00132200).

Findings: Hierarchies and Priorities

The main finding was that women unconsciously create a symptom hierarchy; they prioritize symptoms of the present—those that are visible to everyone—based on internalized ideas about the female body. They simultaneously do and (un)do gender by prioritizing visible symptoms (conforming to gender norms to look more feminine) over reproductivity (not focusing or conforming to the idea of female functionality). This hierarchy is based on which symptoms they want gone first. Interestingly, women did not wish to conform to the expected norms of being fertile and reproductive for now and were more concerned about looking more “womanly.” The following sections explore three main themes: embodied experiences, experiences in relationships and social interactions, and experiences in medical encounters. These are interrelated and illuminate how my participants view their bodies and make decisions about treatment based on their own embodied experiences and through interactions with others.

Embodied Experiences

According to Bartky (2010, 91), a woman's identity is often closely linked to ideas of femininity and that it takes “skill” to sustain gender normativity. Since people are usually only perceived as male or female, having a body that is perceived as “feminine”—that is, a body that has been socially constructed through appropriate practices—is typically essential to a woman's sense of herself.

Participants in this study express their struggles to become “normal” and the need to correct their bodies. This coincided with Shildrick's (2002) concept of a “differential body,” defined as a body that defies norms in some manner, either in terms of appearance or functionality. Thompson and Stice (2001) discuss how young women with PCOS started pathologizing their experiences by claiming that they were abnormal and needed to be fixed. The idea of “fixing” “differential bodies” was also expressed by participants of this study (Janki and Bhoomika) and was connected to ideas of having a more “feminine” appearance. Women mostly used negative connotations to describe their bodily symptoms. They viewed their body as “different,” which revealed how women had internalized standards of gendered embodiment. Their approach to treatment (discussed below) was influenced by these standards which reveal how these are attempts to adhere to gender norms in terms of physical appearance.

Most participants discussed that they wanted to get rid of the bodily manifestations, specifically hirsutism, acne, and weight gain. For instance, as Anika expressed,

These are like all my problem areas of having facial or like, like my arms here. Like I have a lot of arm hair. And I think it's a bit more than like, my friends. I like would always cover my arms since junior high. I think even now I still like cover my arms. And my legs are also very hairy. I think my legs are like two shades or three shades lighter than the rest of my body because I never show it ... makes me very insecure.

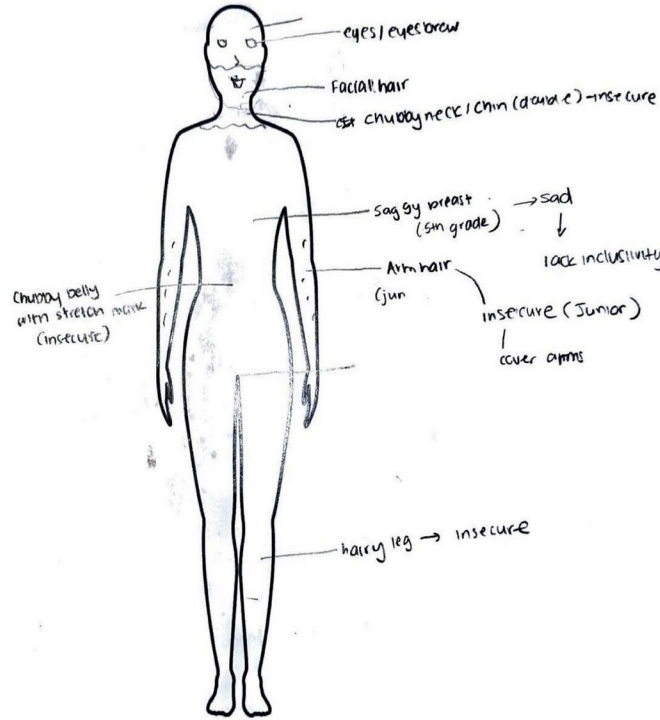


Figure 1: Body map created by Asmi after the in-person interview in response to what she associates with her body in terms of her PCOS journey.

Women were upset since they could not experience “normal” womanhood. Asmi reflects,

Sometimes I feel so much like, I don't feel like a man ever in my life to be compensated, I don't feel like a man. But I also feel like less than a woman sometimes ... I feel like oh, like my hair's falling. Like, my face is like this, not well groomed and stuff. But then especially like, when it comes to shaving, I have to, like, almost shave like every day, just to keep it all.

