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Exploring Psychological Well-being through the Lens of Women with Polycystic Ovary Syndrome (PCOS): A Photovoice Investigation in India

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Abstract

Polycystic Ovary Syndrome (PCOS) is a chronic health condition that can have detrimental effects on a woman's physical and psychological health. Apart from the various clinical manifestations like hirsutism, hyperandrogenism, metabolic disturbances, insulin resistance, obesity, infertility, alopecia, oligomenorrhea, anovulation, etc, women with PCOS are more likely to experience psychological implications like depression and anxiety disorders, eating disorders, obsessive-compulsive disorder, somatization, etc, leading to decreased quality of life as compared to women without the condition. The unique subjective experiences to identify factors of psychological well-being among women with PCOS have not been adequately explored in India in depth through qualitative measures. The study aims to understand and explore psychological well-being among ten women clinically diagnosed with PCOS, aged between 18 to 45 years, by employing a photovoice, which served as a tool of self-reflection as well as a means of creative expression while undergoing psychological distress associated with PCOS. The outcomes from the diary entries were analysed and discussed employing Reflexive Thematic Analysis (RTA) to identify the patterns and themes. The four themes identified from the dataset were, namely, a journey of self-acceptance and unconditional self-love, redefining the concept of "beautiful" and embracing vulnerability, social support, and the need for a safe space to belong, as well as empowerment and personal growth. The study emphasises the importance of awareness of PCOS to reduce the taboo and stigma associated with menstrual health in India and the need for more health facilities to acknowledge and improve the psychological health of women with PCOS.

Keywords: Polycystic Ovary Syndrome (PCOS), Psychological Well-being, Photovoice, Reflexive Thematic analysis, Menstrual Health

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INTRODUCTION:

Emotional dimensions among individuals with chronic ailments are often overlooked when medical care is considered. Understanding the psychological, psycho-social, or cultural aspects of health conditions has always been challenging for healthcare practitioners. (Turner & Kelly,

2000) Ganie et al. (2019) pointed out that the prevalence rate of PCOS in India ranges from 3.7 to 22.5 percent. Polycystic Ovary Syndrome (PCOS) is a disorder of the endocrine system and carries the most common endocrinopathy in women of reproductive age.

Barnard et al. (2007) in their study demonstrated how women with PCOS experienced a lower quality of life due to emotional disturbance, weight, infertility, acne, menstrual symptoms, menstrual predictability, and hirsutism in their study. Hence, psychological well-being is an important aspect that can enhance the quality of life of individuals with chronic conditions. There is a significant amount of psychological burden, which may be because of decreased sexual satisfaction, body image concerns, obesity, and disruptions to feminine identity (Bahadori et al., 2022; Himelein & Thatcher, 2006; Sulaiman et al., 2017). According to studies by de Niet et al. (2010), Ramanand et al. (2013), and Witchel et al. (2019), the clinical symptoms of PCOS, like hyperandrogenism and anovulation, have been shown to negatively affect psychological well-being. This highlights the need for more qualitative research to have an in-depth understanding of the lived experiences of individuals with PCOS, which is also the objective of this study to understand how women with PCOS interpret and cope with psychological well-being while living with the condition.

The psychological well-being of an individual comprises the elements of feeling good and functioning effectively; it's often compromised when there are adverse negative life events in an individual's life, and it interferes with their adaptive functioning. (Huppert, 2009) By looking through Carol Ryff's theoretical model of psychological well-being, which incorporates six positive functioning factors, namely, autonomy, environmental mastery, personal growth, purpose in life, positive relations with others, and self-acceptance,

the current study aims to explore the positive psychological experiences that enhance psychological well-being among women with PCOS.

METHOD

Research Design

To capture the diverse perspectives on their lived experiences with Polycystic Ovary Syndrome (PCOS), the researchers employed photovoice which is type of participatory qualitative research among ten participants diagnosed with PCOS with different symptoms keeping in mind the objective of the research which was to understand and explore psychological well-being among ten women clinically diagnosed with PCOS. The study was conducted with the help of both visual and narrative data through photographs and diary entries. The photographs provide a creative medium for the participants for self-expression and provide them a voice through participation to raise their community needs. (Candace I.J. Nykiforuk, 2001)

The researchers observed a high attrition rate from the participants approached for the study. After briefing the participants regarding the aims and objectives of the study, the researchers had to wait for two weeks until their participation. There were a total of twenty participants who were approached initially, but only ten of them made their submissions. This was observed in the current study as well, when a few of the participants showed disinterest because they felt the procedure was tedious and overwhelming for them. Other reasons for the dropouts may be due to the lack of motivation, stigma, and taboo attached to menstrual health in India.

