Woman Enough?

How Online PCOS Counterpublics Make Space for Alternative Femininities

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Abstract:

Polycystic Ovary Syndrome (PCOS) is a common hormonal condition that affects both the health and physical appearance of women with the condition, often in ways that disturb or go against traditional notions of femininity. In recent years, research on the topic of PCOS and social media use has been explored. Still, studies have yet to examine how women with PCOS utilize these online communities to navigate their gender expression. This study builds on gender performativity and counterpublic theory to make sense of how femininity is negotiated within online PCOS spaces. The data for this study was collected via two semi-structured group interviews and participant observation in a PCOS subreddit. After data was collected, a deductive thematic analysis was conducted to find patterns present in both the interviews and digital discourse. Findings from this analysis revealed that many women with PCOS feel pressured into performing a certain standard of femininity. Failure to perform femininity properly often resulted in social correction for the participants. Online counterpublics, such as Reddit, however, offer safe spaces for gender norms and societal pressures to be questioned and resisted without shame. This research illustrates the power of these spaces by positioning online PCOS communities as necessary counterpublics, fostering environments accepting of alternative gender performance, and providing members with a sense of relief and recognition.

Keywords: *Counterpublics, Femininity, Gender Performativity, Polycystic Ovary Syndrome*

1. Introduction

Polycystic ovarian syndrome, or PCOS, is the most common endocrine disorder affecting women and assigned-female-at-birth (AFAB) individuals of a reproductive age. Despite the condition's prevalence, an estimated 70% of symptomatic individuals remain undiagnosed (Yasmin et al., 2022), with the individuals who are fortunate enough to receive a diagnosis often reporting dissatisfaction with the quality of information and lack of support received (Gibson-Helm et al., 2016). Much of the medical research and discourse surrounding PCOS centers on physiological aspects of the condition, paying particular attention to its impact on fertility, menstrual cycles, and metabolic health. As a result, many patients with PCOS report feeling as though their emotional and mental needs are overlooked in clinical settings.

As a chronic condition characterized by symptoms such as painful and/or irregular menstruation, infertility, heightened levels of testosterone, acne, hirsutism (excessive hairiness), weight gain or difficulty losing weight, and androgenic alopecia, PCOS challenges dominant gender imaginaries. These symptoms can often lead to feelings of low self-esteem, negative body image, and disconnection from gender identity, particularly among cisgender women who are expected to perform a certain standard of femininity. The inability to perfectly conform to such narrow perceptions of womanhood creates a confusing and complex relationship with gender expression. As previous research on the topic of gender has shown, gender is socially constructed through performance, or a series of repeated acts and expressions that correlate to your expected gender roles and expectations (Butler, 1999). Failing to perform these roles and expectations, such as childbirth and hairlessness, can result in shame and lead to real-world consequences for women with PCOS.

Many women with PCOS turn to online platforms in order to find community and address the pressures associated with performing femininity. Subreddits and Facebook support groups house these women, providing a safe space to share and explore alternate discourses, especially those relating to unique gendered experiences. Within these PCOS-specific forums, conversations surrounding gender identity, which are often absent from the mainstream public sphere, can be discussed in a supportive and non-judgemental manner. Women in these platforms are free to discuss neglected and taboo topics such as chest hair and male-pattern hair loss. In doing so, participating in the creation of new embodied knowledge and understanding. As a condition that is distinctly heterogeneous in nature, PCOS has been the root of significant medical and public confusion throughout the decades. This misunderstanding makes it difficult for those without PCOS to relate to or accept the ways in which PCOS can cause a woman's body to fall out of sync with its socially expected functions. Hence, the desire for women with PCOS to be among their peers online. This research positions these online spaces not only as easily accessible support networks, but as critical counterpublics that have emerged in response to the denigration of non-normative gender performance taking place outside of them.

2. Research Aim and Problem Statement

This study explores how PCOS-specific online spaces, hereinafter referred to as online PCOS counterpublics, provide space for women with PCOS to collectively negotiate normative ideals of femininity and practice alternative forms of gender expression. Although existing research has covered PCOS in relation to gender expression, as well as PCOS and online social media use separately, the intersection of these two topics remains under-examined. The aim of this research is to bridge the gap between these two conversations by situating online PCOS forums in Counterpublic theory, arguing that these spaces are integral when it comes to creating normalcy around the gendered performances of women with PCOS.

Through the utilization of counterpublic theory and the theory of gender performativity, this study establishes online PCOS forums, mainly Reddit, as spaces where participants question, resist, reflect on, and rearticulate femininity in sometimes contradictory ways. The main goal of this research is to determine what membership in these groups offers the informants that they are unable to find in other spaces. By examining what these online platforms offer that offline environments do not, the study explores the ways in which the online counterpublic has become a necessary tool for negotiating one's gender. More specifically, this research asks:

How do online PCOS counterpublics enable women with the condition to explore and negotiate alternative gender performances?

3. Theoretical Framework

This research will work to contextualize online PCOS communities by viewing them in relation to broader discourses surrounding gender and counterpublics. In doing so, emphasizing the ways in which these spaces serve as sites where participants are encouraged to question, reframe, negotiate, and even resist dominant narratives. By grounding the study in the theories of gender performativity and online counterpublics, the aim is to formulate a critical lens through which to analyze the discursive and embodied practices emerging in these communities.

Following this lens, the study contributes to the conversation by paying particular attention to how gender expression is negotiated within digital communities that function outside of dominant public discourses. More specifically, this research aims to prove that these spaces are not merely support groups or coping tools, but rather counterpublics that support an environment of collective meaning-making and resistance to gender norms.

The following section proceeds in three parts. First, Judith Butler's theory of gender performativity is examined as a central analytical lens so as to demonstrate how PCOS disrupts normative ideals of femininity. This segment focuses on how PCOS symptoms, such as

hirsutism, can make it challenging to perform gender in the coherent and "feminine" manner that is expected. Second, existing scholarship on counterpublics is explored, pulling specifically from Nancy Fraser and Michael Warner as well as more recent conceptualizations of online counterpublics. This segment works to frame PCOS spaces as alternate discursive arenas that enable participants to articulate experiences and perspectives that are often marginalized or ignored within dominant public spheres. Finally, the two theories are brought together to illustrate how online PCOS communities constitute counterpublics through their ability to facilitate discussions surrounding gender and femininity that might not otherwise occur.

3.1 Gender Performativity

Failure to conform to gendered expectations, both online and in person, can create the potential for social backlash, underscoring Judith Butler's theory that gender is a performance. Butler's ideas subvert early feminist texts by claiming that a stable category of "woman" does not exist. Instead, Butler claims that gender is enacted through repeated acts and "performances." As Butler puts it, "There is no gender identity behind the expressions of gender; that identity is performatively constituted by the very 'expressions' that are said to be its results (Butler, 1999, p. 33).

The ability to perform one's gender is especially significant when many cultures expect a certain degree of gender coherence. Gender coherence can best be understood as the societal expectation for one's sex, gender, and gender performance to all be aligned and consistent. Butler's framework of gender performativity, and the concept of gender coherence, will be particularly relevant when it comes to understanding how women with PCOS navigate their gender expression while constantly confronted with societal expectations.

Although Butler's theory of gender performance has been extended in many directions, this study will concentrate on interpretations that emphasize embodied acts of negotiation. The repetition of gendered acts that Butler describes is not always simple or innate. Understanding the active negotiation that is involved in gender performance will allow for a more nuanced analysis of the simultaneous resistance and reinforcement of normative femininity that takes place in online PCOS counterpublics.