The use of the word “have to,” which came up in a lot of narratives, perpetuates the idea that women must live up to expectations out of fear of being rejected (Fahs 2014). In her study on women with PCOS, Fabricius claimed that medical discourses on PCOS and how knowledge is situated and internalized by women with PCOS “shape not only their social and material practices, but their very subjectivities” (Fabricius 2020, 110). West and Zimmerman (1987, 137) define “doing gender” as the behaviours, bodily compartments, and daily performances that seemingly establish distinctions between men and women, distinctions that are not inherent, necessary, or biological. For my participants, too, their perspectives were influenced by socio-cultural constructs of embodied femininity, which make them adopt coping strategies to avoid the risks of “gender assessment” (West and Zimmerman 1987, 13) and to mitigate perceptions about their incomplete femininity (Fab-

ricius 2020). These strategies of doing gender can be complex and multidimensional, reflecting how the normalizing gaze works from the inside as well, necessitating a great deal of effort and adaptability from individuals.

In terms of PCOS, since the visible symptoms are clearly evident to everyone, these become significant for assessing if women's appearances conform to the expected gendered norms. When asked about what kind of treatment would be ideal for them, most participants in this study expressed that they wanted to "fix" their appearance. The external body is prioritized over the internal functionality—whether it be having regular menstrual cycles or getting pregnant in the future. Naina shared,

As superficial as it sounds, I would want to fix the external part of it. Because my insecurity stems from very much being outward appearances of PCOS. So, if I could change that, if there was medication to change that I would probably take it in a heartbeat.

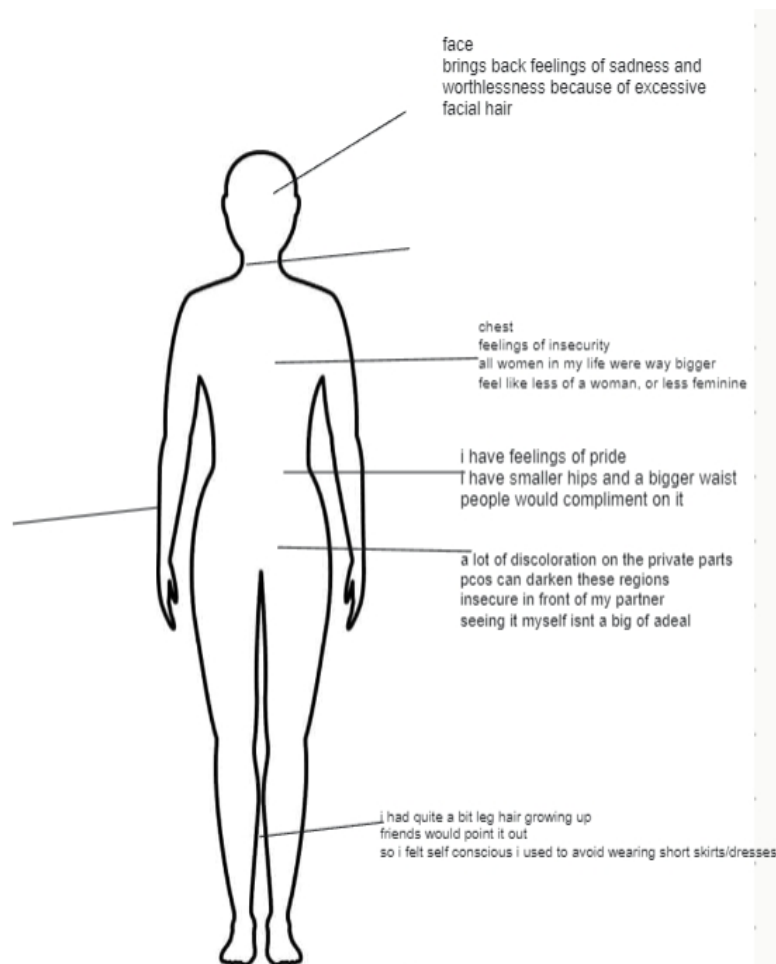


Figure 2: Body map created on the whiteboard by Bhoomika after the virtual interview on Zoom, in response to what she associates with her body in terms of her PCOS journey.

