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Social Repercussions of Polycystic Ovary Syndrome (PCOS): Analyzing Gender Roles and Societal Perceptions

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Abstract

Polycystic Ovary Syndrome (PCOS) is a chronic illness that affects approximately 6 to 12 percent of people of reproductive age (*PCOS (Polycystic Ovary Syndrome) and Diabetes* | *CDC*, n.d.). Common symptoms of this condition include production of excess androgens, cysts in the ovaries, excess hair growth (referred to as hirsutism), irregular periods, and infertility (*PCOS (Polycystic Ovary Syndrome) and Diabetes* | *CDC*, n.d.). Many of these symptoms contradict beauty standards and social roles set in place for women and those assigned female at birth. However, the social effects of this disorder, shame and stigma from not conforming to feminine social standards, are seldom discussed in PCOS scholarship, but pose very real consequences to the wellness of those with PCOS. In this paper, I will be looking at five peer-reviewed articles published between 2011 and 2022 to properly characterize the social effects of PCOS stigma. I analyze the underrepresentation of racialized, transgender, and gender non-conforming people and conclude by calling for increased diversity and intersectionality in PCOS research.

Introduction

I searched for peer-reviewed literature published in journals, with four of the five articles being discovered through the University of Toronto Library's online archives. Each of the articles detail different qualitative analyses and studies *(Figure 1)*. I chose to analyze different qualitative studies and analyses of PCOS in this paper in order to highlight the vastly different social repercussions of PCOS stigma on people living with the condition. It is important to note that, in this search for PCOS research, most literature, particularly older sources, used very gendered language, describing people with PCOS as "women'' and treating it as an exclusively feminine condition. Cisgender women are the prime focus of PCOS scholarship, with literature on the effects of PCOS, particularly its socio-cultural consequences on transgender and gender-nonconforming people, representing a small minority of more recent research.

<u>Summary of Relevant Peer-Reviewed Literature</u>	
Article Title: “Polycystic Ovary Syndrome and Gender Identity” **Published:** 2020	**Article Summary** Early studies with inconsistent criteria and “convenience examples” state that rates of PCOS among transmasculine people was higher than in “the general population” (Liu et al., 2020, p. 529). However, a more recent and larger study did not find this to be true. More studies show that PCOS patients are less likely to identify with traditional feminine gender than their peers (Liu et al., 2020.
	Methods Analyzed studies and relevant literature on transgender people with PCOS. Looked at the correlation between self-perception, gender identity, and PCOS.
	Results/Findings Larger studies with control groups and up-to-date diagnostic criteria for PCOS and gender dysphoria are needed to “clarify” this relationship between the occurrence of PCOS and one’s gender.
Article Title: “Attitudes Towards Transgender People Among Cisgender Women Who Use Vaginismus and PCOS-related Online Forums” **Published:** 2022	**Article Summary** Studying online forums used by those with PCOS and vaginismus (V&PCOS) (Adams et al., 2022, S20). Both are chronic conditions affecting women and those assigned female at birth (AFAB) (Adams et al., 2022, S20).
	Methods 1. Surveying cisgender women on their experiences interacting with transgender people on these forums 2. Analyzing the link between “threats to feminine identity” felt by those with V&PCOS 3. Survey transgender people with V&PCOS on their gender identity and the

	role it plays in their experience living with V&PCOS 4. Explore existing differences in PCOS and vaginismus online forums
	Results Informal observation of these forums indicates marginalization of transgender users by cisgender-users, with cisgender-users’ behavior possibly being linked to threats felt to their femininity (Adams et al., 2022, S20).
Article Title: “Young Women’s Experiences Living with Polycystic Ovary Syndrome” **Published:** 2011	**Article Summary** Analyzing the psychosocial effects of PCOS on young “women” (Weiss and Bulmer, 2011, p. 709).
	Methods Interviewing a sample of 12 young women between the ages of 18 and 23 from New England college campuses. 9 of 12 participants were white, 2 were Black, and 1 was Asian (no further specification was provided) (Weiss and Bulmer, 2011). Pseudonyms were used in place of the participants’ names in the article.
	Results The following themes were present in the responses: 1. Concerns for the future (ex. conceiving children) 2. Feeling “physically inferior” (Weiss and Bulmer, 2011, p. 709) 3. Interactions with healthcare providers 4. Access to accurate information and support 5. Accepting their PCOS diagnosis Participants reported facing various “physical, social, and emotional challenges”, so Weiss and Bulmer (2011) call for holistic treatment approaches for those with PCOS, including psychosocial support for patients.

Article Title: “‘Less than a Wife’: A Study of Polycystic Ovary Syndrome Content in Teen and Women’s Digital Magazines” **Published:** 2016	**Article Summary** Women’s magazines publishing health-related content on PCOS expose predominantly female readers on PCOS, influencing people’s conceptions on the condition and people who live with it (Sanchez and Jones, 2016, e89).
	Methods Used data from the Alliance for Audited Media to identify popular digital teen and women’s magazines with circulation rates less than or equal to about 1,000,001 (Sanchez and Jones, 2016, e89). Searching through magazines over a one-month interval in 2015 resulted in 21 magazines and 170 articles with keywords “PCOS” and polycystic ovary syndrome”, which were analyzed for key themes and issues in magazine representation of PCOS (Sanchez and Jones, 2016, e89).
	Results Through analysis of the 170 articles in 21 magazines, it was found that PCOS was primarily depicted as a barrier to achieving traditional feminine gender roles, with only a minority of sources depicting women with PCOS themselves, advocating for others with the condition (Sanchez and Jones, 2016, e89). Black and Latina “women” were not mentioned in these sources, and the article itself does not mention transgender and gender-nonconforming people with PCOS, using gendered language like “women” to describe the condition (Sanchez and Jones, 2016, e89).
Article Title: “‘I didn’t feel normal’: Young Canadian women’s experiences with polycystic ovary syndrome” **Published:** 2021	**Article Summary** With PCOS being described as “a highly gendered disorder whose symptoms disrupt Western conceptions of femininity,” this can be othering for people living with the condition “within the current socio-cultural context” (Samardzic et al., 2021, 571).
	Methods 10 Canadian women between the ages of 18 and 22 were interviewed on how PCOS affected their