To make sense of this study, clarification of the phrase "normative ideals of femininity" is crucial, particularly when it comes to interpreting how these ideals inform expectations around gender performance. Normative or dominant ideals are those which tend to insist women be hairless, thin, fertile, and so forth. Many symptoms of PCOS, however, can make it difficult to abide by these expectations, as the body can fall out of sync with the strict rules of femininity. One previously conducted study, linking Butler's theory of gender performativity with the experiences of women with PCOS, brings this challenge to light. In "*It's Not Very Feminine to Have a Mustache: Experiences of Danish Women with Polycystic Ovary Syndrome*," Pfister and Romer utilize Butler's framework to make sense of the pressures women with PCOS face to conform. They also consider the negotiation that takes place when women with PCOS make

decisions between "correcting" their appearance to fit in and challenging "the heterosexual matrix by doing gender in a different way" (Pfister & Romer, 2017, p. 172).

For many individuals with PCOS, there is an ongoing effort required when negotiating which societal expectations demand compliance in order to be deemed "presentable." One woman in Denmark noted that "[she] must make sure to remove hair on a daily basis (Pfister & Romer, 2017, p. 176). While another shared that she felt a sense of jealousy when she thought about women with light hair who did not need to shave so often. She felt bothered by her "dark stubble" but then went on to say that at least she did not have a mustache (Pfister & Romer, 2017). Facial hair is a common trait among individuals with PCOS. Despite being so common, however, femininity is often intertwined with hairlessness. The participants' comments reveal that there are "acceptable" and "unacceptable" deviations from femininity. In her case, having darker hair was far preferable to having a mustache.

The above accounts highlight the intense policing that takes place of women's bodies and appearances. And as this research aims to show, the negotiation and performance of gender are not confined to physical spaces. Chib et al's (2021) work on gender performativity in online strategies of trans sex workers offers a strong framework to help clarify digital negotiations. Although the context of this study differs significantly, they provide a strong argument as to how online spaces create avenues for individuals to perform their gender in more fluid ways. Chib et al. position Tumblr, as well as other online forums, as counterpublics and sources of "agentic resistance" for transgender people. Within these communities, "gender performativity…manifests in the presentation of both essentialist (submissive femininity) and provocative (hyper-sexual) embodiments, defying simplistic characterization into the structure-agency dynamic" (Chib et al, 2021, p. 55). Transgender users in these forums subvert binary gender norms by actively navigating and deliberately choosing which norms or standards of femininity to embody and which to defy. In this way, their performance is "agentic" as it allows for some level of control on their part. Similarly, women in PCOS forums perform and resist femininity in complex and often contradictory ways. The PCOS counterpublic is not solely a place of empowerment. Instead, it is a space where normative ideals such as those tied to thinness, body hair, and fertility, are both contested and at times, reproduced. In a singular post, a woman may celebrate her success with removing body hair via electrolysis while simultaneously scorning the misogynistic beauty standards that made her feel the need to do so in the first place. The PCOS counterpublic becomes a place where individuals from all over the world are free to share and perform femininity in a multitude of ways. Some users post about embracing their chin hairs and are met with validation and support. Others seek out advice on weight loss and are met with PCOS-specific meal plans in the comments. And many women turn to the online forum to determine which aspects of femininity they want to embody and which they want to reject.

Just as Chib et al. question whether the content shared in trans online spaces is empowering or discriminatory, the posts within the PCOS counterpublic can be interpreted in many ways. At first glance, some conversations and interactions may appear to reproduce dominant gender norms. However, these discussions also function as practices of community care and validation.

There is a form of everyday resistance at play, even when women reach out to ask for the best supplements to take to reduce androgens. They are normalizing feminine experiences that fall outside of normative femininity. Just as Chib et al. prove, fluid online performances of gender are actually "provocative online behaviors that can counteract marginalization" (Chib et al., 2021, p. 67). These fluid performances, coupled with the social consequences that arise when gender is done "wrong," become especially visible in online spaces where alternative narratives are freely voiced.

3.2 Counterpublics

Counterpublic theory offers a compelling lens by which to further explore the ways in which gender performance is shaped and negotiated. This study utilizes counterpublic theory to argue that online PCOS communities constitute necessary counterpublics, operating as alternative discursive spaces in which to discuss gender differently. To begin, this section outlines the concept of the "counterpublic" as theorized through the works of Nancy Fraser and Michael Warner. In *Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy,* Fraser notes that the original conception of the Public Sphere, as defined by Jürgen Habermas, is exclusionary to marginalized groups. She argues that the traditional notion of the public sphere fails to create space for the sharing of diverse perspectives, ignoring the existence of structural inequalities by suggesting that all citizens have equal access to public discourse. This ideal of the public sphere as a place for finding common interests and equal representation assumes that everyone enters the public sphere on the same footing. In order to combat this supposition, Fraser utilizes a feminist framework to emphasize how women in particular have been disregarded in the public square. She explains that masculinist gender constructs are not yet absent from the public sphere. Consequently, access to public forums does not denote meaningful participation, especially when women have struggled to participate in public discourse even when given the opportunity.

Both Fraser and Warner highlight how Habermas's belief that individuals can come together and bracket their differences for the purposes of "rational" discussion is faulty. The very idea of "rational" discourse is alienating in that it presupposes a right and a wrong way to do discourse, ultimately upholding a mode of knowledge production that privileges masculine perspectives. Michael Warner expands on this more in *Publics and Counterpublics* where he acknowledges how the gender and sexuality movements do not always coincide with the "rational-critical debate" model (Warner, 2005). He claims that "It is not possible to assume … rational-critical debate is a neutral, relatively disembodied procedure for addressing common concerns, while embodied life is assumed to be private" (Warner, 2005, p. 51). For instance, many women's health concerns can not be properly addressed without the inclusion of gendered and embodied knowledge. Yet talks of menstrual cycles, fertility issues, and hormonal disorders such as PCOS have been dismissed as too "private," and have therefore struggled to gain visibility in the public sphere. But in online spaces, spaces crafted specifically for individuals

with PCOS, these topics receive a great deal of attention. Counterpublic theory highlights the importance of creating spaces that resist dominant norms and center experiences that are usually ignored. It also offers insight into new ways to legitimize diverse experiences of gender expression and make room for those whose voices have been overshadowed. Thus, the creation of alternate discursive spaces, or counterpublics, is vital.

Building on Fraser and Warner's critiques of the traditional public sphere, many contemporary scholars have taken to envisioning new forms of counterpublics, namely those situated within the digital realm. For the purposes of this study, Graham and Smith's analysis of Black Twitter in "The Content of Our #Characters: Black Twitter as a Counterpublic," will be cited as a key reference. Their work contributes to the theory of online counterpublics by combining aspects of digital sociology with discussions of race and ethnicity. More specifically, their research offers a framework for understanding how marginalized groups can utilize social media platforms for the sake of identity formation, community building, and the resisting and reshaping of dominant norms. Similarly, this study covers an intersection by examining how PCOS and gendered experiences are negotiated within online counterpublics.

Graham and Smith make several key arguments within their article that can be applied to the case of PCOS counterpublics. For instance, they note that according to Fraser's own definition, counterpublics should act as "spaces of withdrawal and regroupment" (Fraser,1990, p. 68). In the case of PCOS-related forums, specifically subreddit pages and Facebook groups, there is an expectation that members either have PCOS or strong suspicions that they do. In other words, there is an assumption of shared lived experiences. The forums are created to operate outside of the mainstream, offering space to step back and focus on shared interests and identities. And as per Warner's interpretation, they are also spaces that generate new rules, practices, and values that differ from those within the dominant public sphere. Warner argued that counterpublics are not merely oppositional, but productive and transformative. PCOS subreddit pages and Facebook groups take on this productive element through the establishment of their own internal community guidelines. Rules regarding what can and cannot be posted, the rejection of promotional content, and the moderation of non inclusive or hurtful language all make for a distinctive discursive space.

