

## On the borderlines of health, beauty, and enhancement: an analysis of Polycystic Ovary Syndrome

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THEMATIC ARTICLE

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**Abstract** *This article analyzes the publications of women who suffer from Polycystic Ovary Syndrome (PCOS) in Facebook groups. PCOS is a metabolic syndrome experienced by a vast number of women of childbearing age. Some of its main symptoms are acne, weight gain, and unwanted hair. On the other hand, the treatment focuses on changing the lifestyle associated with diet control and adopting new habits. The analysis of statements and pictures posted by the participants of the groups, which express their before-after transformations, reveals that diagnosis, treatment, and perception of PCOS are currently deeply associated with aesthetic factors. Finally, we discuss how this event is linked to the historically produced binary gender pattern centered on body differences and how it illustrates the emphasis on self-enhancement, especially concerning its expression in body and aesthetic standards.*

**Key words** *Polycystic Ovarian Syndrome, Gender, Aesthetics, Anthropology*

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## Introduction

This article is nested in the study on new forms of knowledge circulation and access to biomedical technologies in contemporary settings linked to bodily and subjective transformations. In particular, it focuses on discourses about Polycystic Ovary Syndrome (PCOS) produced and disseminated among users in Facebook groups on the topic. PCOS is presented as a metabolic syndrome that affects 6% to 16% of women of reproductive age, a number based on specialized literature and adopted by reference institutions, such as the Brazilian Federation of Gynecology and Obstetrics Associations (FEBRASGO)<sup>1</sup>. The metabolic syndrome encompasses a state of clinical and laboratory abnormalities associated with an increased risk of developing cardiovascular diseases, hypertension, and diabetes (Soares *et al.*<sup>2</sup>). It can affect several areas of the patient's life, such as hormonal, nutritional, and reproductive health. The analysis of women's statements and their references to health professionals reveals that diagnosis, treatment, and public perception of the event are deeply associated with aesthetic factors, such as weight gain, acne, and unwanted hair. Although PCOS is the subject of great controversy in the medical field, as we can see in Wang and Mol<sup>3</sup> and Buddhavarapu<sup>4</sup>, among different experts and involving a dispute over the most appropriate forms of diagnosis and treatment, we shall strictly focus here on how the syndrome is experienced and described by the participants of the groups analyzed.

In this sense, we noticed in the groups the production of a contrast between what can be called "updated" and "outdated" performance (performance in the sense proposed by Mol<sup>5</sup>) of PCOS. The "updated" performance expresses the preference of users of Facebook groups and indicates their criticism of what they consider outdated. In this version, PCOS is understood as a metabolic syndrome that affects "the whole", that is, all dimensions of women's health. The preferably multidisciplinary treatment emphasizes a lifestyle change, which includes adopting a healthy diet, physical activity, and not taking contraceptives. This conception is in tune with "correct" forms of diagnosis and therapeutic approach and the most updated information. It contrasts with an "outdated" approach, a term created through the analysis of group posts, representing the most traditional treatment used for a long time to combat the problem. In this last setting, PCOS is fundamentally conceived as an

ovarian syndrome, treated by gynecologists with the extensive use of contraceptives to regularize the menstrual cycle. Users of the groups do not agree or are not directly concerned about adopting a precise definition of PCOS. They are more interested in resolving their complaints through appropriate treatment. However, we identified the updated performance as the dominant perspective, as it is more recommended and accepted among participants.

As will be demonstrated throughout the article, the empirical material significantly revealed an emphasis on lifestyle changes to combat the problems associated with PCOS and improving, above all, the aesthetic factors associated with the syndrome. This process was often translated by photos and descriptions that reported the "before-after" versions of the body transformation movement, mainly regarding weight loss and the reduction of unwanted hair and acne. We suggested that the emphasis given to the expression "before" and "after" revealed the need for a material demonstration that the desired changes were achieved through the women's efforts during treatment. We proposed that how PCOS is presented in groups is associated with the prevailing self-improvement rationale in our society to understand the importance of transformation.