Fabricious' (2020) research shows how PCOS bodies are negotiated intersubjectively and are relational to others. The possibility of infertility is a concern for women in the current study but it is again something relational, i.e., for most of the women it is not a problem that they have to deal with now but in the future which would also impact people close to them. Symptoms that are visible to everyone become the locus of insecurity whereas future concerns become more relational. That is, future concerns will only matter to some people involved (like family and intimate partners) and might not be as evident as external symptoms. Hrithika says,

I do want to have kids in the future. It's not that I don't want to, I feel like this is something I kind of go into denial about ... it's a problem for the future, not now.

Another aspect of contradicting experiences of gender conformity was related to menstrual irregularities. Irregular menstrual cycles were an aspect of concern for most of my participants, which added to their doubts about the internal functionality of their bodies. However, not everyone had similar experiences. Some of my participants, for instance, said that they felt ashamed and believed that they are not feminine because their missed menstruation is a reflection on their gendered identity (Thorpe 2016). However, for Bhoomika and Clarissa, the absence was not a problem and they were more inclined to rectify the external symptoms. They stated how getting an IUD was a huge relief for them since they did not have to deal with the hassles of menstrual cycles or prolonged birth control. They were open to contraceptive methods for their convenience. Tandoğan et al. (2024, 2) argue that “regular menstruation is associated with femininity and fertility.” But these two women resisted the idea of associating femininity with bleeding regularly. It was again based on their preference of dealing with visible symptomatic manifestations.

Experiences from Relationships and Social Interactions

Illness consists of experiences at “levels of self, others and society” (Wright et al. 2020, 1731) and the prevailing societal factors that shape people's understanding of illness also impact how people interpret, respond to, and act upon illness. In this section, I discuss how my participants' embodied experiences were also influenced by their relationships and other people's perspectives. Women shared that irrespective of whether people around them knew about their diagnosis, their physical symptoms like acne, hirsutism and even weight, had always been pointed out and were the subject of scrutiny and social rejection, especially by other women. Bhoomika shared,

So, this brings back feelings of sadness and worthlessness because of like, excessive facial hair growing up, especially because not just once, like, a few times, growing ups, random aunties that we know would comment on it.

Most of the interactions about these physical symptoms circled around the topic of marriage or finding a partner based on how they looked.

It makes things very hard because a lot of things are focused on appearance. It's always about what are people gonna say about you? Like, no one's gonna marry you, like marriage is not my only goal in life! (Mehekdeep)

Some women also reported that they were not concerned about fertility as much as other people were, but shared that there was a sudden pressure on them to be extra careful with their lifestyle.

I have no thoughts about my uterus, man. But people have a lot of thoughts about my uterus. People love to make it my vending machine. (Ayana)

Suddenly, I mattered to them [parents] more. My response wasn't that bad to getting that news. But my parents, they were more like taken aback about it. Because like, they went to all the depth like, oh my god, what if she's infertile? (Aishi)

These women were part of a minority among the participants, who were not worried about having a “functional” body for reproduction.

Having kids is going to be a problem, which, you know what? That's okay. I've had a massive fear of childbirth since I was eight. So, I think it worked out for me in that case, I don't think I could ever physically want to be pregnant. I would give [sic] a surrogate if I had to or even adopt one frankly. (Asha)

These participants' approach to fertility and motherhood is influenced by choice and alternatives to conventional forms of motherhood; however, it is also affected by the stigma of infertility they might face later in their life. This results in an unconscious navigation to future plans to become a mother—the focus may not be on the internal or bodily functionality but is centered on the social role of becoming a mother. These women challenge norms about reproductivity but conform to norms of motherhood.

The women in this study elaborated on how interactions with other people “otherized” them since PCOS might disrupt normal expectations of how their bodies should be and how their life should unfold. First, the symptom manifestations do not align with the ideal image of what a woman should look like. Second, these women have a syndrome that might affect their fertility, and hence they get stigmatized even before they try to get pregnant. These interactions or the people in these interactions act as the “guardians of normalcy” who remind these women that there is something wrong with them, that they are incomplete as women.