Returning to Graham and Smith's analysis, another way they demonstrate that Black Twitter constitutes an online counterpublic is through their investigation into the exact content being discussed in Black Twitter. They state that within it, "there [is] not just a different perspective on issues, but different issues [being] discussed altogether" (Graham & Smith, 2016, p. 446). Similarly, in PCOS forums, the topics discussed deviate from more mainstream discourse. Much of the readily available information and conversation surrounding PCOS adopt a heavily medical tone, revolving around infertility and symptom management. In online forums, however, women can share their experiences with male-pattern baldness, facial hair, weight gain, and even irregular breast shapes. Unique gendered experiences, often ignored in clinical settings, can be discussed in depth. In this way, the digital environment possesses an unexpected social weight, as individuals come together to better understand themselves and their experiences in the

real-world. Graham and Smith make it clear that Black Twitter is more than hashtags and online chatting. Instead, they bear in mind that "the interactions on Twitter can be of consequence to African Americans in areas outside of that social media platform" (Graham & Smith, 2016, p. 446). If a woman with PCOS were to post a photo of her beard outside of a PCOS-specific forum, she might be met with ridicule or even social backlash. Alternatively, within an online PCOS group, she is much more likely to find support, validation, and perhaps even a sense of normalcy. In other words, a failure to perform femininity "correctly" on the wrong platform can have real consequences, both socially and mentally.

3.3 Connecting Frameworks

Nancy Fraser refers to counterpublics as "bases and training grounds for agitational activities directed towards wider publics" (Fraser, 1990, p. 68). While the online forums discussed in this study do not constitute large movements explicitly working to undermine or takedown normative femininity, they do function as discursive training grounds. Within the bubble of the online PCOS counterpublic women are taught, via their peers, to think differently about themselves. New ways of performing gender are made possible when women speak with other women whose experiences mirror their own. Ultimately, framing online PCOS forums through the lens of gender performativity and counterpublic theory, particularly as extended to digital spaces, allows for an interpreting of these spaces not just as supportive communities but as ambiguous sites of embodied knowledge sharing and resistance to the overly rigid practices of gender coherence. The theoretical framework provided is evidence that online PCOS communities do not need to be radical to be significant, but rather offer safe spaces to voice the feelings and experiences that might otherwise remain unsayable in dominant public spheres.

4. Methods

4.1 Research Design

This study employed a phenomenological research design in order to explore the ways in which PCOS affects the gender expression of women with the condition, while also examining the importance of PCOS-specific online forums in navigating these experiences. Phenomenology focuses on intersubjectivity and explores how individuals make sense of their shared experiences. The study aligned with this approach by investigating how the shared experiences that come with having PCOS are processed collectively by members of the online counterpublic. Collecting data from group interviews as well as posts from an online forum allowed for the interpreting of both individual reflections and group dialogues on the topic of gender expression.

Utilizing qualitative methods in order to prioritize the voices of each participant was essential to the study. A phenomenological design, in particular, aligned best with the goal of emphasizing the importance of embodied experiences and participant perspectives.

Phenomenological research often lends itself to interviews in an effort to gather research that is rich, detailed, and truly captures the lived experiences of the participants. To follow this design, group interviews were combined with online participant observation. First, a series of small group interviews to gather the in-depth personal narratives of the participants were conducted. Bringing participants together in an online group setting created the space for them to interact and examine the extent to which their experiences reflect a broader social phenomena. This stage of group interviews was integral in determining how counterpublics can act as spaces for reflexivity, providing each participant with the opportunity to think about their own experiences in relation to others. Next, in order to capture even more depth, participant observation took place within a PCOS subreddit. Combining these two methods specifically acted as a form of triangulation, comparing participant narratives to digital interactions.

4.2 Researcher Positionality

As a woman diagnosed with PCOS nearly seven years ago, I began this research with an embodied understanding of many of the challenges described by the participants. Reflecting on my own experiences with gender performance helped to guide the design of the study and allowed me to empathize and relate to the participants on a deeper level. Sharing selective details of my own PCOS journey with Participants during interviews helped to strengthen trust and foster a more comfortable environment for them to share in. Still, these personal disclosures were offered sparingly and chosen with intention so as to not risk projecting my own assumptions and perspectives onto the interviewees. After multiple women had discussed grappling with feelings of diminished femininity, I occasionally chose to share a brief account from my own life. A story about choosing to change in the bathroom rather than the school locker room before and after gym class to hide body hair, for instance, illustrated a shared understanding and could then be used to invite further reflection. At times, these moments also served as transitions into follow-up questions surrounding social interactions or social pressures.

My position as a researcher combined with first-hand experiences with many of the issues brought up in interviews, meant that I occupied a dual positionality throughout this study. This dual positionality as both an “outsider” as the researcher and an “insider” through shared diagnosis, created a tangled dynamic that I recognized at the outset of the study. In order to maintain a sense of rigor and ensure that my own experiences did not seep into the data, a reflexive approach was taken. By staying attentive to the implications of dual positionality and reflecting throughout, I remained aware of the power dynamics involved and worked to prioritize the participants' perspectives.

4.3 Participant Recruitment

Participants were recruited via a scouting survey posted to various public PCOS forums and support groups on Reddit and Facebook. The survey was created using Google Forms to ensure accessibility as it did not require participants to sign in. It was created to collect basic demographic information such as age and gender identity, and it consisted of seven short questions. Survey respondents were informed that the purpose of the form was to gauge interest in participating in a small group interview. Their responses to the survey, including time zones, served as a way to ascertain general availability. Using the email addresses provided, a Doodle link with multiple date and time options was sent out to participants so that groups could be scheduled. Respondents were made aware of the fact that survey responses would be deleted within six weeks of participant selection.

Ultimately, the amount of group interviews held, as well as the composition of each group, was determined by the responses to the scouting survey. Given the online nature of recruitment, a snowball sample approach could not be followed. Instead, respondents who expressed interest in the study and were able to join one of the scheduled group interview sessions were selected.

4.4 Group Interviews

The primary method of data collection for this study consisted of two small group interviews conducted over Zoom. Group 1 included three interviewees from different continents and time zones, and Group 2 included four. Both sessions lasted between 60-90 minutes and were conducted in English. Audio from the interviews was recorded on a separate device (with informed consent), and participants were asked, but not required, to turn on their cameras to create a more comfortable exchange. In both interviews all participants chose to have their cameras on, making up for some of the emotion and connection that can be lost in online interviews. The environment fostered within these calls proved to be supportive and welcoming of vulnerability and sharing. And the decision to hold smaller groups ensured a feeling of intimacy and was less intimidating for the participants.

Group Interviews were semi-structured and were guided by a set of prepared questions as well as a topic list that had been prepared in advance. Questions and topics selected for the interviews were influenced by preliminary themes discovered within online communities and academic literature. Conversations centered around gender expression and relationships to femininity as well as the digital community engagement of the participants. Prior to the interview date, participants received a confirmation email providing a brief overview of some of the themes to be discussed. The purpose of this email was to allow the interviewees time to reflect and reduce some of the pressure they might feel before joining a group interview.

The decision to conduct group interviews over one-on-one interviews was driven by their potential to foster collective meaning-making and allow for meaningful interactions between participants. Observing the exchanges taking place between interviewees provided insight into the ways women with PCOS collectively navigate complex subjects such as gender expression.

4.5 Participant Observation

In order to triangulate the data collected from the two interviews, participant observation was conducted within the r/PCOS subreddit group. Over a period of one month, posts and comment threads relating to gender expression, femininity, body image, and identity were monitored and coded. The data collection process was designed to take on a non-intrusive approach, with Reddit serving as the sole observational platform. Unlike with PCOS-related Facebook groups that tend to restrict access and require membership to view posts, all posts and comment threads within the subreddit were publicly accessible. Still, any identifiable information was removed from the final data.