Research question

The research question for the study is: "What are the positive psychological experiences that enhance psychological well-being among women with PCOS?"

Participants

To ensure accurate representation, only the participants who had been clinically diagnosed and underwent some form of treatment for PCOS were taken for the study.

Inclusion criteria:

Women with a clinical diagnosis of Polycystic Ovary Syndrome (PCOS) aged between 18 to 40 years undergoing hormonal therapy for PCOS or who underwent some form of treatment modality for PCOS recently within a year in India were recruited for the study. They were well-versed in English, and a majority of them were single women, whereas two of them were married among the ten. The participants submitted their photographs along with their diary entries from within a week from across northern and southern metropolitan cities of India.

Exclusion criteria:

Women diagnosed with thyroid disease, high prolactin levels, non-classical congenital adrenal hyperplasia, Cushing Syndrome, or any other diagnosis with similar clinical features of PCOS were excluded from the study. Participants who never underwent any form of treatment modality for PCOS were excluded as well. Lastly, women who are currently undergoing pregnancy were excluded from the study.

Measures

The participants were provided a Google Form where they could submit their photographs and diary entries describing their reasons for choosing their respective photographs, which provided a visual representation of their experiences. To ensure trustworthiness, the researcher made

reflections on the data with the supervisor during the first stage of data analysis, and member checking was also done with the participants during theme generation. (Shenton, 2004).

Procedure

The participants for the study were recruited through purposive sampling and the sample size was ten. The researcher actively participated in rapport-building with the participants for more than two weeks and briefed them regarding the objective of the research. The participants were then introduced to the concept of photovoice and requested them to make their photograph and diary entries submissions within a week. They were requested to self-reflect and pen down their thoughts about their understanding of psychological well-being while undergoing different intensities of physical and psychological distress associated with PCOS. Although, the participants were not given a definition of psychological well-being before their participation. After receiving informed consent about their voluntary participation, the researcher circulated a Google form which included their socio-demographic details like their name, age, educational qualification, occupation, religion, socio-economic status, marital status, family type, year of diagnosis, level of adherence in seeking hormonal therapy for PCOS and reason for discontinuing hormonal therapy if any. The participants were assured their details would be strictly confidential throughout the research process. They were asked to ponder and reflect on their thoughts over a week about what was the most important factor that helped them alleviate their psychological health and cope with the distress related to PCOS. They were instructed to provide a photograph that best fits their situation, along with a small write-

up as a diary entry describing their thoughts associated with the photograph. The participants were instructed to state the reason why they chose the photograph and how it alleviated their emotional health and overall functioning while living with PCOS. This helped the researchers explore and understand the various ways these participants enhanced their emotional health and psychological well-being while living with the condition.

Ethical Considerations

The study was approved by the Research Conduct and Ethics Committee of the CHRIST Deemed to be University, Bangalore. Informed consent was obtained from all the participants recruited in the study. The COREQ (Consolidated Criteria for Reporting Qualitative Research) Checklist was used in the study to help the researchers report important aspects of the research team, findings, and interpretations, study methods, etc. (Tong et al., 2007) Socio-demographic details and informed consent for participation were also received from the participants in the Google form stating that all the data shared by them will strictly confidential, will only be used for academic purposes and shall be deleted once the study is completed.

Researcher Positionality

The researchers were mindful that their positionality in the study may influence the research process in a number of ways, firstly as women and secondly, their own personal experiences or close encounters of women clinically diagnosed with PCOS may shape their interpretation of the data. However, the researchers were committed to being reflexive about their positionality and

to using it to deepen their understanding of women's experiences with psychological well-being while undergoing psychological distress associated with PCOS.

Qualitative Analysis

The data received through the Google form were analysed using the Reflexive Thematic Analysis (TA) approach to develop patterns across the ten cases, which is a six-phase approach that views qualitative research as reflexive, creative, and subjective, taking the researcher's subjectivity as a resource rather than a threat. (Gough & Madill, 2012) By sharing their reflective diary entries and photographs, the participants functioned as co-researchers by offering their valuable insights into their psychological well-being and lived experiences with PCOS. Along with coding the narrative data from the diary entries, the researchers also provided their interpretations by maintaining a personal journal for both the visual data (photographs) and narrative data (diary entries). The integrated findings led to the development of the main themes for the study.