Experiences from Medical Encounters and Consultation

Chrisler (2004) expands on Foucault's theory that medicalization defines and upholds standards of health and femininity by extending the power of medical authority into daily life. In alignment with Chrisler's argument, women in this study typically follow strict social norms in an effort to fulfil and maintain conventional notions of femininity which in turn make them prioritize certain health aspects when it comes to treatment for PCOS. In the following sections, I will illuminate how women in this study seek treatment through biomedicine to normalize their bodies according to the internalized gendered notions of femaleness. At the same time, most of the women resist some medicalized notions of femaleness. In other words, the processes of both doing and undoing gender are present in women's narratives.

Health Hierarchy in the Medical System

In this section, I elaborate on how a health hierarchy for the female body is pre-constructed in the medical world. By health hierarchy, I refer to patient-doctor interactions in which doctors focused on reproductivity as the only concern and dismissed all other concerns of my participants. The construction of health hierarchy typically happens because most illnesses or conditions are viewed from biomedical perspectives that perpetuate the standard of normalization (Foucault 1973).

All of the participants in this study expressed that they have been extremely frustrated, confused, and anxious because of their encounters with their doctors. Some participants complained that practitioners failed to appropriately address other symptoms because they placed too much attention on the issue of reproduction. Participants (un)do gender with regards to medicalized health expectations and state that they were more concerned about symptoms that currently affect them or their ability to relate to other women. Reiterating a similar observation made by Kitzinger and Wilmott (2002), some of the women in my research also reported that they believed their doctors either under- or over-diagnosed PCOS. For instance, Ayana shared how the doctor made her feel like a “baby producing machine” and talked about the trivialization of appearance-based symptoms like acne by the doctor.

I went to see the university doctor and I told him that my PCOS is getting really flared up ... my chin hair just erupting, I started getting a lot of acne. And my periods were getting a bit irregular. And then he asked me, “Are you planning to get pregnant anytime soon?”... He was like, if you're not planning

to get pregnant, then we don't need to do anything about it. That was very difficult, because it just made me feel like I'm like a baby producing machine.

Based on her experiences, Ayana read this interaction as one where the doctor's focus was on restoring fertility, which led to the dismissal of other health problems. She states, "At one point, honestly, I was thinking, should I tell him that I am thinking of getting a baby? Because then maybe he will treat it?"

Twenty-year-old Naina talked about how the negligence of the doctor led to her delayed diagnosis.

I was pretty frustrated for the most part.... It just kind of sucked having to go through the Canadian healthcare as a woman because you are always brushed off as it's just stress, you're in school, like you're anxious, that's why you have irregular periods and all of this. But the main reason is that you are young and you don't need to get pregnant

A very clear health hierarchy was evident in the women's narratives about their interactions with doctors, where there was a prioritization of reproductivity. Women's voices remain excluded in the treatment process. The doctors' focus on pregnancy undermined all other problems these women reported and eventually shifted the responsibility of managing this syndrome to the women themselves.

The concepts of standardization, health, and abnormality that underpin biological understandings of PCOS were evident in these medical encounters. In the case of PCOS, it gets more complex since women are not only examined or judged as patients but also as female bodies. If pregnancy was not an issue that these women reported, all other symptom corrections were shifted to their own responsibility.

Navigating Treatment: Rejecting /Accepting Birth Control

As discussed in the previous sections, embodied experiences and interactions with other people influence women's perspective of their bodies and what is more important for them in terms of symptom treatment. In this study, the women rejected or accepted birth control based on how this treatment addressed the symptoms that they prioritized. It is important to note that I did not ask details or the dosage of the medication; however, all my participants used the word "birth control" or "contraceptives" to describe the hormonal treatment they were prescribed. Bhoomika rejected birth control stating that it did not help her the way she expected it to.

Contraceptives were not really useful for me. I got laser treatment done ... that was quite expensive. But honestly, my mental health has really benefited from the lack of facial hair. Yeah, birth control, I was on it. But I found that it like, hindered my weight loss goals. I honestly don't mind spending money on something that actually does something with my symptoms rather than adding more problems in my body.

For the women who rejected birth control, when they were assessing the treatment, they stressed how their feminine appearance was not "fixed" by it. The only time they mentioned health was when they talked about side effects, which were again mostly future possibilities.