Findings from these observations were recorded and compiled into a detailed codebook. The codebook includes anonymized quotes taken directly from subreddit posts, contextual replies to demonstrate interactions, applied codes, and notes. In order to better structure the findings, codes from the data were grouped and organized into four key themes that occurred most frequently. For instance, codes such as negative body image, bodily betrayal, and social correction were grouped under the theme *Disruption of Femininity*. Codes that were less prominent or unrelated to the research question were eliminated from the final analysis. The four key themes explored within the posts included:

- Disruption of Femininity
- Compliance and Resistance
- Counterpublics as Relief & Support
- Medical Dismissal

Each post discovered during the one month period was coded using this framework. Memo-writing was also employed during the collection of data to keep a written record of ideas and reflections throughout the process. Codes from the posts were later compared with those from the interviews to identify shared patterns and determine which themes and discussions were most prominent. Comparing the data from the interviews to the data collected during participant observation ensured that the findings were grounded in the participants' perspectives rather than researcher assumption.

4.6 Data Analysis

Both group interviews were transcribed using Otter. AI and analyzed using deductive thematic analysis. Prior to collecting the data, a list of predetermined themes informed by the research question, review of relevant literature, and preliminary observations of online forums was created. The initial themes provided a framework for the coding process and shaped what patterns were to be sought out in the data.

As the coding process began, both of the interview transcripts and subreddit posts, attention was paid to the ways in which the data aligned with, challenged, or generally expanded upon the initial themes. In this way, the coding was used to assess whether or not the patterns I had expected to find were truly reflected in the data. It offered validation and ensured that the

themes were an accurate reflection of the participants' experiences. So while the analysis was mainly deductive, it still allowed for the revealing of emergent insights that added nuance to the thematic structure. Particular focus was given to moments in interviews and posts that revealed shared phrasing and feelings surrounding the topic of gender expression and diminished femininity. These patterns helped highlight the ways individuals with PCOS make sense of their unique gender expressions, both on their own and as a collective within online spaces.

4.7 Ethical Considerations

Given the sensitive nature of the topic at hand, the protection of participant data was of utmost importance throughout this process. All participants received a digital consent form prior to the interviews that provided a description of the study, the recording process, and how their data would be handled. Participants were also made aware of the fact that they would be able to skip questions, request for certain contributions to be removed, or withdraw from the interview at any time. They were reminded of this information once more before the interviews began. Recordings from each interview were taken on a separate device so not as to rely on a conferencing platform to tape sensitive information. Interview recordings, as well as other sensitive information collected during the process, were stored safely in OneDrive and accessible only to the researcher. Names as well as any other identifying information were removed during transcription, and pseudonyms were created and used for the findings.

5. Findings

The following section reviews findings from two group interviews as well as a month's worth of posts collected from the r/PCOS subreddit. While all of the data collected informs this research, the analysis focuses on instances from discussions and posts that were the most generative in terms of exploring how women with PCOS navigate and negotiate their femininity, both in their day-to-day lives and within the online PCOS counterpublic. The analysis is structured around three key themes that emerged across both interviews and posts. First, moments where participants discuss feeling less feminine or as though their bodies are working against certain gendered standards are explored. Phrases such as "different" or "not like other girls/women" that appeared across the data are examined here. Second, I highlight instances where the tension between adhering to gender norms and resisting them is present. Many women expressed frustrations with the "oppressive" and "strict" standards that women are held to while simultaneously desiring to better fit in. After discussing this paradox, the role of the online counterpublic is further examined. How does this digital space serve as a refuge? How do women come together here to interact and make sense of these negotiations? The full impact of the online PCOS counterpublic is brought to light before delving into further conclusions and limitations regarding the study.

It is important to note that not all participants were impacted by PCOS in the same way. Although all participants described either struggles with body image issues or feeling unfeminine at some time or another, their experiences were quite diverse. For some, symptoms such as hirsutism were the main concern. For others, struggles with weight gain, infertility, or irregular menstrual cycles were their main source of insecurity. This analysis does not select one symptom to focus on but rather attends to the broader question of how participants make sense of a wide array of symptoms and find ways to navigate gendered expectations through online engagement. In doing so, this analysis also pays close attention to moments of what I will hereby refer to as "social correction." Social correction will be used to capture subtle, although sometimes more overt, moments where individuals without PCOS attempt to fix or guide the appearances of participants. While social correction is mostly done without malicious intent, the suggestions and tips given by those without PCOS often reinforce narrow standards of femininity. Overall, the social pressure and outside commentary touched upon in this section speaks to the broader need for women with PCOS to seek out commonality and support in online forums. As the findings reveal, the online PCOS counterpublic offers a rare safe space to talk about and practice alternative ways of doing femininity.

5.1 Bodily Betrayal and the Disruption of Femininity

Pressure to Perform

Interviewees and subreddit posters alike described feeling less feminine at times. The different symptoms of PCOS, as reflected in the data, can make it so that the body deviates from dominant norms surrounding feminine appearance and behavior. This disruption challenges gender coherence, at times compelling women with PCOS to work harder in their performative efforts to assert their femininity in social contexts. Olivia explains how she sometimes goes along with what other women are saying, even when she can't relate:

> But I think with other people I meet, I just pretend I have the same problems. If people mentioned having periods or pregnancy scares I'm like, "Oh yeah, definitely." Because I just don't even want to get into it… I think because it is a bit of a sore spot that I am, like, different, or like, I'm not the same as them, or like, woman enough that I have the same problem. (Olivia)

Here, Olivia refers to the discomfort that arises from confronting differences between herself and other women who do not have PCOS. Rather than deal with the ramifications of facing this difference head-on, she chooses to "pretend" to be the same, performing a version of femininity that she feels is expected of her. This interaction echoes Judith Butler's concept of gender as a repeated performance. Although Olivia's experiences differ from those of her peers, she decides in this moment to act out a more socially acceptable version of womanhood so as to ensure that her gender identity is affirmed. Like Olivia, many women with PCOS express concern about how others might react should they find out their bodies function differently from those of other women. For Eileen, this fear of judgment became a reality. After struggling to conceive with her

former partner, she decided to share her diagnosis with his family with the hope of receiving support and understanding. Instead, she had the misfortune of hearing deeply stigmatizing remarks.

> We decided to be open with that person's family and let them know, like, hey, you know, she has PCOS, and this is something that might take a while. Of course, you know, everybody gossips, whatever. But I overheard the aunts and the grandma commenting, "Oh, well what kind of woman can she be if she can't conceive, if she can't give birth?" …So at that point, hearing that, I was rock bottom [with] my depression. Yeah, I wasn't going anywhere. I refused to go outside. I refused to eat. And in my head, I was really believing these things, that not being able to conceive or have a child doesn't make me a woman. (Eileen)

Eileen's experience illustrates how a woman's inability to fulfil her expected reproductive roles can lead not only to social backlash but to an identity crisis as well. Butler describes femininity as being socially constructed and socially enforced. With this example we can see how women's bodies are policed. The aunts and grandma learned that to be a woman means to perform certain duties, such as childbirth. Eileen's inability to give birth "the natural way" put her identity in question. Together, Olivia and Eileen's stories illustrate how performing gender in a way that does not align with normative expectations can lead to social consequences. Whether these differences are concealed, like with Olivia, or confronted, like with Eileen, the risk of being placed in a deeply uncomfortable position or having one's identity questioned altogether remains.

Social Correction

Outside the bubble of the online PCOS counterpublic, misunderstandings and misinformation surrounding PCOS are common. Zoe, who identifies weight gain as her primary insecurity, observes how many of her female friends are "on the shot." She describes them as "very feminine" and engaging in "stereotypically feminine stuff." They often share their success stories and urge her to get on "the shot" to lose weight as well. She doesn't want to explain that her PCOS makes it more difficult to lose weight. But she doesn't expect her friends to understand her lived experiences. How could they? "I don't think my girlfriends even know about what Jolene [a hair bleaching cream] is!" (Zoe). Like Zoe's friends, many without PCOS try to offer advice despite not knowing very much about the condition.