RESULTS

The researchers started with familiarisation of data that involved reading and re-reading of the diary entries to be familiar with the data in-depth, which became the first phase of the analysis. In this stage, the researcher maintained a personal journal to note down her viewpoints and any important information that may be relevant to the research question. Preliminary notes were made by the researcher in this phase. An example of preliminary notes made during the familiarisation phase has been presented below:

Figure 1*Example of preliminary notes made during phase one*

“ The participants have undergone a deep state of extreme vulnerability in the initial days of their diagnosis.”

“They have rekindled the relationship with their vulnerable self and moved in a state of surrender and acceptance.”

“ Social withdrawal is common in almost all the cases.”

“They view their support system like her family, close friends and significant other as a safe space to be emotionally naked and be their true self.”

“Enhanced confidence and positive self-talk observed after continuing hormonal therapy.”

The second phase involved generating initial codes where any relevant information addressing the research question was coded. This phase of coding is performed in order to produce shorthand descriptions or labels of relevant information to the research question. (Byrne, 2022) A brief excerpt of the researcher generating the initial codes from the data has been presented below in brief: **Figure-2**-

P1 : “I have lived alone by myself for the past decade and during this period I have usually kept to myself. I do not interact as much with people and I keep my struggles and successes to myself as well.” Code- Solitude and social withdrawal

P2: “My experience with PCOS always makes me feel like a lot is taken from me whilst what is given back constitutes side effects. There has been no lingering joy and moment of peace since my diagnosis. Coupled with anxiety, dogs and puppies are the only solace and wellspring of happiness in the desertscape of PCOS.” Code- Depth of sadness and vulnerability

P5: “. Occasions like these where I'm surrounded by people who I love and who love me, helps me to forget stress, be in the moment and enjoy parts of life as and when it comes. It is a huge strength to know that eventually everything works out, and you are never alone.”

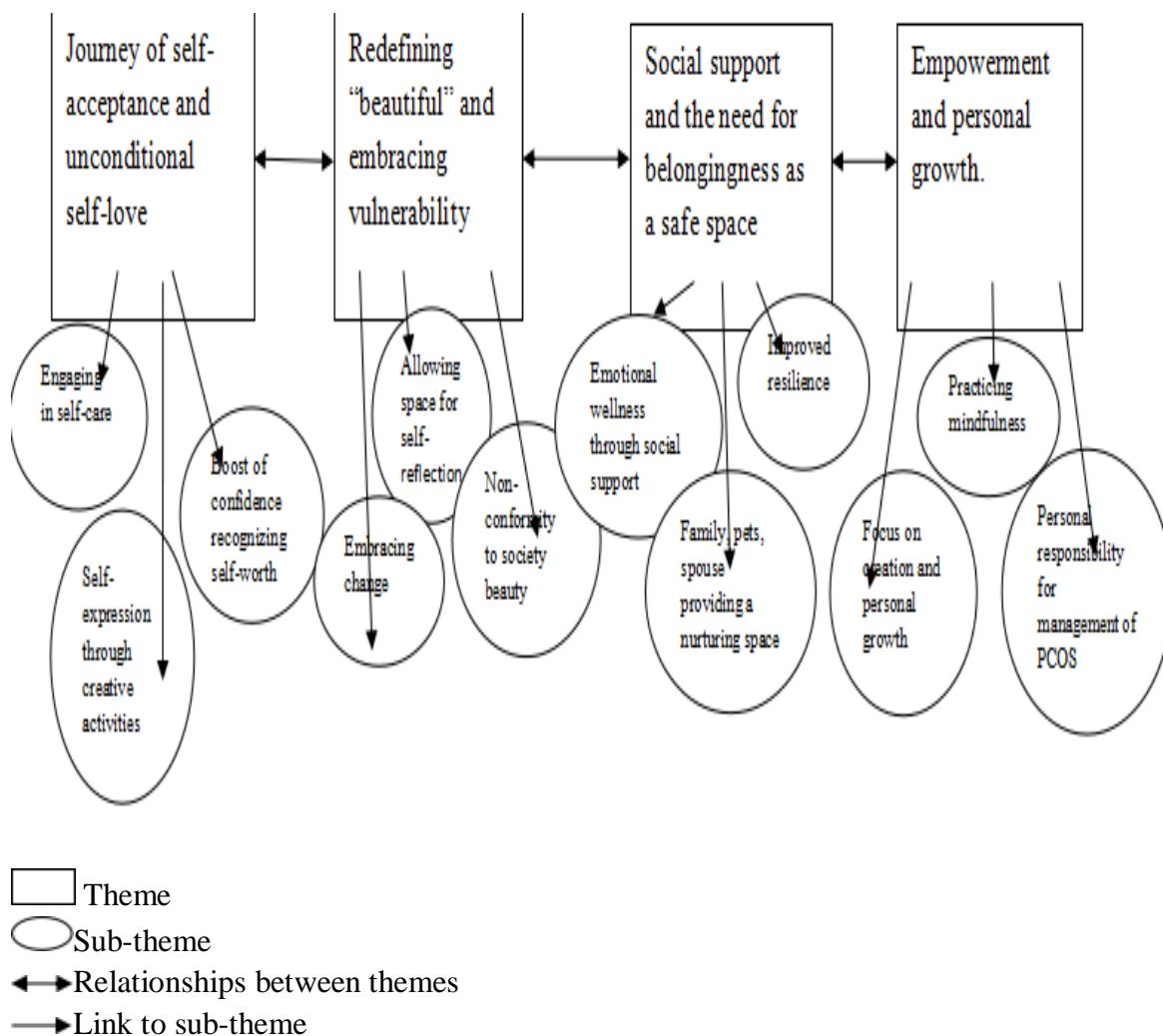
Code- Need for belongingness and being mindful