Improvement is understood here through the perspective of Rose<sup>6</sup>, who questions the role of life sciences in producing contemporary truths and subjectivities. His most general hypothesis concerns the relationship between the emergence of "somatic ethics" and its articulation with the "spirit of biocapital". He presents this idea through the molecularization, optimization, subjectivation, expertise, and bioeconomy concepts. Optimization is particularly relevant for this analysis, presented as the use of contemporary medical technologies to heal pathologies and control the vital body and mind processes. These technologies would be associated with improvement as something directed towards the future and the emergence of individuals who consume these new life control desires and possibilities. Rose<sup>6</sup> argues that innovation does not lie in there being a will or improvement practice but in the fact that they begin to shape the lives of individuals. He associates this process with transitioning from normalization to customization of bodies, sensations, desires, and emotional and cognitive abilities. Aligned with this, subjectivation describes the process by which the subject is led to believe that health promotion is a personal matter of self-management and responsibility.

We suggest that the search for an idealized body according to strict gender standards described by women in PCOS Facebook groups illustrates this improvement process. The emphasis on changing lifestyles and the “before-after” illustrations can also be interpreted as anchored in this self-improvement rationale. In this case of gender performativities associated with PCOS, the improvement focuses mainly on enhancing aesthetic aspects essential for these women and directly associated with the need for hormonal balance. If, in the “outdated” performance, the consumption of contraceptives was enough to treat PCOS, in the “updated” performance, predominant in the material analyzed, the use of contraceptives becomes controversial, and the big issue is “combating” a supposed excess of male hormones through eminently global strategies. In this sense, the PCOS-associated symptoms, the description of the treatments adopted, and their success reveal a strong connection with the projection of an idealized female body in which the so-called male hormones would need to be overly controlled.

This article continues with the presentation of the methodological aspects of the research. Next, we report the empirical results observed during the monitoring of the Facebook groups, underscoring the aesthetic symptoms emphasized by the participants as typical of PCOS, the cause of much suffering, and their transformative attempts, signaled in the posts that indicate the “before” and “after” lifestyle change. In this sense, we present the synthesis of observations about weight gain, unwanted hair, and acne in more detail. In the final discussion, we highlight how this event is linked to the historically produced binary gender pattern centered on bodily differences.

## Methods

### The proposed approach and Facebook groups

This investigation is anchored in works that discuss the relevance of the Internet and social networks in the contemporary context, such as Hine<sup>7</sup>, Segata and Rifiotis<sup>8</sup>, Leitão and Gomes<sup>9</sup>, and Miskolci and Balieiro<sup>10</sup>, debating the emergence of new forms of sociability and identity production via engagement in groups, like on Facebook. In particular, we should pay attention to the relevance of social media in the configuration of female self-representation forms that have

emerged in the most recent setting, as observed in Dobson<sup>11</sup> and Rohden and Silva<sup>12</sup>.

In this sense, we monitored six PCOS-related groups on Facebook. Field insertion occurred in September 2020 through the personal Facebook profile of one of the authors via a simple search on the same social network for the terms “Polycystic Ovary Syndrome” and “PCOS”. The posts were monitored and analyzed until July 2021. Entry and participation in the groups were directly negotiated with the administrators, and the research objectives were informed. All ethical care was taken to ensure the anonymity of the participants and the non-identification of the groups, including using fictitious names when necessary. When reproduced here, the posts had their original spellings, highlighting the particular interaction between the groups.

We selected six private groups established from 2014 to 2019, with at least six thousand participants (Group A: 6,763 members; Group B: 9,401; Group C: 10,044; Group D: 11,160; Group E: 20,105; and Group F: 184,818). All had a significant number of interactions, including posts, likes, and comments. After the period of fieldwork and constant monitoring of the groups, the posts that triggered a more significant number of interactions were selected for a more in-depth content analysis using the central categories of the investigation. We identified that they addressed, above all, topics related to aesthetics and pregnancy. We also observed a direct relationship between the process of diagnosing women with PCOS and the moment they entered the groups. When diagnosed with PCOS, women seek support in these spaces, whether to clarify doubts, discuss relevant topics about the syndrome, or share complaints, among other possibilities. Most participants also consume PCOS-related content on Instagram and YouTube, produced mainly by health professionals. As has been observed in recent studies, for example, Silva<sup>13</sup> and Cavalheiro and Rohden<sup>14</sup>, using digital spaces to discuss issues related to health and well-being has become increasingly common. However, the novelty we underscore here is the strength or impact of sociability in groups to shape the “updated” perspective on PCOS, centered on changing lifestyle and improving oneself.