> And I've kind of had this experience, especially when I was a teen, of when you don't fit that standard, other girls like to kind of try to make changes to you, not in a cruel way. I think it comes from a good place or, you know, just from a place of curiosity. I was really masculine as a teen, you know, I was mistaken for a boy pretty frequently. I can't tell you how many times I got called young man. And I had a lot of very feminine friends and I kind of had this experience of whenever they would see how hairy I was, or whenever my hair got a little long and I wanted to cut it short again, or the fact that I just didn't pluck my

> eyebrows, or wear makeup, they would get together and they'd be like, can you let us do your nails, or do your eyebrows, your eyelashes, or, hey, here's some shaving tips. (Violet)

During the interview, Violet described feeling as though her "lack of femininity" has barred her from social experiences with other girls. She mentions feeling embarrassed when she applies makeup because "[her] PCOS makes [her] feel kind of like an imposter when [she tries] to present [herself] more femininely" (Violet). This sense of impostorhood stems from a struggle to align with normative femininity. Even a small deviation, such as not wearing makeup, can be a disruption to one's sense of belonging within their gender. This pattern of feeling less feminine or shut out from certain aspects of womanhood is not unique to the interviewees. Reddit posters frequently express similar sentiments of feeling like "less of a woman." Additional examples of posts from the subreddit that reinforce this theme, organized within a codebook, can be found in the appendix.

5.2 Compliance and Resistance: Navigating the Performance

While the previous section highlighted the ways PCOS can disrupt the performance of femininity, this section turns its attention to the ways women with PCOS navigate, resist, and sometimes adhere to gendered expectations. Many interviewees showed signs of an internal battle. The negotiation of femininity was not straightforward for them but rather an ongoing struggle between rejecting societal pressure and the desire to be seen as normal. This complex relationship revealed in the interviews and Reddit posts demonstrates how gender is not simple or innate but something that is constantly renegotiated based on different social contexts.

Internal Conflicts and Negotiations

Anna reflects on the past year, stating that her hirsutism has been impacting the way she sees her own femininity. Although the excess hair bothers her, she says that she has been working on this issue in therapy and "trying to consume healthy discourse about what femininity really is" (Anna). She concludes this thought by acknowledging that "there are so many women that go through this, and they're not any less feminine than [she is]" (Anna). At multiple points in the interview, Anna returns to the topic of hirsutism, pointing out the usefulness of online community:

> I feel like I really try to find online community, like online advice on how to deal with maybe different supplements that I can take, or how to approach a doctor in regards to talking about how to navigate the whole hair situation. (Anna)

While Anna recognizes the harmful nature of narrow ideals of femininity, she still actively seeks out advice on how to rid herself of the excess hair. The negative feelings surrounding hair on women's bodies are caused by "societal pressure" (Anna). Many of the individuals interviewed recognized this, with some mentioning how the availability of information and imagery online has added to these pressures.

Digital Pressures

> I think that there's way stronger pressures now than there used to be. Because if I compare it to my teenage years or my young years, yes of course there were tons of pressures. The 2000s were not a very good time for body image, but there were less sources of it. (Lucia)

Lucia, who identifies as Agender and has "made it a choice" to not "ascribe to that type of femininity," suggests here that social media has made women more susceptible to critique. Unlike earlier decades where television shows, movies, and magazines mediated beauty standards, the ready availability of social media platforms has made it so that users are exposed to a never-ending stream of curated beauty and unrealistic expectations.

> Especially with the age of everything online, I feel like standards of beauty and femininity are becoming a lot more, I want to say oppressive. That's not the right word I'm looking for, I mean yes, but also a lot stricter. When we have things like laser hair removal readily available in, you know, every small town all over the world and in beauty clinics everywhere. There's this really strict standard of - you must have long, beautiful hair, and your body should be soft and smooth, and you shouldn't have excessive body hair growth. And you know, other standards of femininity, like being small, or I really dislike this word but dainty. You know, just expecting a very hyper-feminine standard to apply to all women. (Violet)

Violet goes on to say that she feels concerned for anyone who has endocrine disorders and finds it difficult to fit these standards. "There aren't a lot of spaces, outside of the PCOS spaces, where you can really discuss how it feels to not be able to fit that standard because of your body working against you" (Violet). As Violet notes, the online PCOS counterpublic provides a rare platform to discuss alternate versions of femininity. For that reason, I now turn attention to the r/PCOS subreddit posts in order to further examine the impacts of the discourse occurring within the online PCOS community.

Gender Navigation Within the Counterpublic

The posts within the Reddit community echoed and reinforced many of the patterns observed in the group interviews, providing particular insight into the negotiation of gendered expectations as they unfold online. In one post, entitled "PCOS has ruined me and I don't feel like a girl," a frustrated teenager vents about how she feels excluded from experiences that other girls have. She feels defeated and as though she is some kind of "hair beast." The responses to the post fully encapsulate the kind of tension and negotiation that takes place within the online PCOS counterpublic in real time.

> …The brain is so powerful if you tell yourself you really are a beautiful person you'll start treating yourself like you are, and it will show. Facial hair and excessive weight are always going to be demonized and unfortunately that's not something that always goes away, so learn to accept it or find reasonable ways to manage it. During black friday I found an insane deal on laser hair removal…

The tensions that come with negotiating one's gender expression become especially visible online. Unlike with interviews, where moments of negotiation are often reflected upon retrospectively, Reddit threads such as the one above capture these negotiations as they are unfurling. In the reply to the original poster, the commenter offers emotional support, touches upon the harsh and unfair realities of societal beauty standards, and provides a practical tip on hair removal. While the commenter's advice at the end may seem like a reinforcement of normative femininity, interactions such as these are less about endorsing dominant gender norms and more about providing guidance on surviving within their confines. The back and forth interactions in the subreddit offer a window into the ways in which gender is collectively negotiated rather than something that is experienced alone. In a post titled "Hirsutism ruins my self-esteem," one user laments about how she feels "disgusting" and "like a man nowadays." Members of the subreddit page rushed to her comment section, leaving 42 comments offering empathy, support, advice, and reminding the poster to be less hard on herself. After reading through the comment section, the poster made an edit to their original post, writing:

> EDIT: i wasn't expecting so many people to comment, Thank you all so much for kind words and advice!❤️im just going to have to be patient and continue trying things until i find the right regime. I must remember we are all human and everyone has their own insecurities and to not take it so hard on myself.

Taken together, the conversations in the subreddit illustrate that compliance and resistance do not always exist outside of each other. Similarly to the Tumblr pages Chib et al. described, gender norms are navigated in ambivalent ways within these groups. Because gender identity is not fixed, but a series of acts shaped through social interactions and discourse, it is possible for posters such as the one above to fluctuate between feeling betrayed by their bodies' failure to fit the feminine standard and feeling "human" and worthy of kindness.

Fluid Expressions and Rearticulations

The fluctuations and fluidity described above are not only contemplated and discussed by posters. Some women, such as one poster who describes having a "neck beard" for the past several years, actively choose to embrace more fluid forms of femininity. She writes that she has kept her beard for as long as she has out of a "feminist urge to stay hairy." However, after years of embracing her facial hair, she comes to the subreddit to share her recent and spontaneous decision to shave:

> …It's barely been an hour and I kind of regret it? I've spent so long being too 'proud' to shave it, and now I have a stubbly itchy neck… I swear I almost feel a bit guilty for getting rid of beardtrice. Why am I tearing up?