Examples of generating initial codes in phase 3

The third phase begins with generating themes from the relevant codes generated from the whole dataset and interpretation of collective meaning-making across the dataset. The researcher developed an initial thematic map comprising of the themes and

sub-themes depicting the relationships across themes and links to sub-themes. The fourth phase is where the researcher reviewed the potential themes and developed the finalized version of the thematic map which has been shown in the figure below:

Figure 3
Finalized thematic map in stage four:



The fifth stage includes defining and naming themes where the researcher has to present a detailed analysis of the thematic framework illustrating the relationships between themes

and how it adds relevance to the research question. Here, the researcher has made the necessary changes in naming the themes and was mindful if any theme has to be excluded.

There were a total of four themes that were generated from the data set namely, journey of self-acceptance and unconditional self-love, redefining "beautiful" and embracing vulnerability, social support and the need for belongingness as a safe space, empowerment and personal growth. The sixth and the final phase of the analysis included producing the final report which is discussed in depth in the discussion section.

DISCUSSION

The current study has used Reflexive Thematic Analysis as an interpretative approach to data analysis and revealed four themes relating to the participants' experiences with psychological well-being while living with Polycystic Ovary Syndrome (PCOS). The first theme "journey of acceptance and unconditional self-love" highlights the experiences by the participants where they expressed the importance of indulging in self-care, engaging in activities of creative expression like dancing, painting, traveling, sports, yoga ,and meditation, undergoing treatment regime for PCOS, having a balanced diet, following a disciplined lifestyle, etc that helped them cope the condition and bring in positivity in their life. They have expressed that since they are aware of the fact that PCOS has no cure and they have to live with it their entire, they have consciously made an effort to accept the reality and live with it. Acceptance of the diagnosis can always help in the adaptation process but decreased support and stigma in the surrounding environment can affect a person negatively. (Stroumpouki et al., 2020) Hence, it is very vital for the person to embrace the uncertainty and embark on a journey of loving themselves unconditionally. The second theme "redefining beautiful and embracing vulnerability" pointed out their feelings of insecurities, low self-esteem,

negative body image, grief, and sadness associated with PCOS, and finally paving towards loving themselves enough to not let societal standards of beauty define them. The participants expressed how seeking help and support from their loved ones including their family, attachment to their pets, and positive relationships with their friends provided them a safe space devoid of judgments and allowed space to feel vulnerable and be their authentic self. Self-scrutiny paves the way towards self-consciousness that, in turn, gives way to self-confidence. (Gabler, 2016) Thus, considering the amount of mental strain the women with PCOS undergo with beauty ideals, they should strive to first build a healthy relationship with themselves. The process of reconstructing the self during the recovery process amidst enforced change is certainly a challenging task for women living with a chronic condition; however, accommodating this transition in their daily lives can bring forth positive changes. (Kralik et al., 2006) This was highlighted in the third theme, "social support and need for belongingness", as a safe space to nurture their overall well-being and promote emotional wellness. Social support can be an important facilitator for psychological support among women with PCOS and uplift their psycho-social well-being. (Ranasinghe et al., 2023) There is a significant positive association of social support and health-related quality of life among women with hirsutism, which is a common clinical symptom of PCOS. (Ekbäck et al., 2014) The participants in the current study expressed how social support was a strong determinant of their emotional wellness and how inclusive among their family and peers boosted their self-esteem. The last theme, "empowerment and personal growth," emphasises how individuals can hit rock bottom and yet rise from the ashes by