We observed a common profile among group participants regarding ethnicity/skin color, social class, and age. This is not data collected directly from them and rigorously systematized, but our perception through information and pictures posted on social networks. Thus, we can indicate

that the users of the groups were primarily white, aged 18-40, and predominantly middle and lower-middle class. Some participants reported being clients of the Unified Health System (SUS).

## Results

### The transformation value seen in the “before” and “after”

The publications analyzed reproduce a prevalent structure, with texts and pictures characterized by the expression of the “before-after” dichotomy, where the “after” moment seems to represent an achievement for the participant, a better moment than the previous one. The different measurements of the women’s bodies and feelings of joy when the participant achieves her goal or sadness when the goals are not achieved are traversed by time. Some accounts are very objective and only talk about the participant’s current situation, while others are more detailed and inform about the process, from before diagnosis to the present moment. The more detailed publications generally include comments on the diagnosis (appointments, tests, and chosen professionals), the treatment followed (chosen diet, whether or not engaging in physical activity, and whether or not using any medication), and any difficulties and achievements. Bruna’s story can be understood as an excellent example of the posts analyzed:

*Hi beautiful!*

*The three women in the photos are me at different stages of my life:*

*1 photo: At the end of 2015, I weighed about 63 kg. My life was hectic. I ate terribly and had high cholesterol and triglycerides. I worked out a lot to compensate for my bad diet. I had much acne and lived on medication. I still didn’t know I had PCOS. I was taking contraceptives.*

*2 photo: At the end of 2018, I was at my highest weight, 87.5 kg. Cholesterol and triglycerides were good. The food was better. I ate real food. Zero physical activity. (I have severe back problems and ended up becoming very sedentary). I had stopped taking contraceptives.*

*3 photo: This is now: 75.4 kg. Seeking to balance with nutritionist and endocrine monitoring. Taking contraceptives and eating better, without restrictions, just with balanced meals. Light physical activity (If my spine allows it, I do it. If I feel pain, I don’t). -12.1 kg. I hope to come here with the fourth picture, with my goal achieved.*

Bruna presents three photos to express the “before” and “after” and contextualizes under what circumstances the photos were taken. It is interesting to note that in the case of this participant, her goal was not achieved linearly; that is, in the second photo, she says that she gained weight and improved some aspects of her health and habits. She comments on her diet, body measurements, physical activity, and contraceptive use. Pictures of her were produced at different stages and express body changes associated with a new “lifestyle”, necessary for good PCOS management.

When we considered the comments during the interactions, which were also the subject of our analysis, we noticed an intense search to reinforce and assist the transformation project narrated and illustrated in the pictures. Comments congratulating women who have managed to lose weight are frequent. Along with them were questions, tips about what was done, and some venting from other participants. When this happens, the woman who published seeks to inspire the participant in question, telling her not to give up on her goal. This general posting structure and the interactions were perceived in the three aspects associated with aesthetics, which we will describe below.

### Centrality attributed to weight gain

Comments about losing weight are necessarily identified when discussing weight gain in groups. Women with PCOS may experience weight gain and difficulty losing weight due to endocrine bodily changes. According to the participants, the main reasons for weight gain are insulin resistance and increased male hormones.

We identified two situations regarding the weight variable in the context of the groups: women who only have an abdomen fat concentration and those with increased overall body measurements. Sometimes, these situations can be experienced by the same woman.

The strong presence of pictures illustrates these two situations in groups. Generally, only one picture regarding abdomen fat concentration is shared. Several pictures are displayed in the case of weight gain as a whole. They fit the “before” and “after” profiles mentioned above. The most common feature in these publications is sharing photos that show women’s bellies. Many accounts are permeated by dissatisfaction, insecurity, and suffering. Some participants often report having been mistaken for pregnant women,

which considerably affects their self-esteem. They believe that the leading cause of these situations is the consumption of inflammatory foods, such as sugar, bread, cakes, refined carbohydrates, milk, and dairy products. For this reason, part of the PCOS treatment, which focuses on changing lifestyle, includes having a healthy diet, which, for some users, is understood as adopting a low-carb diet (lower carbohydrate intake and consumption of quality carbohydrates, that is, whole grains).

As previously stated, it is uncommon to find discussions about weight gain that do not refer to the need for weight loss. Women who manage to control the syndrome's symptoms, especially the aesthetic ones, talk about their weight loss and that it was essential to adjust the other symptoms. Weight loss always appears as a "facilitator" to gain control of other PCOS symptoms. We found in the groups some statements that informed us about the need to control the syndrome to lose weight. However, on the other hand, we identified comments regarding the need to lose weight to control the syndrome, thus configuring a controversial setting concerning weight loss in the PCOS. The recommendation is to lose weight first to get pregnant and reduce facial hair. In this sense, it is widespread to mention foods to consume or stop consuming to achieve the goal of losing weight.

The participants' comments uncovered the main steps for a woman with PCOS to lose weight, which are divided into three axes: nutrition, physical activity, and medications or supplements. The diet focuses on the need to adapt to a low-carb diet. As for physical activity, the recommendation is to carry out an activity that requires more strength, such as weight training. Regarding medications, the main ones mentioned are Glifage and Metformin, commonly used to treat diabetes and which, in this case, would also help with weight reduction by improving the patient's insulin levels. Finally, the Myo-inositol supplement fulfills a similar function to the abovementioned medications for promoting weight loss.

In this sense, when perceiving the strong incentive and pressure to establish a new care routine, we see how self-management is fundamental for thinking about changes concerning the participants' body measurements. It becomes only possible to understand the emphasis on weight loss by considering the ongoing management of what one eats, how much one eats, what type of physical activity one does and for how long, what medication or supplement one takes, and whether it is consumed correctly.

### The discomfort with acne

As already mentioned, group participants understand PCOS as a disease that affects the whole, and the most advocated treatment must involve multidisciplinary monitoring. In this sense, there is no single explanation for the more significant presence of acne in women with PCOS. However, the main reason cited is increased male hormones or, in medical terms, hyperandrogenism. This hormonal change can increase skin oil texture and acne. For this reason, this is the first path to investigate when women have this complaint.

As this is one of the main complaints and discomforts of women with the syndrome, one would expect sharing publications with pictures of women's body parts that highlight the amount of acne and the body site with the highest concentration. The photographs showed blackheads, red pimples, and pimple marks, mainly on the face. Paula exemplifies the discouragement of many with her situation:

*Well, girls, PCOS got the best of me. I can't stand waking up and seeing myself like this! Everyone looks and asks what happened to my face [...]. I don't want to arrive at my long-awaited graduation in December with a face like that. I'm tired!*

It is interesting to observe Paula's report and pay attention to the section "*PCOS got the best of me*", characterizing living with the syndrome as a battle in which Paula feels like a loser. When we understand that PCOS is treated through lifestyle changes, it is also necessary to understand that maintaining this properly managed healthy lifestyle is impossible all the time. Aesthetic symptoms such as acne can become disordered at these times, or even within the recommended management. In this sense, group participants associate a healthy lifestyle with skin with little or no acne. Many people comment on the need to treat the cause and not the consequence of the problem, in this case, treating hormonal dysregulation and not just the acne itself. Participants often refer to this as treating "from the inside out".

We also identified, in the case of acne, sharing tips on how to control it. Foods to consume or stop consuming, medicines, herbal medicines, names of acids, moisturizing creams, soaps, and homemade recipes for this purpose. As Bruna said, "*living with PCOS is a real rollercoaster. There are days when my self-esteem is at its lowest point, and I cry a lot and start my skin cleansing routines again*" and other care routines. Like so many other women, her story shows how the dimension of self-control and lifestyle changes

toward managing PCOS are perceived as significant battles that involve a lot of commitment and dedication.

### **The fight against unwanted hair**

The presence of unwanted hair is one of the symptoms that most bothers women with PCOS. According to group participants, the leading cause is the increase in so-called male hormones in women's bodies or insulin resistance. In this sense, managing this symptom is also associated with a change in women's lifestyle.

In publications about hair, some women share pictures of their bodies to show the amount, thickness, color, and site where hair grows most frequently. Through the participants' reports and the photos shared, we observed a pattern in the hair of women with PCOS, characterized by accelerated growth and in sites typical of male bodies. Hair may also become thicker and darker. The main body parts depicted in the pictures were the participants' faces, necks, and thighs. Some pictures also depict ingrown hairs. As Jana exemplifies:

*I have much hair all over my body, and I've always suffered similarly. I wear jeans more than I wear shorts. It's hard to see other ordinary girls wearing shorts, bikinis, and everything else, and I can't. I hate my body and that hair much more.*

Jana's report relates the presence of hair to suffering since she does not feel like "other normal girls" who, she says, can wear shorts and bikinis, while she cannot or may not because she has much hair. Jana states that she hates her body and her hair, presenting a sensitive narrative traversed by issues related to her self-esteem. She exemplifies well the various publications we found in the groups expressing the participants' dissatisfaction over their bodies. Like many other participants, Marcela also comments:

*I go through the same thing: hair all over my body. I feel so ashamed and suffer a lot from it. On my face, it's the worst because people look and say, "Wow, do you have a beard?" I don't know where to hide my face, and other than that, I have a dark neck and armpits: it's horrible.*

At various times in the groups, we observed comments that made us think that the hair on the face bothered the participants the most, which could be explained because the face is the most difficult or even impossible place to hide hair, with no alternative other than waxing. The reference to the beard appears regularly in the publications, further illustrating how facial hair

causes significant discomfort to the participants and strains the concept of femininity, which is highly valued by traditional beauty standards. The mention of darkened body parts may be due to insulin resistance, such as due to some hair removal methods.

The publications and comments also include discussions about hair removal methods. Wax, thread, razor, laser, and small electronic devices are the main methods discussed in the groups. The participants affirm that wax makes the skin more flaccid, the thread causes much pain, and the blade thickens the hair, making it more resistant and accelerating its growth. The laser requires a high investment – and there are only a few specific types that work for women with PCOS – and electronic devices also cause pain. Pain is a category that appears frequently in comments about waxing. However, it becomes acceptable to most participants when they think about the procedure's final result. In this sense, hair growth slowdown and thinning compensate for the pain felt and are often sought. Once again, we see the production of a need due to social pressure for a hairless female body and face and the prescription of treatments that require coping with aesthetic discomfort and adopting regular self-management practices to face the problem.

### **Discussion**

Based on the empirical material observed, we would like to discuss some implications of the fact that PCOS, as evidenced by women who expose their diagnostic and therapeutic trajectories on social media, is centered on factors associated with the aesthetic dimension. This work did not aim to discuss the medical controversies surrounding PCOS and even to delve into the extent to which aesthetic signs would or would not be associated with other factors that would indicate the syndrome from a medical viewpoint. We aimed to analyze women's public statements about their experience with PCOS. In this sense, we should underscore the intense exchange of experiences and knowledge regarding symptoms, treatments, and professionals recommended to monitor the problem, which undoubtedly converts these group participants into "expert patients", as proposed by Dumit<sup>15</sup>. Next, we will discuss some points that allow us to advance the interpretation of this event.

The first of these refers to the fact that, although posts about PCOS emphasize the recur-

rence of contraceptive use, we could not observe the broader debates over the controversies surrounding the use of these medications. More objectively, as most participants in the groups have already tried contraceptive treatment, a medication used preferentially for many decades to treat PCOS, this becomes the focus of the debates. They are, above all, supporters of updated performance who condemn the use of contraceptives, as they would only hide the symptoms of the syndrome that would return more intense when the treatment was interrupted. In this debate, the focus is on the inadequacy of contraceptives as a way of approaching PCOS. However, we did not identify, for example, a more comprehensive discussion about their adverse effects, as has been shown in research on public controversies and activism of women who consider themselves harmed by the use of these medications, as in Santos<sup>16</sup>, Pissolito<sup>17</sup>, and Kloppel<sup>18</sup>.

We could suggest, perhaps, that the lack of articulation in this debate occurs for two reasons. The first concerns the fact that its relationship with contraceptives was primarily due to its secondary aesthetic effects, such as skin improvement and weight loss, and that, somehow, places these remedies in the particular and, in principle, less politicized context of so-called lifestyle medications<sup>19</sup> and the use of hormonal implants for aesthetic and performance-enhancing purposes<sup>20</sup>. The second reason is that women in the groups may focus on changing their lifestyles individually. Supporters of the updated PCOS performance have already discredited the therapeutic value of contraceptives. They are oriented towards the search for new treatments in which the commitment to adopting new habits aimed at aesthetic improvement becomes central.

As we can observe in the descriptions presented, the diagnosis and the treatment and, above all, the complaints and the satisfactory results, in most cases, focus on aesthetic aspects. Acne, excess hair, and weight gain are fundamental indicators of something wrong and require clinical monitoring. We want to consider precisely how much these indicators (or symptoms) are associated with traditional and strict beauty and femininity standards. If we were not in a society that overemphasizes such demanding standards regarding the female body, the concerns and suffering of women and teenagers regarding the presence of acne, hair, and a body that is not necessarily thin would not be so intense.

Smooth skin, the absence of hair in “unwanted” sites, and a slim silhouette are associated with

a historically produced and valued female body model. This model prioritizes containing “excesses”, skin roughness, hair, and fat, which could indicate greater proximity to the male body. According to gender standards constructed over the last few centuries and which still resonate, men’s and women’s genders and bodies should represent complementary opposites. As medical literature illustrates, mainly from the 19<sup>th</sup> and mid-20<sup>th</sup> centuries, from the skeleton through muscles and other different tissues and internal and external organs, ideally, they should demonstrate the binary and radical distinction between male and female. According to Laqueur<sup>21</sup> and Rohden<sup>22</sup>, this distinction would be deeply associated with the current social order and the social roles attributed differently to men and women. Currently, the search for beauty and “perfection” continues to be deeply marked by binary gender differentiation and associated with unequal opportunities in the neoliberal context, as observed in Jarrin<sup>23</sup> and McRobbie<sup>24</sup>.

Furthermore, inspired by the work of Butler<sup>25</sup>, we suggest that it is about understanding how gender is a constantly embodied and updated operational matrix. Through standards referenced by many doctors and desired by women, intervention and normalization practices constitute updates or recitations of the binary gender norm that prescribes the existence of highly differentiated bodies. Part of this process is promoting ideals compulsorily assumed by many people who cannot recognize alternatives or divergent and viable standards in this societal model.

In this sense, we understand how hormones reemerge as fundamental entities guiding the gender performances experienced by group participants. As described in the literature, the so-called sexual hormones have played a central role in defining and even prescribing gender differences. As Oudshoorn<sup>26</sup> showed in a pioneering way, the “discovery” of hormones exclusive to male and female bodies in the first decades of the 20<sup>th</sup> century promoted a new logic of differentiating men and women based on these “messengers”. Besides chemical messengers, hormones also produce patterns of differentiation concerning gender binarism. From then on, the production of femininity and masculinity pictures would become associated with these “substances”.

In the case of the material analyzed here, the frequency and insistence on what is defined as an “excess of male hormones” in female bodies, which would characterize PCOS, reveals how much this logic of hormonal differentiation con-

tinues to be present and how the performativities of the feminine gender for the women in the groups are associated with aesthetic standards related to what historically have been defined as “secondary sexual characteristics”, resulting from the presence or lack of a specific hormone.

Finally, we should draw attention to the fact that this transformation, in the analyzed event, centered on aesthetic factors, may not necessarily imply a healthier life. The search focused on suppressing undesirable aesthetic factors, which are not necessarily indicators of health problems, can, in itself, become a factor that produces

suffering for these women. As discussed in Edmonds and Sanabria<sup>27</sup> and Rohden<sup>28</sup>, we should consider that the search for an improved life can also lead to a less healthy life or new risks associated with new practices. As a result, it becomes increasingly important to analyze and understand the practices and discourses related to diagnoses and therapeutic resources that circulate, especially on the Internet and social networks, among people who use different treatments and identify the meanings and rationale involved in adopting new practices and ideas and moralities associated with possible diagnoses.



## **Collaborations**

The article is authored equally at all stages by F Rohden and AS Corrêa.

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