The moment above captures the emotional complexity that comes with negotiating one's gender expression. The poster found that removing her beard, which she playfully refers to as "beardtrice," did not make her feel better but instead brought her a sense of guilt because she knew she was doing "what's expected of [her] as a woman." Her post may seem insignificant if viewed as a simple and reversible grooming decision. But her account reflects an internal

conflict that comes with deciding whether to follow her feminist instincts by resisting gender norms or to make herself and her appearance more socially acceptable. Her post also further demonstrates how certain reflections are made possible within the online PCOS counterpublic. A conversation surrounding beards on women would certainly be seen as taboo outside of this space. Within the forum, however, discussions on fluid gender performance, frustrations with societal expectations, and even feelings of dysphoria are met with respect and understanding. One user, for instance, spoke on how they had been feeling more masculine as of late, writing: "I crave femininity without any road blocks so bad. Relying on a pill to feel like a woman is so defeating…" The replies to this post yet again confirmed that normally stigmatized aspects of gender are not off-limits within PCOS communities:

> This is an important conversation to have - you experienced gender dysphoria bc of PCOS. its not exclusive to trans people, and neither is gender affirmation medical care (when men start taking testosterone at 50, that is HRT due to gender dysphoria)...imo gender dysphoria in cis people is such an important convo and it lowers the stigma for trans people.

This interaction highlights the uniqueness of the counterpublic in terms of its ability to serve as a space for individuals to discuss and make sense of their gendered experiences in ways that are not often possible elsewhere. Rather than telling the original poster that her feelings were invalid, the commenter sympathized with the poster's feelings and offered up a new way of reframing their experience. It is very likely that the original poster, being a cis-woman, had never considered herself as experiencing symptoms of gender dysphoria. Through the support of the PCOS community, however, she was provided with new ideas and language by which to comprehend her struggles. Women with PCOS who experience feelings akin to dysphoria are able to withdraw to online forums in order to collectively make sense of these challenges. And as many of the participants commented, the online forums they frequent serve not only as spaces of connection and learning, but as a great source of relief.

5.3 PCOS Counterpublics as Spaces of Withdrawal and Relief

Relief from the Isolation

Although PCOS is a very common condition among women and AFAB (assigned female at birth) individuals, most people with PCOS do not have the opportunity to interact with others with PCOS in their day-to-day lives. Among the interviewees, only one person mentioned having someone close in their life with PCOS that they could talk to. Being surrounded by people who do not understand your condition can be a very isolating experience. But finding others with PCOS offline can feel impossible, especially when it is not a topic that comes up naturally in conversation. This lack of offline connection experienced by the interviewees underscores the importance of online platforms.

> [There are] very lonely people out there if they don't have enough positive people around them. Because even I felt- because my mother is a doctor- even she [didn't] know what was

> going on with me. So I was really scared. I used to cry a lot, like, what is going on with me? … I think the internet has definitely helped in, you know, showing that there are people who are suffering with PCOS. (Tara)

Tara's account reflects a broader theme among participants. Navigating a health condition as complex as PCOS alone can feel overwhelming. For many, PCOS forums became a place of emotional healing. And for Eileen specifically, stumbling upon a Facebook support group helped to guide her through a very difficult stage in her life:

> Trying to conceive and wanting to do it before a certain age, especially with PCOS, can be extremely hard. It leads you down this path of, you feel like you're not a woman… I was in a bad depression stage and one day I was just on Facebook… and then I happened to see a PCOS group on Facebook. I joined it, and in a way, it kind of uplifted me a little bit. I'm seeing all these other women and their stories and everything, and it helped. (Eileen)

Like Eileen, the rest of the participants spoke highly of the online communities they were part of. These spaces proved to be especially important since many felt it to be too much of a hassle to speak to others about their condition offline. Olivia, for instance, recently began sharing with her close friends. Still, she expressed that she preferred not to talk about her PCOS with others too much, even keeping most of the details from her family. Violet seemed to agree when it came to keeping certain things to herself:

> I just feel like when talking to my family about some of the symptoms that I experience, I kind of have to take charge of the conversation before they can misinterpret what I'm saying. And it's just kind of easier not to tell them certain things, because there will be a lot of unsolicited advice…or them saying that that's not from your PCOS, that's just normal. (Violet)

Violet's experience sharing with her family demonstrates how even well-meaning conversations can become too laborious for women with PCOS, leading them to withdraw. Online forums are appealing for women like Olivia and Violet because they are a space where little needs to be explained. There is a shared understanding and a shared struggle. And perhaps because of this shared struggle, most interviewees expressed a desire to help others within the forums. Eileen remains in contact with a woman from her group who is on her third child, thanks to advice Eileen shared regarding supplements. Lucia, who has developed an eating disorder due to her PCOS, attempts to shield younger girls in the community from harmful advice about overly restrictive diets. Zoe uses her Master's in public health as well as her passion for research to educate others about lesser-known aspects of PCOS, such as how it can lead to higher risk of yeast infections. And Anna notes that solving other people's problems in the forum helps take away some of her own worries. Each interviewee utilized the online PCOS counterpublic in their own unique way, and yet all seemed to note that there was something special about the space. The connections taking place within them do more than simply create community, they also create a great sense of relief. There is a comfort in knowing that the people reading your posts can relate to many of the things you describe. And a relief in knowing that your version of

femininity will not be criticized or questioned. When asked what piece of advice she would offer to someone who had been newly diagnosed with PCOS, Zoe exclaimed:

> In a big sign with flashing lights I'd say "You are not alone! This is actually way more common than you know!"... And then also, find community. In person, on the internet, wherever you can. Just so then you're out of your usual echo chambers. (Zoe)

6. Limitations & Future Perspectives

Future PCOS research would benefit from further inspection into the relationships between patients and medical teams, with particular attention paid to the ways in which this strained relationship pushes many with PCOS to seek out online communities. While the focus of this research remained on gender performance and online discourse within PCOS counterpublics, many participants expressed frustrations with the quality of their medical care. This theme emerged quite frequently in the data, and while these instances were coded as "medical dismissal," ultimately the findings were not included in this study. Interviewees spoke about feeling uncomfortable with their doctors, feeling bounced around, and feeling as though their concerns were dismissed or not taken seriously enough. Some participants shared that their doctors did not want to test them for PCOS. While others noted that even after diagnosis, "the best thing they [the doctors] said for me was to get on birth control" (Eileen). Certain interviewees even expressed that their primary reason for joining an online forum was the sense of dismissal and confusion they felt following their doctor's appointments.

Although these online forums may be considered by some to be sites that contradict medical advice or spread misinformation, this framing fails to notice the critical role the counterpublic plays in complementing medical care. These online PCOS counterpublics do not replace the need for more comprehensive medical care, but rather they fill in the gaps left by the medical system. In doing so, validating the lived experiences of PCOS patients and addressing areas of uncertainty. As one interviewee noted, "It's nice to find a community online comprised of other women who aren't going to tell you that your problems are in your head or that you're just hormonal" (Violet). These communities are not meant to discourage members from seeking medical care. Instead, they function as useful extensions to medical care. Future research should explore these online PCOS counterpublics further by examining the ways in which they supplement medical care. Future studies should also consider sourcing participants from online forums, specifically focusing on the topic of medical dismissal in greater depth in order to give this topic the attention it deserves. To see an example of how medical dismissal appearing in posts from the r/PCOS subreddit was coded for this study, refer to the appendix.

7. Conclusion

The purpose of this study was to explore how online PCOS forums act as critical counterpublics, serving as safe spaces to discuss, negotiate, and perform alternative gender expressions. The research examined how women with PCOS use these spaces to question, resist, and at times operate within dominant ideals of femininity. This issue is significant as PCOS is a commonplace condition affecting the gender expression and self-perception of many individuals. By concentrating on the voices of women actively navigating these challenges, this research illustrates the importance of recognizing gender as being enacted and socially enforced. Gender is a performance. And for women with PCOS who experience a wide range of symptoms, from androgenic alopecia to infertility, this performance is disrupted. Understanding how these online communities enable more nuanced and fluid possibilities for gender expression provides greater insight into the embodied realities of women with PCOS. As many of the symptoms caused by PCOS can be deeply stigmatized, this study argues that online PCOS counterpublics are necessary for creating more compassionate conditions to explore gender.

