



POLYCYSTIC OVARY SYNDROME

The impact of PCOS on self-image, self-esteem

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AN ESTIMATED 12% of women worldwide live with polycystic ovary syndrome (PCOS) – a hormonal disorder affecting women in their reproductive years – yet it remains an under-researched condition that is not discussed openly. In celebration of Women's Day on August 9, we want to shine a light on this important issue.

Women with PCOS may experience absent or irregular menstrual cycles, excess male hormones such as testosterone that can result in acne, excessive body and facial hair, hair thinning, and the appearance of cysts on ovaries. Patients with PCOS may also be diagnosed with associated medical conditions, such as insulin resistance, infertility, heart disease and diabetes.

Considering these related health problems and symptoms, it is not surprising that PCOS can negatively impact a woman's physical well-being, ability to be productive and social interactions. Some women with PCOS have reported withdrawing from social life. Additionally, many of the symptoms – especially those relating to the hormonal profile of patients with PCOS – leave women feeling less feminine and negatively impacts their self-esteem and self-image.

In a recent study, we explored the impact of PCOS on the self-image and self-esteem of women in the Western Cape. At the time, there had been no in-depth interview-based studies on how PCOS affects self-image and self-esteem – specifically among South African women living with the con-

dition. We used interviews and body mapping as our research methods.

Body mapping is a novel, arts-based technique that allows us to explore patients' personal bodily experiences – usually in relation to a health condition. It involves the creation of a to-scale outline of the person's body that the participant then fills with figurative representations of their experiences.

For example, participants may draw areas in which they experience pain or indicate symptoms such as acne on their body maps. They may use several forms of expression, such as images and words extracted from magazines, to depict their bodily experiences of the disease. Throughout the process, we asked women to reflect on how their bodies felt and how they experienced their bodies. We also interviewed them after the body mapping process to gain deep insights into how PCOS impacted their self-image and self-esteem.

Our data provided a rich description of their bodily experiences with PCOS. A clear theme of "disrupted femininity" emerged from the study. Women highlighted the impact of symptoms related to the presence of too many male hormones, such as hirsutism (hair growth in areas of the body typically considered to be male patterned e.g., on the face), weight gain, hyperpigmentation, alopecia (loss of hair from areas where it is normally found) and acne had on their self-image and femininity. These symptoms often left them feeling less feminine, with some participants going as far as to use the term "hairy beast".

Sadly, this term suggests the expe-

rience of not only feeling less womanly but potentially even less human. Participants used other words to describe themselves, including "hippo", "worthless" and "the DUFF", an acronym for the colloquial term "designated ugly fat friend". At times, the gravity of these words almost appeared lost in their flippant delivery, revealing just how normal it felt for some of the women to express deep loathing and criticism towards themselves.

The participants noted that the extent of their damaged self-image led to excessive self-policing. Many said that they spent quite a bit of time and money to control their acne and remove unwanted hair. Some reported fixating on these issues, noting that the symptoms made them self-conscious – leading to social withdrawal and negatively impacting their career progression, as they lacked the confidence to be more visible in their roles at work.

While physical appearance was one factor that negatively impacted their self-esteem and self-image, the struggle to conceive caused great distress for many and reinforced feelings of failure as a woman. Participants described the feminine ideal bodily functioning as having regular, manageable periods and the ability to conceive easily. While these beliefs represent traditional, cis-normative (the assumption that people whose gender matches their birth sex are normal, and that everyone else is not) definitions of womanhood and femininity and are thus not all encompassing, they represent very real, raw and commonly shared experiences.

In a particularly poignant state-

ment, one woman compared her body to a broken photocopier, unable to fulfil the one purpose (reproduction) she believed her body was intended for. This not only speaks to the devastating impact of PCOS on self-worth but also to an underlying belief that the purpose of the female body is to reproduce, and that failure to do so renders it useless. It gives one pause to consider just how much weight societal norms and messaging surrounding women and their bodies carries.

Our participants often referred to society-wide beauty standards for women as significantly contributing to how they evaluated themselves as women. It is difficult to escape what we deem as beautiful in a world dominated by the media, which seeks to represent beauty and femininity within a narrow spectrum. Furthermore, what is desired in relation to women's appearances and purpose are often driven by commercialisation. For the women we spoke to, much of their condition positioned them outside of the realm of what is aspirational for women, thereby negatively impacting their self-image and self-esteem.

We were saddened by our findings but are hopeful that raising awareness about the experiences of women with PCOS – and highlighting the negative impact of their symptoms on their self-esteem and self-image – can lead to increased compassion and understanding towards patients.

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