	own self-perception and sense of belonging (Samardzic et al., 2021). 6 of the 10 participants identified as White, 2 were Middle Eastern, and 2 were Middle Eastern and Mediterranean, therefore not Iing other racialized groups In the data (Samardzic et al., 2021). While there is mention of non-heterosexual and gender non-conforming people with PCOS, cisgender women are still the primary focus of this study and article (Samardzic et al., 2021).
	Results Young women described feeling abnormal due to their symptoms and concern over meeting feminine gender norms. The authors argue that labeling desirable traits as "normal" can have adverse effects on women's self-perception, which are only reinforced by gendered biases when PCOS patients seek out care (Samardzic et al., 2021). The authors argue for an intersectional feminist approach to treatment to capture different lived experiences (Samardzic et al., 2021).

FIGURE 1. Summary of selected peer-reviewed literature.

Through this analysis of peer-reviewed scholarship, I have identified two key themes: the underrepresentation of racialized, transgender and gender-nonconforming people and the poor depiction and perception of PCOS.

Underrepresentation of Racialized People with PCOS

Of the five selected peer-reviewed articles, three of them contained race data on the participants of these qualitative studies. The first article "Young Women's Experiences Living with Polycystic Ovary Syndrome" analyzed the psychosocial effects of PCOS by interviewing 12 young "women" in New England. With 9 of 12 participants identifying as White, this makes up 75% of participants (Weiss and Bulmer, 2011).. In the second study outlining race data, titled "'Less than a Wife': A Study of Polycystic Ovary Syndrome Content in Teen and Women's Digital Magazines" and published in 2016, it was found that out of 170 articles in 21 magazines, there was no mention of Black and Latina people with PCOS (Sanchez and Jones, 2016). The third article, "'I didn't feel normal': Young Canadian women's experiences with polycystic ovary syndrome" published in 2021, 6 of 10 participants in qualitative interviews were White, with only 4 others identifying as Middle Eastern or Middle Eastern and Mediterranean (Samardzic et al., 2021). This is the largest oversight of racial inclusion of the five selected articles, since this article excludes all people of color who do not identify as Middle Eastern or Middle Eastern and Mediterranean. Therefore Black, Asian, Indigenous, and Hispanic people were not included in or consulted for the collection of this data. In addition to more intersectional holistic approaches to understanding PCOS, I call for more data transparency on race-based data in studies of this nature, in order to ensure that literature on this subject is inclusive of all races of people living with PCOS.

Underrepresentation of Transgender and Gender-Nonconforming People with PCOS

As noted, the majority of research on PCOS centers the experiences of cisgender white women, neglecting the unique experiences of BIPOC and gender-nonconforming people living with the condition. Of the five selected peer-reviewed articles, three of them either do not mention or seldom mention transgender and gender-nonconforming people with PCOS. The first two articles, "Young Women's Experiences Living with Polycystic Ovary Syndrome" published in 2011 and "'Less than a Wife': A Study of Polycystic Ovary Syndrome Content in Teen and Women's Digital Magazines" published in 2016, bear no mention of the unique experiences of transgender and gender non-conforming people at all. The third article in question, "'I didn't feel normal': Young Canadian women's experiences with polycystic ovary syndrome" published in 2021, did mention transgender and gender-nonconforming people, however, the focus of the article was still primarily cisgender women. There was no in-depth analysis of the unique challenges facing the LGBTQ+ community in navigating PCOS and its socio-cultural stigma. The article does, however, call for researchers to investigate how PCOS is presented in and navigated by those who are gender non-conforming (Samardzic et al., 2021, p. 584). While I disagree with this study's marginalization and exclusion of racialized, transgender, and gender non-conforming people with PCOS in its data collection process, I do agree with this call for future research, especially the addition of "an intersectional analysis" in this academic research (Samardzic et al., 2021, p. 584).

Conclusion

To summarize, in this paper, I looked at five peer-reviewed articles published between 2011 and 2022 to properly characterize the social effects of PCOS stigma. I analyzed the underrepresentation of racialized, transgender, and gender non-conforming people and called for increased diversity and intersectionality in PCOS research. I analyzed five selected peer-reviewed journal articles, published between the years of 2011 and 2022. With each article providing qualitative analyses of different social repercussions and sociocultural consequences of living with PCOS, I did this to ensure that this analysis is as encompassing of the full social experience of having PCOS as it possibly can be. In this analysis of peer-reviewed literature, I found that PCOS research centers the voices of cisgender white women, thus marginalizing racialized and transgender and gender-nonconforming people with PCOS. This is evident through the overrepresentation of white women in qualitative studies, with three peer-reviewed studies providing race data on participants indicating that white women made up over 50% of participants, and the exclusion and marginalization of transgender and gender-nonconforming people with PCOS in the articles. I call for more inclusion and an intersectional approach to facilitating this to best encompass unique experiences and challenges faced by people with PCOS from underrepresented groups.

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