Just like the participants who expressed that birth control was not helpful, the participants who reported that birth control was a helpful treatment option in their PCOS journey focused on the femininity aspect more than health. For these women, the fact that the visible symptoms got "fixed" was the most important part. They were definitely satisfied that their menstrual cycles became regular but their contentment was more concentrated on visible physical symptoms. The focus was more on how these "markers" were lessened or absent and how that made them feel like a normal "woman" during these phases when they were on medication. For example, Janki said:

I have a lot of acne, as soon as I leave the pill, like, or if I'm missing pills, I can see that, you know, those differences in my skin. So, now, if I have to take it, it's gonna fix my other problems as well. So, it's balancing the stuff that my body is not able [to do].

Women who took hormonal contraceptives accepted the risks of this treatment because it addressed symptoms they ranked as high priority. The side effects of hormonal pills were secondary to the regulation of womanhood inside the body. This can be related to Irni's approach of "relationality of risk," where the risk of not taking these pills supersedes the risks of taking them (Irni 2017).

Clarissa shared how she plans to remain on birth control in the future since it is an "easy option" for her and that "the only adverse effects would be I'd be hormonal or nauseous or have extreme mood swings for about a month or so until I settled, and then I'd be back at the normal." For her, less facial hair and having periods are more important than experiencing the negative side effects of birth control.

Although these women were (un)doing gender and rejected the idea of fertility and reproductive capacity, they still were doing gender to maintain their physical appearance. There was a conflation of health and femininity. The approach to treatment in these cases is not an attempt to get a healthy body but rather a body that is fulfilled in terms of femininity and womanhood. This is essentially based on ideas of feminine gendered embodiment.

Conclusion

In this article, I argue that women unconsciously create a symptom hierarchy, which has two separate aspects. They prioritize external symptoms of PCOS over reproductivity, which also makes these symptoms become more important than the potential or experienced side effects of taking birth control as a form of treatment. The majority of participants reported that they had faced prominent and sometimes severe side effects of taking birth control, but they still continued with it. In this study, women mostly struggle with phenotypical normative femininity norms (Esteban-Gonzalo et al. 2020). Phrases like "problem areas," "insecurity," "worthlessness," "less feminine" were part of the conversations when asked about specific labels that these women created in the body maps (presented earlier), especially based on symptoms that are visible to everyone. There was a clear prioritizing of less body and facial hair growth, less acne, a slimmer body, and regular menstrual cycles over the side effects and other health problems that could have been caused by the treatment. Women conform to gender norms and "do gender" through this prioritization by complying with ideas of how a female body should look. At the same time, they challenge the essentialized and medicalized norms of how a female body should function and, in that process, "undo gender." Hence, women's efforts to get rid of any "unfeminine" symptoms are about both conforming to and challenging gendered norms of the female body.

It is important to note that resistance becomes contextual for PCOS bodies. While women may internalize socially constructed narratives that objectify them through appearance-based ideals, some women actively reinterpret these ideals as strategies of resistance in relation to fertility and constructions of womanhood. Their narratives in this study show how the female body is a site of negotiation, contradiction, and agency. Women might fall into the cycle of reinforcing ideals of feminine appearance, but they resist the essentialization of their body just for procreation. The processes of doing and undoing gender are negotiated by the women through the conflation of femininity and health. In terms of identity, women in this study express that they always experience a state of liminality, a condition of ambiguity and uncertainty in which they feel difficult to categorize themselves. They are always trying to "be a woman" which suggests that, with the symptoms and treatment, they do not see themselves as a complete woman. This state of liminality can also be seen as an opportunity to resist gendered conceptions of bodies both in terms of health and femininity. It can lead to the questioning of the "ideal female body."

As Oksala asserts, “Power inscribes the limits of normal bodily experiences, but it is exactly the existence of these limits that makes their transgression possible” (Oksala 2004, 108) . This study argues that dominant views of the female body—where femininity is equated with reproductive norms and standards of feminine appearance—are challenged but also accepted by some women. The experiences of women with PCOS shows that they resist and reshape these norms, offering more complex understandings of womanhood. Illness narratives over the last few decades have demonstrated the importance of patient accounts in expanding the body of knowledge (Bennett et al. 2020). This research study provided a platform for self-reflection for these women and showed how experiential knowledge resists the medical paradigm and essentialized expectations of the female body. My participants’ notions of what is more important when it comes to identifying as a woman may serve as an analytical lens to reframe our understanding of gendered health conditions. These not only challenge medical norms but might also serve as a pathway for healing where women relate to others beyond their predetermined reproductive role.

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