The following section restates and builds upon the key findings from this study in order to directly address the research question: How do online PCOS counterpublics enable women with the condition to explore and negotiate alternative gender performances? First, each of the three key themes will be revisited in an effort to elucidate their central points and make any additional theoretical connections. After touching upon these themes, the discussion will culminate by bringing these ideas together to demonstrate that online PCOS counterpublics do indeed enable women with PCOS to explore and negotiate alternative gender performances.

The first theme, *Bodily Betrayal and the Disruption of Femininity*, confirmed that while gender is a performance, it can still be done "wrong" in the eyes of others. Even for women with PCOS, who are unable to prevent their body from acting as it does, the pressures to conform to fit a certain standard of femininity are very real and pervasive. For some participants, failure to meet these ideals, whether it be through their weight, irregular menstruation, or infertility, resulted in social correction and feelings of shame. The real social consequences that result from not performing gender as expected, even for cisgender women, speak to Butler's idea that gender is not inherent or simple. These consequences also account for the necessity of online spaces that offer refuge. In the second theme, *Compliance and Resistance: Navigating the Performance,* we saw how these social pressures led to internal conflicts for many of the participants. Some noted that social pressures and high expectations for women's bodies are exacerbated by the hypervisibility of social media and the discourses taking place in other digital spheres. This revelation stood as proof that offline pressures are often replicated online. However, as interviewees noted, the online PCOS counterpublic offered something special in that it provided a space where many of those pressures were alleviated. In the discussions highlighted in the second theme, interviewees and posters alike demonstrated how participating in online forums enabled them to express thoughts that would otherwise remain private. The third and final theme,

PCOS Counterpublics as Spaces of Withdrawal and Relief, revealed yet again the significance of the counterpublic, especially for those lacking support systems offline. All but one interviewee expressed that they did not have other people with PCOS in their lives. For that reason, many are left feeling isolated and misunderstood. The online PCOS counterpublic, however, caters to their needs by offering a sense of relief. For some, this relief came specifically from having the ability to conversate with others in spaces where their version of femininity is not questioned. The constant labor and exhaustion that comes with performing femininity properly melts away in these forums.

In summation, this study has shown how online forums, referred to throughout as the online PCOS counterpublic, have created nurturing and respectful environments that enable women with PCOS to explore, negotiate, and at times rearticulate their gender performances. Within these spaces, that serve as alternate discursive arenas, members of the community take charge of their narratives, reframing what it means to be feminine either through outright resistance and critique or by normalizing alternative expressions of femininity. This study contributes to broader conversations surrounding gender, digital spaces, and embodiment. In doing so, drawing attention to the complex lived experiences of those with PCOS and highlighting the importance of peer-based communities. Overall, this study underscores the transformative potential of online counterpublics in acting as spaces where the narrow boundaries of gender expression and femininity can be reshaped.

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9. Appendix

Appendix A1: Participant Overview Table

Group Type	Participant Pseudonyms	Date Conducted	Format
Focus Group 1	Lucia, Olivia, Violet	May 18, 2025	Online Zoom
Focus Group 2	Anna, Eileen, Tara, Zoe	May 25, 2025	Online Zoom

Appendix A2: Codebook for r/PCOS Subreddit

During the month of May, 33 posts from the r/PCOS Subreddit were coded for themes relating to gender performance, feelings of diminished femininity, community support, and so forth. The codes below are selected examples that demonstrate the coding process and illustrate how the key themes were applied.

Theme	Post/Quote	Reply	Codes Applied	Notes
Disruption of Femininity				
	"Does anyone else feel like less of a woman because they have pcos? I'm 19 and was diagnosed with PCOS after never having a regular cycle. I am a healthy weight, exercise, and eat well. I haven't got my period in around 5 months and a friend today asked me for a pad. Because my periods are so irregular and light, I don't usually carry pads in my backpack or other bags like normal woman. I told her I was sorry but didn't have a pad. She then jokingly said "What type of girl doesn't carry pads?" I'm not sure why but	"By her logic why didn't she have her own pads? Sometimes I do, but more in the fertility regard than something else. Being a woman is so complex, there isn't truly just one "thing" or one "box" that makes or break what it means to be one."	• Bodily Betrayal • Comparisons to "typical" women • Social Correction/invalidation	Interaction between OP and friend reveal that failure to perform gender (not having pads) results in negative social consequences (in this case shame) Reply to post supports OP by validating feelings reframing interaction (why didn't her friend have pads?). Reply pushes OP to rethink interaction and challenges her feelings of shame

	this struck a nerve. I struggle with some mild hirsutism, with thick black hair (I'm pale and light-haired), on my upper lip, toes, and nipples. I feel less like a woman because of this and the fact I don't have normal cycles. I also have never experienced cramps so when people complain about them, I sit there in silence. I just feel like fraud and wondered if anyone else felt like this?"			
Compliance and Resistance				
	" I think a critical aspect of the mental health impacts of PCOS is how many of the symptoms/effects like weight gain in mid section, mood swings, hair loss on head, hair in unwanted places, and higher testosterone, are all things that may lead a woman to be seen as less conventionally attractive to the public eye... As much as we would like to go against the patriarchy and internalized misogyny, I think a lot of us still want to be thought of as beautiful and desirable. Even though I have a boyfriend of 4 years who loves all of me, stubby beard and tummy included, I still feel this pressure from the outer world to appear a certain way to be acceptable. In the comments, please say something that makes you feel beautiful and desirable. Something that isn't related to diet/weight loss or hair removal. How do you feel beautiful, PCOS	"i agree with you, OP. Definitely struggled a lot with trying to fit a particular archetype and feeling a lot of shame of not fitting in. Accepting more and more my own feelings of androgyny and nonbinaryness, and that actually looking like a dude-chick is kind of hot, and finding more people who are in this inbetween world has been really helpful for me. I do find that the more I hang out with queer people the more comfortable with my body I have become."	• Questioning/Resisting Norms • Negotiation of Femininity • Support from Counterpublic/Community Care	Original post acknowledges internalized misogyny and "conventional" standards of beauty. Post starts conversation and builds solidarity.

	symptoms/effects included?"			
Counterpublics as Relief & Support				
	"Tips for educating male partner? Me and my partner are going through a bit of a rough patch, and I believe that its underlying problem is due to side effects of PCOS. I have little to no sex drive so our libidos aren't matching, fertility issues (primary amenorrhea), negative body image, hirsutism etc Are there any books/videos that you can recommend to show to a male partner to help them understand how PCOS affects us?"	" ... I'd say stick to reputable sources. If you're English speakers, Mayo Clinic has some stuff up that gives a general overview. Else I recommend looking up reputable health care providers and see if they have resources. My insurance has a glossary for instance. Where do you get your info from? Share the sources with him. If you can, maybe take him to an appointment of yours so he can ask questions to the doc (make him think of them beforehand tho)... In the end, he needs to be willing to learn and accept the fact that your body works against you and you're not giving an excuse. I wish you best of luck and sending you a hug 🤗"	• Bodily Betrayal • Support Seeking • Social/Relational Strain	Relationship challenges linked to symptoms of PCOS. Failure to perform (libido, etc.) has social consequences. Post also demonstrates emotional labor that comes with educating those with PCOS. Op reaches out for support. Replies to OP demonstrate that counterpublic creates safe space. Also interesting to note that ppl in counterpublic do indeed share medical/clinical resources.
Medical Dismissal				
	"Why does medical help for pcos feel nonexistent I just got to see an obgyn for my pcos for the first time in a while and it feels like they didn't even care like they just brushed it off and asked if acne and facial hair bother me I of course said yes and all she said was that she would prescribe something for that and some birth control and that next time she will see me is in a year🙃 then with my primary doctor all she told me was to see the obgyn so I feel like I'm screwed n	"Because women are inferior and men should be the focus.. there isn't research in it much and doctors are not familiar. I told a doctor that I had this and they said they never heard of it but would look into it. Decided to give them a chance anyway and came in again ~6 months later to see how my "diabetes" medication was treating me and again they never heard of pcos and told me yet again they would research it... BS. Pcos also is different per woman, I do believe it should be broken down even further rather than a	• Frustrations with Medical Care • Reliance on Peer Support/Information	Poster expresses frustration with lack of care and guidance. Like many she has only been offered birth control. Interactions with doctors have left her feeling hopeless. Reply to OP suggests that this experience is not uncommon (systemic problem). Anger at the one-size-fits-all approach to PCOS treatment.

	stuck with pcos forever none even told me how to manage it or what caused it or even more about pcos when i did ask all I got was "well it just means your hormones are imbalanced" I learned more from this thread than with the doctors I have"	broad spectrum. Some people are skinny and get told no way you have pcos because you have to be fat.. again BS. So many uneducated doctors, lack of researching, and businesses against healthier people due to the money they can make off of them."		