building resilience over time with patience and personal growth. The participants shared their experiences of actively making efforts to build medical adherence with PCOS, focusing on having a positive outlook of life, recognise their psychological needs and trying to live in the present rather than stressing on things that are out of their control. Group counselling focused on building supportive relationships with sharing narratives of illness experiences can have a positive psychological impact on women with PCOS.(Roessler et al., 2012) This can be an effective initiative taken by all the educational institutions to help the students who needs any kind of psychological support. Photo voice as a methodology aims at facilitating deep exploration of lived experiences which are often taken seriously, allows critical reflection of on the positioning of personal experiences. (Liebenberg, 2018) Critical consciousness as an important element of photovoice was brought into play by the participants when they expressed that engaging in this photo voice made them form a deeper connection with themselves and their surroundings and refine their spatial information. An enhanced understanding of their spatial experiences was personally empowering for all the participants. Hence, all four themes seen among the participants align with Carol Ryff's model of psychological well-being that includes elements of positive relations with others, self-acceptance, and personal growth, which were observed as important determinants to psychological well-being in individuals with chronic illness.(Ryff & Singer, 2008) The photo voice investigation allowed the participants to define psychological well-being for themselves and reflect on what parts of their journey in coping with PCOS are worth keeping and what requires change.

It also allowed the participants to introspect their own needs and perceive things through new lenses. The study also attempted to de-stigmatise and raise awareness about menstrual health in India. Although PCOS is quite rampant in the recent times, women still face hesitation to openly seek help because of the taboo associated with PCOS. They often feel that they will be labeled as "less feminine" and majority of Indian women are still oblivious about the psychological implications of PCOS. Hence, this community of women who are mostly under represented needs to collectively raise their voices and feel empowered enough to seek help and set an example for the generations to come.

Since the physical symptoms of PCOS were found to be mostly associated with psychological distress, the quality of life of women with the condition automatically gets degraded. (Zangeneh et al., 2012) Hence, adopting a multi-disciplinary approach to treat PCOS while considering the psychological aspects of the condition can be fruitful towards patient-care. (Borghi et al., 2018) Healthcare providers should develop specific psychological interventions to improve impaired psychological well-being among women diagnosed with PCOS. Educational institutions should use their campus spaces to provide a safe space for the students to come and seek support on how to manage their psychological well-being, along with battling the clinical symptoms of PCOS.

CONCLUSION

The findings from the current study explored the various kinds of subjective positive experiences that women with PCOS incorporate to bring forth psychological well-being in their own ways. The study also highlighted the need for ample awareness for

the psychological implications of PCOS that might deteriorate the quality of life of the affected population since it was observed that the participants have not explored the possibilities within their experiences. The study had limitations like a small sample size, high attrition rate, personal biases and the possibility of social-desirability and misinterpretation within the data set. Most of the research done on PCOS symptom-based in nature, which are dominated by medical research, focusing more the clinical manifestations of the condition. There is a dearth of qualitative studies exploring meaning-making and lived experiences of women with a clinical diagnosis of PCOS in India. This photo voice attempted to bring fourth positive individual empowerment results and gain a better understanding of the lived experiences of people from underrepresented populations like PCOS. The phrase "a picture is worth a thousand words" is best applicable in this research where the participants photographed their personal experiences of experiencing psychological well-being while living with PCOS. The photographs threw light on the research question. The researchers intend to share the photographs in a group setting too and interpret the findings collectively within a group, including the participants, an expert in the field of psychology and gynaecology. This group cohesiveness might bring forth collective consciousness, where all the members share their experiences and exchange knowledge about the condition. The discussion is expected to bring out a sense of critical consciousness about the psychological implications of PCOS and the importance of holistic wellness. The study also attempts to bring out the element of social change by allowing the women with PCOS to voice out their lived experiences and represent themselves without any

hesitation, considering the taboo and myths surrounding menstruation, their expected "role of a woman" and the pressure of keeping up with the societal standards of femininity. Future research on PCOS using photo voice can include a larger sample size since the findings in the current study cannot be generalised to represent the entire affected population with a diverse range of symptoms with varying intensities. Considering the assumption that green environments enhances psychological well-being in humans, educational institutions can also focus on adapting a space-based holistic approach by to support student's experiences with psychological distress. (Gullone, 2000) There is limited research on the genetics of psychological well-being. (Pluess, 2015) Hence, future research can come up on more studies in understanding of the bidirectional interplay of gene and environment and how they influence psychological well-being through a person's developmental stages, which might help reinforce quality of life among individuals living with chronic ailments.

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