10. Ethics & Privacy Checklist

CHECKLIST ETHICAL AND PRIVACY ASPECTS OF RESEARCH
INSTRUCTION
This checklist should be completed for every research study that is conducted at the Department of Public Administration and Sociology (DPAS). This checklist should be completed *before* commencing with data collection or approaching participants. Students can complete this checklist with help of their supervisor.
This checklist is a mandatory part of the empirical master's thesis and has to be uploaded along with the research proposal.
The guideline for ethical aspects of research of the Dutch Sociological Association (NSV) can be found on their website (http://www.nsv-sociologie.nl/?page_id=17). If you have doubts about ethical or privacy aspects of your research study, discuss and resolve the matter with your EUR supervisor. If needed and if advised to do so by your supervisor, you can also consult Dr. Bonnie French, coordinator of the Sociology Master's Thesis program.

PART I: GENERAL INFORMATION
Project title: Woman Enough? How Online PCOS Counterpublics Make Space for Alternative Femininities
Name, email of student: Jamilah Conner, 698225jc@eur.nl
Name, email of supervisor: Jess Bier, bier@essb.eur.nl
Start date and duration: 23/03/2025- 22/06/2025
Is the research study conducted within DPAS YES - NO
If 'NO': at or for what institute or organization will the study be conducted?
(e.g. internship organization)
PART II: HUMAN SUBJECTS
1. Does your research involve human participants. YES - NO

If 'NO': skip to part V.
If 'YES': does the study involve medical or physical research? YES - NO
Research that falls under the Medical Research Involving Human Subjects Act (WMO) must first be submitted to an accredited medical research ethics committee or the Central Committee on Research Involving Human Subjects (CCMO).
2. Does your research involve field observations without manipulations that will not involve identification of participants. YES - NO
If 'YES': skip to part IV.
3. Research involving completely anonymous data files (secondary data that has been anonymized by someone else). YES - NO
If 'YES': skip to part IV.

PART III: PARTICIPANTS

1. Will information about the nature of the study and about what participants can expect during the study be withheld from them? YES - NO
2. Will any of the participants not be asked for verbal or written 'informed consent,' whereby they agree to participate in the study? YES - NO
3. Will information about the possibility to discontinue the participation at any time be withheld from participants? YES - NO
4. Will the study involve actively deceiving the participants? YES - NO
   Note: almost all research studies involve some kind of deception of participants. Try to think about what types of deception are ethical or non-ethical (e.g. purpose of the study is not told, coercion is exerted on participants, giving participants the feeling that they harm other people by making certain decisions, etc.).

1. Does the study involve the risk of causing psychological stress or negative emotions beyond those normally encountered by participants? YES - NO
2. Will information be collected about special categories of data, as defined by the GDPR (e.g. racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data for the purpose of uniquely identifying a person, data concerning mental or physical health, data concerning a person's sex life or sexual orientation)? YES - NO
3. Will the study involve the participation of minors (<18 years old) or other groups that cannot give consent? YES - NO
4. Is the health and/or safety of participants at risk during the study? YES - NO
5. Can participants be identified by the study results or can the confidentiality of the participants' identity not be ensured? YES - NO
6. Are there any other possible ethical issues with regard to this study? YES - NO

If you have answered 'YES' to any of the previous questions, please indicate below why this issue is unavoidable in this study.
My participants will be discussing details of their PCOS experiences that have the potential to bring up some negative emotions. They will also be sharing certain details of their diagnosis and symptoms. All sensitive data will be protected and deleted after receiving a thesis grade.
What safeguards are taken to relieve possible adverse consequences of these issues (e.g., informing participants about the study afterwards, extra safety regulations, etc.).

Participants will be made aware of the ability to stop the interview at any time, skip questions, or take back something that was said. They will be made aware of how the study will be used and their information will be anonymized in the thesis.

Are there any unintended circumstances in the study that can cause harm or have negative (emotional) consequences to the participants? Indicate what possible circumstances this could be.

Since the topic itself is sensitive it is possible that participants may have negative emotions come up as they share their feelings. For instance, talking about feeling less feminine may be distressing. However, participants will be made aware of the topics that will be discussed in the interviews beforehand so there should be no surprises.

Please attach your informed consent form in Appendix I, if applicable.

Continue to part IV.

PART IV: SAMPLE

Where will you collect or obtain your data?

I will be creating a survey in GoogleForms, conducting interviews in Zoom, and saving data in the OneDrive.

Note: indicate for separate data sources.

What is the (anticipated) size of your sample?

I expect to interview between 3-4 participants in a series of 2-3 group interviews

Note: indicate for separate data sources.

What is the size of the population from which you will sample?

I will be sampling from online communities with thousands of members.

Note: indicate for separate data sources.

Continue to part V.

Part V: DATA STORAGE AND BACKUP

Where and when will you store your data in the short term, after acquisition?

Data will be stored in OneDrive and will be deleted after I receive a thesis grade. Survey data, on the other hand, will be deleted before this as it will be deleted after I get my sample of respondents.

Note: indicate for separate data sources, for instance for paper-and pencil test data, and for digital data files.

Who is responsible for the immediate day-to-day management, storage and backup of the data arising from your research?

I will be solely responsible for this. I will look to my thesis supervisor for instruction and tips on how to best manage this.

How (frequently) will you back-up your research data for short-term data security?

I will back-up my data as frequently as necessary. This is something that I will discuss with my supervisor before I begin collecting data to ensure that no mistakes are made.

In case of collecting personal data how will you anonymize the data?

Names and sensitive identifying data will not be included in my thesis. For the purposes of my own data storage I will create pseudonyms for my participants so that their real names can be

deleted immediately. Any data stored on my computer will not be shared with anyone and will be deleted as quickly as possible after I receive my grade.

Note: It is advisable to keep directly identifying personal details separated from the rest of the data. Personal details are then replaced by a key/ code. Only the code is part of the database with data and the list of respondents/research subjects is kept separate.

PART VI: SIGNATURE

Please note that it is your responsibility to follow the ethical guidelines in the conduct of your study. This includes providing information to participants about the study and ensuring confidentiality in storage and use of personal data. Treat participants respectfully, be on time at appointments, call participants when they have signed up for your study and fulfil promises made to participants.

Furthermore, it is your responsibility that data are authentic, of high quality and properly stored. The principle is always that the supervisor (or strictly speaking the Erasmus University Rotterdam) remains owner of the data, and that the student should therefore hand over all data to the supervisor.

Hereby I declare that the study will be conducted in accordance with the ethical guidelines of the Department of Public Administration and Sociology at Erasmus University Rotterdam. I have answered the questions truthfully.

Name student: Jamilah Conner
Date: 23/03/2025

Name (EUR) supervisor:
Date: