

Navigating Identity: The Lived Experiences Javanese Women with Polycystic Ovary Syndrome (PCOS)

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Abstract / Abstrak

Polycystic Ovary Syndrome (PCOS) is a hormonal disorder in women of reproductive age, characterised by a constellation of symptoms including menstrual irregularities, hyperandrogenism and the presence of polycystic ovaries. In a culturally rich context such as Java, the experience of living with PCOS can be highly complex, with various cultural, social and personal factors interacting in a multitude of ways. This study explores how Javanese women with polycystic ovary syndrome (PCOS) navigate their identities within the sociocultural and religious context of Indonesia. A phenomenological approach was employed in the investigation, whereby in-depth interviews were conducted with ten Javanese women diagnosed with PCOS. Thematic analysis identified four key themes from the thematic analysis of the research data and were subsequently interpreted as a representation of the lived experiences of Javanese women with PCOS. The four identified themes are as follows: (1) thoughts about the illness, (2) perceptions of gender roles, (3) religious aspects and (4) social interactions.

Polycystic Ovary Syndrome (PCOS) adalah gangguan hormonal pada wanita usia reproduktif yang ditandai dengan gejala seperti ketidakteraturan menstruasi, hiperandrogenisme dan ovarium polikistik. Dalam konteks budaya yang kaya seperti Jawa, pengalaman hidup dengan PCOS bisa sangat kompleks karena berbagai faktor budaya, sosial, dan personal saling berinteraksi. Penelitian ini mengeksplorasi bagaimana wanita Jawa dengan polycystic ovary syndrome (PCOS) menavigasikan identitas mereka dalam konteks sosial budaya dan agama di Indonesia. Dengan pendekatan fenomenologi, dilakukan wawancara mendalam berkaitan dengan pengalaman mereka pada sepuluh orang wanita bersuku Jawa yang mengalami PCOS. Empat tema dihasilkan dari analisis tematik yang dilakukan pada data penelitian dan kemudian diinterpretasikan sebagai gambaran hidup wanita Jawa dengan PCOS. Keempat tema tersebut adalah: pemikiran tentang penyakit, persepsi peran gender, aspek keagamaan dan interaksi sosial.

Keywords / Kata kunci

PCOS;
Javanese Women;
Identity;
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*PCOS;
Wanita Jawa;
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Introduction

Polycystic Ovary Syndrome (PCOS) is one of the most common endocrine disorders affecting women of reproductive age worldwide, including in Indonesia. PCOS is characterized by a range of symptoms such as menstrual irregularities, hyperandrogenism, and polycystic ovaries, all of which can have significant impacts on both the physical and psychological health of affected women (Williams, T., et al., 2016).

PCOS is a hormonal disorder frequently experienced by women, with effects that extend beyond physical health to psychological well-

being as well (Williams, S., et al., 2015). In some women, PCOS leads to difficulties in achieving pregnancy (Istiqomah et al., 2023).

In 2015, it was found that 67 out of 93 PCOS patients (72.04%) experienced infertility. Additionally, 78.8% of PCOS cases were recorded among women attending a private obstetrics and gynecology clinic in Palembang between 2014 and 2017 (Wahyuni et al., 2022). At a hospital in Surakarta, approximately 57.5% of women reported ovulation disorders at the obstetrics and gynecology outpatient clinic.

Meanwhile, a study conducted across three hospitals in Semarang recorded 108 cases of

PCOS in 2020, 121 cases in 2021, and 152 cases in 2022 (Hanani et al., 2023). In Indonesia, the total number of women with PCOS remains inadequately documented. PCOS cases are still not officially recorded due to a lack of clarity in reporting and case registration (Istiqomah et al., 2023). According to Hanani et al., (2023), the varied distribution and absence of comprehensive national data collection have led to limited attention being paid to women with PCOS in Indonesia.

Numerous studies have explored the experiences of women with PCOS through quantitative approaches. For instance, Bazarganipour et al. (2013) examined the relationship between PCOS and quality of life, finding that women with PCOS tend to experience elevated levels of anxiety, depression, and reduced self-esteem. Other research has investigated psychological variables such as body image dissatisfaction, self-control, and treatment adherence (Karjula et al., 2017). However, qualitative inquiries into the lived experiences of women with PCOS remain relatively limited, and those that do exist are predominantly situated in Western contexts.

In Javanese culture, womanhood is closely tied to fertility, marriage, and family roles (Geertz, 1961; Mulder, 2005). Values such as rukun (harmony) and nrimo (acceptance) shape expectations for women to be resilient and submissive. Such norms may intensify the psychosocial burden of PCOS, especially for those unable to fulfill traditional roles (Bennett, 2012). This study addresses a gap in the literature by exploring how Javanese women with PCOS navigate their identity. A qualitative phenomenological approach was chosen to capture the depth of their subjective experiences within their sociocultural context.

In a culturally rich context such as Javanese society, the lived experience of women with Polycystic Ovary Syndrome (PCOS) can be highly complex due to the interplay of cultural, social, and personal factors. Javanese women live within a community deeply rooted in tradition and strong social norms. They are expected to contribute significantly to the well-being of the family (Milyan et al., 2021). Fertility plays a central role in the social construction of women's identity, particularly in cultural settings where motherhood is seen as a defining aspect of womanhood. Marston et al. (2018), in their qualitative study conducted in Ghana, provide a nuanced exploration of how fertility regulation practices

intersect with women's identity work. The study frames fertility control not merely as a health or personal choice, but as a socially embedded act tied to a woman's ability to perform and maintain socially acceptable roles. In Indonesia, women identities are often shaped by cultural values that emphasize the roles of mother, along with societal expectations, particularly concerning fertility and reproductive health (Bennett, 2012).

In Javanese culture, the extended family is considered the cornerstone of social life. The more children they have, the more fortune they get (Hasanah, 2022). Children are regarded as blessings and sources of joy for the family. They are also seen as heirs who will continue the family lineage, preserving its name and traditions. Moreover, children are expected to care for their parents in old age, making parenthood a long-term social and emotional investment (Kreager & Schröder-Butterfill, 2007). Javanese traditions related to family formation, such as prenatal welcoming ceremonies, continue to be practiced as a form of social capital (Sarbaini, 2021; Widyaningrum, 2017).

Within this cultural framework, PCOS may pose a significant challenge, affecting how Javanese women perceive and navigate their identities. The Javanese ethnic group tends to adopt a more protective stance toward their cultural heritage when confronted with globalization and modernization. As a response to social and economic changes, they are more inclined to preserve cultural identity (Arifin & Karen, 2024; Kismini et al., 2023).

This study aims to explore the lived experiences of Javanese women with Polycystic Ovary Syndrome (PCOS), with a particular focus on how they navigate their identities while living with the condition. The research will examine various aspects, including how Javanese women manage PCOS symptoms, how they perceive themselves in relation to the condition, their personal experiences of living with PCOS, and the stigma or support they encounter from their surrounding environment. This study is expected to provide in-depth insights into how a medical condition such as PCOS affects women's identities within a specific cultural context. By understanding the lived experiences of Javanese women with PCOS, the research aims to contribute to the development of more effective and culturally sensitive intervention strategies to support women with PCOS in Indonesia. In addition, this study also has the potential to enrich

the literature on identity and health in culturally rich societies such as Java.

Method

Culture plays a crucial role in shaping the understanding of illness and health. It can influence the development of medical disease processes as well as contribute to variations in health outcomes (Matsumoto & Juang, 2017). In Javanese culture, illness (*lara*) is understood as an imbalance or disruption that may originate from various sources, both physical and supernatural. Disease is perceived as an abnormal bodily condition caused by forces beyond human control (Wicaksono, 2013). This study employed a qualitative approach using a phenomenological method to explore the lived experiences of Javanese women with PCOS. This approach was deemed appropriate for capturing and understanding the participants' subjective experiences. A non-probability sampling technique was utilized, in which individuals in the population did not have an equal chance of being selected as sample members. Specifically, the study adopted a snowball sampling method, whereby the initial participants were asked to identify or recommend other individuals who could potentially participate in the research (Creswell, 2013).

The participants involved in this study were Javanese women diagnosed with PCOS, aged between 18-45 years. The researcher explained the purpose of the study and gave informed consent to the participants, followed by asking for consent to conduct in-depth interviews at an agreed time in the date range from 12 April-22 May 2024. The sample size was determined by data saturation, the point at which there was no new data or themes related to the subject's experience.

Semi-structured interviews were conducted to collect data regarding life experiences, self-perception, and identity navigation. The interviews were conducted online via zoom meeting at a time agreed between the researcher and the subject. The use of online meetings is based on several reasons, including a much richer experience of illness and aspects of this experience can be revealed and identified through online media. Including women with PCOS where it is possible that they can say more about an issue online than they might in person (Williams, S., et al., 2016). Often women with PCOS feel that they are socially isolated (Williams, S., et al., 2015).

Based on the willingness and permission of all subjects, all interviews were recorded. The

following questions were asked to women with PCOS, 'How do you feel after being diagnosed with PCOS?' and 'How has it affected your psychological well-being?' and questions such as 'How do you live with PCOS?'. After being transcribed verbatim, the interviews were analysed using coding to identify key themes. Grouping the codes into larger themes to reveal patterns and relationships between themes.

To enhance data validity, member checking was employed by involving participants in reviewing the findings to ensure that the interpretations accurately reflected their perspectives (Creswell & Creswell, 2018).

Results

Interviews were conducted with 10 women with PCOS, no children, of different ages, status and occupations. Subjects were informed of their rights regarding participation in the study. Subjects were referred to by initials during analysis to preserve their anonymity.

Table 1
Participants

Initial	Age	Marital Status	Occupation	PCOS Duration
DR	35 years	Married	HR Staff	9 years
DS	24 years	Single	Student	2 years
CC	26 years	Married	Bank Teller	2 years
DW	26 years	Married	Teacher	3 years
NM	28 years	Married	Housewife	4 years
FE	32 years	Single	Bank CS	3 years
BN	33 years	Married	Marketing	5 years
SY	40 years	Married	Teacher	13 years
WR	23 years	Married	Housewife	2 years
ZF	34 years	Married	Housewife	6 years

Four major themes emerged from the data analysis: Thoughts about illness (subthemes: understanding of illness and treatment), gender roles (subthemes: failure of a woman and family expectations), religious aspects (subthemes *ikhtiar* and *tawakkal*) and social interactions (subthemes: stigma and support).

Thoughts about illness

Understanding of the disease

Prior to receiving a PCOS diagnosis, the women participating in this study were already aware of irregularities in their menstrual cycles. However, due to the common belief that such irregularities were normal, participants often felt no need to seek professional medical assistance.

The following quote from participant DR illustrates her early awareness of menstrual irregularities.

..dari gadis udah ngeuh banget kalau ini siklus mens-nya gak beres. Ya masa dua bulan bisa gak mens. Tapi saat itu ya nurut aja sama orang tua, kalau ini tuh normal banget, nanti juga kalau udah nikah pasti normal.. (menstrual irregularities, T1.1)

Table 2
Themes and Subthemes

Themes	Subthemes
Thoughts about illness	Understanding of illness Treatment
Perceptions of gender roles	Failure of a woman Family expectations
Religious aspects	<i>Ikhtiar</i> <i>Tawakkal</i>
Social interactions	Stigma Support

In alignment with DR, participant CC shared a similar experience,

..Sebetulnya udah dari pas aku sebelum nikah juga udah ngerasa banget ini haidnya kacau. Tapi keluarga bilang, gak perlu ke dokter.. itu mah normal.. obatnya nikah.. (menstrual irregularities, T1.1)

Participant NM also expressed a similar perception regarding the symptoms she experienced.

..badanku kan emang besar ya, udah tahu kalau ada yang salah dengan kesehatanku dan akan memengaruhi masa depanku nanti, mm.. apapun itu. Tapi orang-orang disekitarku buat aku mikir, kalau banyak kok orang-orang yang tetep hidupnya panjang, punya anak banyak, meskipun kondisinya sama kaya aku.. (obesity, T1.1)

Although they were aware of menstrual irregularities, they did not consider the condition severe enough to warrant medical attention. However, after marriage, they came to realize the significant health implications. As participant SY reflected,

..andai saya gak ngikuti apa yang disaranin budhe saya, mungkin saya saat ini sudah bisa punya anak banyak. Ya maklum juga namanya orang desa, ya percaya saja pada pengalaman

orang yang lebih tua... (aware of the health impacts, T1.1)

Furthermore, SY explained that some still believe her difficulty conceiving is due to missing certain traditional rituals before marriage.

..harusnya ada slametan khusus biar saya bisa hamil dan punya anak. Tapi waktu itu gak kami lakukan karena ya berkaitan dengan waktu dan biaya juga. Kami pikir siraman saja cukup.. (accept all possible causes, T1.1)

Similarly, FE, an unmarried participant, described her perception of the symptoms she experienced.

..PCOS ini kan ora jelas sakitnya dimana, mbak. Jadi karena gak kerasa sakit apa-apa, ya sudah. Ke dokter juga kan buat, apa katanya. Orang-orang hanya bilang jangan stress, nanti normal lagi hormonnya. Padahal ya sekarang ternyata malah gak bisa disembuhin sindrom-nya.. (illness but not sick, T1.1)

A lack of understanding of PCOS and misinterpretations of diagnostic criteria often lead to delayed diagnoses (Authier et al., 2020; Lin et al., 2018). Lin et al. (2018) reported that many women with PCOS hold misconceptions about the diagnostic criteria. Those who are aware of their vulnerability to negative health outcomes are more likely to adopt health-promoting behaviors.

Participant DS, who is unmarried, pointed out that diagnostic limitations contributed to the delayed diagnosis

..Kata dokter aku tuh gejala PCOS. Ketahuannya ya karena haid gak lancar, berat badan yang tidak ideal sama jerawat teh. Nah, kan biasanya untuk lebih jelas dilihat kan sel telurnya gimana. Ini gak bisa. Disuruh nikah dulu katanya.. (limited medical diagnosis, T1.1)

PCOS diagnosis typically involves ultrasound imaging of the ovaries through transvaginal ultrasound (Williams, T. et al., 2016). The decision to perform a transvaginal ultrasound in unmarried women should be based on clear medical indications, patient comfort, and sensitivity to cultural and social norms. Health services and practices are also shaped by cultural influences (Hernandez & Gibb, 2020; Iwelunmor & Airhihenbuwa, 2017). Religion plays a role in shaping values, ethics, norms, and national identity, including in healthcare practices (Tumanggor, 2010).

Treatment

Women with PCOS often feel that their main symptom is infertility. So their main focus is the ability to conceive and give birth. In fact, PCOS has long-lasting effects that can affect physical and psychological health (Rushinaidu & Eswari, 2023).

As quoted by the married subject DW, that her focus now is how to treat her infertility.

..aku gak tahu sampai kapan aku harus minum inlacin ini. Pengen muntah rasanya tiap minum. Tapi aku harus tetep minum, biar bisa hamil.. (Drug consumption, T1.2)

As is known, one of the drugs given by doctors for PCOS therapy is the use of inlacin or metformin. PCOS is also a major metabolic disorder that has a major risk factor for dysglycaemia and Type 2 Diabetes Mellitus in women is PCOS (Hidayat et al., 2023). Therefore, most PCOS cases are treated using the drug Metformin which can affect glucose production, peripheral glucose utilisation, insulin levels, insulin receptors, significantly reducing hepatic glucose production, fatty acid levels, and insulinemia.

In line with DW, BN also expressed the same thing regarding medication.

..Obat PCOS itu gak murah. Belum biaya konsultasinya, obat yang kita minum juga mahal. Itu beda lho biaya dokter kandungan biasa sama yang konsultan. Yang biasa ngobati PCOS tuh dokternya gak murah. Belum lagi pakai madu sama obat-obat tradisional biar cepet hamil.. (cost of treatment, T1.2)

SY, a 40-year-old married participant, had been trying to conceive for many years. She had undergone various alternative therapies in her efforts to achieve pregnancy.

..saya juga menjalani terapi alternatif. Sengat lebah di area vital, lidah ditempelin lintah, bekam, segala macam pengobatan saya lakukan agar bisa hamil. Karena kami juga ada rasa bahwa Tuhan dan semesta belum takdirkan. Saya coba selamatan juga. Tapi masih juga belum.. (alternative treatment, T1.2)

Despite such efforts, health professionals frequently recommend lifestyle management as the primary approach to managing PCOS. Women with PCOS are advised to adopt healthier habits and, when necessary, pursue appropriate medical treatments (Mousa et al., 2009).

Perceptions of Gender Roles

A Sense of Failure as a Woman

Participants DS and FE expressed that their physical appearance made them feel as though they were not “real” women. DS, who struggles with obesity, shared,

..Aku gendut banget ini teh. Mana jerawat. Kan perempuan tuh harus cantik biar ada yang mau nikahi.. (Perception of beauty, T2.1)

FE shared similar sentiments due to her atypical appearance.

..Mungkin karena kelihatan bukan kaya perempuan. saya kan ada kumisnya. Belum lagi ini tangan kaki bebulu semua. Ya kali ada yang mau sama saya. Ya laki-laki akan memilih cewek normal dari pada saya cewek jadi-jadian. Belum lagi resiko untuk susah hamil.. (Hirsutism and feeling of abnormal, T2.1)

Likewise, ZF described her sense of failure as a wife.

..ketika tidak bisa hamil dan melahirkan, sering kali kami para istri yang disalahkan. Selama ini saya sudah berusaha, tapi saya selalu gagal untuk memberikan suami saya keturunan.. (Women and fertility, T2.1)

Family Expectations

Infertility was often linked to a perceived failure to meet familial expectations. Participant BN explained the pressures and cultural expectations within her Javanese family.

Subject BN reported experiencing expectations from her family and others around her to have children.

..Apalagi orang Jawa, ritualnya banyak. Sebelum menikah saja ada pasang tuwuhan, kaya pisang setandan biar cepet punya anak. Nanti banyak lagi selamatannya. Ada tingkeban, tedak siten, sementara saya belum bisa kasih anaknya.. (Hope and effort, T2.2)

WR expressed the emotional toll of repeated failure to conceive.

..Aku sedih banget, mbak. Aku kaya gak berguna. Ngapain aku nikah? Tahu gini mending suamiku nikah aja sama yang lain. Pasti kalau nikah sama yang lain sekarang dia udah punya anak. Aku bilang sama suami, aku bukan perempuan sepenuhnya kalau gak bisa hamil dan melahirkan.. (Helpless as a wife, T2.2)

Religious Aspects

Ikhtiar

For SY, faith and religious beliefs were essential in navigating life with PCOS.

..Yang saya bisa hanya ikhtiar. Sisanya, tawakkal saja.. Gimana Allah. Kalaupun suami saya ingin berpisah, ya Allah aja yang atur.. (Surrender, T3.1)

Similarly, NM remained persistent in her efforts to fulfill her and her family's hopes.

..Sejauh ini, aku akan usahakan apapun usaha yang sekiranya akan membuat aku sembuh dari PCOS.. Gak ada lagi waktu buat aku merenung sedih. Ya capek ada juga, istirahat dulu ya sudah usahanya nanti tetep dilanjut lagi.. (Keep moving, T3.1)

Tawakkal

Despite having stopped actively trying to conceive, DR expressed that she still held onto hope.

..Usaha sudah, meskipun sekarang gak terlalu ngoyo. Pasrah aja sama Allah. Allah pasti tahu kok waktu yang terbaik.. (Believe in God, T3.2)

SY highlighted surrendering everything to God enabled her to live more peacefully and without excessive worry.

..Kalau saya gak tawakkal sama Gusti Allah, saya mungkin akan terus terusan khawatir dengan hidup saya ke depannya, gak tenang kan gak enak ya? Sekarang ya dijalani saja sesuai dengan kemampuannya.. (Believe in God, T3.2)

Social Interactions

Stigma

All participants reported experiencing some form of social stigma. FE described being mocked for her appearance.

..dulu saya sering banget dikatain monyet atau si kumis. Wah, parah sih. Kayanya saya udah gak berharga banget jadi manusia disamain kaya binatang.. (Different physical appearance, T4.1)

DS had a similar experience, being ridiculed because of her body size.

..itu sih udah jadi kaya nama panggilan aja. "mpal, mpal.." ya itu awalnya dari gentong karena badanku kan mirip gentong kali ya teh. Diplesetin jadi empal gentong. Sampe sekarang dipanggilnya, di empal.. (Different physical appearance, T4.1)

Participants ZF, CC, and BN reported being labeled as "infertile women," often even by close family members. ZF noted how her family, despite having good intentions, pressured her to try various treatments.

..ya dibilang, kasihan itu suamimu disangka mandul. Makanya coba dulu pengobatan ini, itu... (Stigma of infertility, T4.1)

BN received similar remarks from those closest to her.

..punya anak buat yang sudah menikah itu ya dibilang wajib enggak, katanya. Tapi nanti siapa yang akan urus kamu.. (Impact of stigma, T4.1)

Support

Like the stigma, all participants emphasized the need for support from those around them to cope with PCOS. DR highlighted the importance of support in her journey of acceptance.

..Alhamdulillah orang tua dukung apapun langkah yang aku ambil. Suami juga gitu. Keputusan apapun, pasti aku diskusiin sama suami. Kalau misal suami ngerasa ada yang bikin nyaman, ya diobrolin. Jadi sama-sama ngerti.. (Family support, T4.2)

BN echoed the importance of spousal support in her efforts to conceive.

..Minimal suami paham lah ya. Aku tuh capek. Minimal ayok support aja aku mau ke dokter mana, aku mau obat apa, vitamin apa.. waktunya hubungan ya ayok lakuin.. (Family support, T4.2)

Discussions

This study aims to navigate the identity of Javanese women living with PCOS. The findings indicate that women with PCOS often recognize irregularities in their menstrual cycles, but due to a lack of understanding, they experience delays in obtaining a proper diagnosis (Authier et al., 2020). Within Javanese culture, beliefs about illness and its causes are often influenced by spiritual traditions and ancestral religious beliefs (Laksono et al., 2020).

Javanese women are commonly positioned as the cornerstone of family harmony, with reproductive success being a crucial component of their identity and social role. Women are seen as pangudi tuwuh, a concept referring to their role as the source of life for future generations through pregnancy, childbirth, and breastfeeding (Lailisna, 2022). Thus, infertility is not merely a medical

issue but also a psychosocial and cultural concern, significantly affecting women's self-esteem, social relationships, and mental health.

When infertility is associated with social stigma, women often choose to remain silent, avoid open discussion, and suppress feelings of shame in order to preserve family harmony and personal dignity. Javanese women are traditionally characterized as modest, obedient, emotionally considerate, hardworking, generous, diligent, other-oriented, and *nrimo ing pandum*—accepting one's fate as divinely ordained (Hanipudin & Habibah, 2021). The participants in this study often responded to stress with tactical and rational behavior, demonstrating psychological resilience. However, such attitudes may also result in emotional suppression, loneliness, and feelings of failure as a woman. These factors motivate Javanese women with PCOS to persist in their efforts despite persistent symptoms and challenges.

A Javanese woman is culturally expected to endure even the harshest realities. They are adept at concealing suffering and finding personal meaning in adversity. Regardless of their partner's actions, Javanese women are expected to remain respectful and committed (Nurhayati et al., 2023; Puspitasari et al., 2022). Consequently, several participants reported complying with suggestions from their social environment regarding early symptoms.

Knowledge about illness is a key factor influencing health behavior. One widely used theoretical framework is the Health Belief Model (HBM), introduced by Rosenstock (1966). HBM posits that individuals are more likely to undergo health screenings if they believe they are capable of doing so and are motivated to maintain their health (Ogden, 2023). A lack of awareness about PCOS has also been documented in previous studies, which highlight insufficient information, negative experiences with healthcare professionals, prolonged diagnostic processes, and inadequate clinical, educational, and emotional support (Lau et al., 2022). Due to dissatisfaction with available information, many women with PCOS resort to online searches for further understanding (Gibson-Helm et al., 2016).

Another prominent theme identified in this study is the perception of gender roles. One aspect of these roles involves the ability to conceive, which is closely tied to notions of fertility. Infertility emerged as a primary concern among women with PCOS, often leading to diagnosis

only in their 20s or 30s, typically in the context of fertility treatments (Cooney & Dokras, 2018).

A study of Iranian women with PCOS found that infertility was the most commonly reported issue (Bazarganipour et al., 2013). Consistent with findings by Tabassum et al. (2021), who reported infertility as a major predictor of decreased overall quality of life in PCOS cases.

Infertility, therefore, becomes a central focus of treatment for women with PCOS. In Javanese culture, the desire to have children is deeply influenced by tradition, family values, and religious beliefs. The Javanese tend to preserve their cultural heritage, supported by historical factors such as royal traditions, cultural centers, social structures, spiritual beliefs, and governmental policies (Koentjaraningrat, 1985). Javanese tend to adopt a more protective approach to their culture in the face of globalisation and modernisation. They tend to better maintain their cultural identity in response to social and economic changes (Arifin & Karen, 2024; Kismini et al., 2023).

There is significant social pressure on married Javanese women to bear children. All six participants in this study stated that having children is essential for fulfilling their identity as women, continuing the family line, realizing dreams and hopes, and ensuring well-being in old age. This demonstrates the high value placed on childbearing in Javanese culture. The extended family is central to social life in Javanese society, with children regarded as blessings and sources of familial joy (Hasanah, 2022; Kreager & Schröder-Butterfill, 2007).

They are seen as lineage bearers and caretakers of aging parents, making childbearing a long-term social and emotional investment (Situmorang et al., 2024). Traditional family rituals, such as prenatal celebrations, continue to be practiced for their social capital (Sarbaini, 2021; Widyaningrum, 2017).

In this cultural context, where traditional values emphasize women's roles in the family and reproduction, infertility can lead to serious psychological consequences, including low self-esteem (Bazarganipour et al., 2014). Women experiencing infertility often report diminished self-acceptance, resulting in heightened stress (Pelupessy et al., 2023). Low self-esteem is also associated with negative body image (Alkheyri et al., 2024). and reduced quality of life in women with PCOS (Çoban et al., 2019; Rzońca et al., 2018).

Beyond infertility, physical appearance-related symptoms—particularly in unmarried women with PCOS—are major predictors of psychological distress (Thorpe et al., 2019). Many women with PCOS feel that they do not meet societal standards of femininity due to symptoms such as excess weight, hirsutism, or irregular menstruation. There is concern that they are unable to fulfill expected gender roles (Samardzic et al., 2021).

In addition to feelings of failure as women, some participants reported feeling devalued due to PCOS-related symptoms such as infertility. This often results in low self-esteem, perceptions of being incomplete women, and exposure to gossip, all of which are shaped by strong cultural expectations surrounding pregnancy and motherhood (Taghavi et al., 2015). Women with infertility issues often face negative stigma from family and community members, leading to deep emotional distress (Suzanna et al., 2022). Participants expressed feelings of being misunderstood and judged for issues largely beyond their control, and reported inadequate emotional support from those around them. They described the difficulty of helping others understand and validate their experiences. (Thorpe et al., 2019).

Percy et al., (2009) have suggested that nurse-led support groups may help mitigate the emotional impact of PCOS. Social support has been shown to positively affect persistence in symptom management among individuals with PCOS. Therefore, educational support for family and friends could be valuable in reducing misperceptions and perceived judgment (Bazarganipour et al., 2014; Williams, S., et al., 2016). Social support—from family, friends, romantic partners, and communities—is a crucial resource that enables women with PCOS to navigate daily life. Support is even found within online forums, where women with PCOS can connect and empathize with one another (Authier et al., 2020; Williams, S., et al., 2016).

In Indonesia, there is a prevailing belief that PCOS primarily causes infertility. However, PCOS is not solely a physical condition; it also has psychological dimensions (Cooney & Dokras, 2018; Romero et al., 2013). Further research is needed to explore how women with PCOS make sense of their symptoms and how these affect their lives.

In addition to social support, religious belief emerged as a key contributing factor that helps women with PCOS manage their daily lives. All

participants mentioned faith as an essential coping mechanism. Simarmata and Lestari (2021), in their study of infertile couples, found that faith and karma are deeply embedded cultural and religious constructs associated with infertility.

The psychological consequences of infertility in the Javanese cultural context cannot be overlooked. Multiple studies have shown that infertility increases the risk of depression, anxiety, and low self-esteem, particularly when women feel they cannot meet long-standing social expectations. Family, community, and even spousal pressure may intensify emotional burdens. Nevertheless, cultural values such as *tepa selira* (empathy for others) and extended kinship networks can also provide substantial support. When interpreted positively, these values allow women to draw strength from community solidarity and spirituality—two key components of Javanese cultural resilience.

Thus, psychosocial interventions for infertile women in Java must consider local cultural contexts, integrating culturally grounded emotional support with mental health promotion strategies that honor traditional values while addressing individual psychological needs.

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Nevertheless, cultural values such as *tepa selira* (empathy for others) and extended kinship networks can also provide substantial support. When interpreted positively, these values allow women to draw strength from community solidarity and spirituality—two key components of Javanese cultural resilience (Widiyanti, 2024). Thus, psychosocial interventions for infertile women in Java must consider local cultural contexts, integrating culturally grounded emotional support with mental health promotion strategies that honor traditional values while addressing individual psychological needs. Global studies examining the link between religiosity and health have shown a generally positive association, suggesting that religious involvement is frequently correlated with improved health outcomes (Zimmer et al., 2019). In several countries, religious participation has been linked to better overall health.

To the best of the researcher's knowledge, this is the first study to explore how Javanese women live with PCOS. The qualitative approach employed in this study is a key strength, allowing for a deeper understanding of the lived experiences of women with PCOS. Understanding these experiences is essential for providing appropriate support and improving their quality of life.

This study has several limitations that should be acknowledged. First, the sample consisted of ten Javanese women, all of whom identified as Muslim and were residing in Central or East Java. As such, the findings may not be generalizable to women from other ethnic groups, religious backgrounds, or geographic regions within Indonesia, where cultural and social expectations regarding womanhood may differ. The reliance on self-reported data could introduce social desirability bias, especially considering the sensitivity of reproductive health and gender issues. As with most qualitative research, these findings are context-dependent and reflect interpretations shaped by both participants and the researcher during a specific period.

Conclusion

This study navigates identity through the lived experiences of Javanese women with PCOS and identifies four overarching themes: beliefs about illness (subthemes: understanding of the condition and treatment), perceptions of gender roles (subthemes: perceived failure as a woman and family expectations), religious aspects (subthemes: ikhtiar and tawakkal), and social interaction (subthemes: stigma and support). The study highlights how religious beliefs and social support can serve as vital coping resources, enabling Javanese women with PCOS to endure physical symptoms and societal stigma while continuing to engage meaningfully with their lives. The lived experiences of Javanese women with PCOS reveal identity as a fluid and negotiated process, shaped by cultural values, religious beliefs, and social norms. Understanding these dimensions can inform more holistic and culturally sensitive support strategies for women with PCOS in Indonesia and beyond.

Reference

Alkheyir, Z., Murad, M., Das, P., Aljenaee, K., Kamel, C., Hajji, S. A., Flood, J., Atkin, S. L., & Ali, K. F. (2024). Self-esteem and body image satisfaction in women with PCOS in the Middle East: Cross-sectional social media

- study. *PLOS ONE*, 19(4), e0301707. <https://doi.org/10.1371/journal.pone.0301707>
- Arifin, A., & Karen, L. (2024). Resilient traditions: Exploring the cultural meaning of Javanese wayang kulit in heritage preservation. *Jurnal Ilmu Pendidikan Dan Humaniora*, 13(2), 106–120.
- Authier, M., Normand, C., Jegou, M., Gaborit, B., Boubli, L., & Courbiere, B. (2020). Qualitative study of self-reported experiences of infertile women with polycystic ovary syndrome through on-line discussion forums. *Annales d'Endocrinologie*, 81(5), 487–492. <https://doi.org/10.1016/j.ando.2020.07.1110>
- Bazarganipour, F., Ziaei, S., Montazeri, A., Foroozanfard, F., Kazemnejad, A., & Faghihzadeh, S. (2013). Psychological investigation in patients with polycystic ovary syndrome. *Health and Quality of Life Outcomes*, 11(1), 141. <https://doi.org/10.1186/1477-7525-11-141>
- Bazarganipour, F., Ziaei, S., Montazeri, A., Foroozanfard, F., Kazemnejad, A., & Faghihzadeh, S. (2014). Health-related quality of life in patients with polycystic ovary syndrome (PCOS): A model-based study of predictive factors. *The Journal of Sexual Medicine*, 11(4), 1023–1032. <https://doi.org/10.1111/jsm.12405>
- Bennett, L. R. (2012). Infertility, womanhood and motherhood in contemporary Indonesia. *Intersections: Gender and Sexuality in Asia and the Pacific*, 28. <https://doi.org/10.25911/5F8H-1Y66>
- Çoban, Ö. G., Tulacı, Ö. D., Adanır, A. S., & Önder, A. (2019). Psychiatric disorders, self-esteem, and quality of life in adolescents with polycystic ovary syndrome. *Journal of Pediatric and Adolescent Gynecology*, 32(6), 600–604. <https://doi.org/10.1016/j.jpbg.2019.07.008>
- Cooney, L. G., & Dokras, A. (2018). Beyond fertility: Polycystic ovary syndrome and long-term health. *Fertility and Sterility*, 110(5), 794–809. <https://doi.org/10.1016/j.fertnstert.2018.08.021>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). SAGE Publications.
- Creswell, J. W., & Creswell, J. D. (2018). *Research design* (5th ed.). SAGE Publications.

- Geertz, H. (1961). *The Javanese family: A study of kinship and socialization*. Free Press of Glencoe.
- Gibson-Helm, M., Teede, H., Dunaif, A., & Dokras, A. (2016). Delayed diagnosis and a lack of information associated with dissatisfaction in women with polycystic ovary syndrome. *The Journal of Clinical Endocrinology & Metabolism*. <https://doi.org/10.1210/jc.2016-2963>
- Hanani, D. S., Anis, A., & Ika P, N. V. (2023). Hubungan dukungan sosial terhadap kecemasan pasien polycystic ovary syndrome (PCOS). *Detector: Jurnal Inovasi Riset Ilmu Kesehatan*, 1(3), 197–211. <https://doi.org/10.55606/detector.v1i3.2238>
- Hanipudin, S., & Habibah, Y. A. (2021). Karakter wanita dalam tradisi Jawa. *AT-THARIQ: Jurnal Studi Islam dan Budaya*, 1(2). <https://doi.org/10.57210/trq.v1i2.78>
- Hasanah, E. (2022). Java Community Philosophy: More Children, Many Fortunes. *Genealogy*, 7(1), 3. <https://doi.org/10.3390/genealogy7010003>
- Hernandez, M., & Gibb, J. K. (2020). Culture, behavior and health. *Evolution, Medicine, and Public Health*, 2020(1), 12–13. <https://doi.org/10.1093/emph/eoz036>
- Hidayat, S. T., Mulyantoro, I., Damas, S., & Tjandrawinata, R. R. (2023). The effect and safety assessment of Metformin and DLBS3233 (A bioactive fraction of *Lagerstroemia speciosa* and *Cinnamomum burmannii*) on improving metabolic parameters in women with Polycystic Ovary Syndrome. *International Journal of Women's Health*, 15, 971–985. <https://doi.org/10.2147/IJWH.S409685>
- Istiqomah, N. Q., Abidin, Z., & Candoruk, A. (2023). Quality of Life in The Community of Women with Polycystic Ovary Syndrome (PCOS): A Phenomenology Study. *Psympathic: Jurnal Ilmiah Psikologi*, 10(2), 123–136. <https://doi.org/10.15575/psy.v10i2.28829>
- Iwelunmor, J., & Airhihenbuwa, C. (2017). Culture, a social determinant of health and risk: Considerations for health and risk messaging. <https://doi.org/10.1093/acrefore/9780190228613.013.221>
- Karjula, S., Morin-Papunen, L., Hautala, L., Frilander, L., Soini, Seppänen-Näkkäläjärvi, M., & Tapanainen, J. S. (2017). Psychological distress is more prevalent in fertile age and infertile women with PCOS compared to healthy controls. *Acta Obstetrica et Gynecologica Scandinavica*, 96(2), 217–225. <https://doi.org/10.1111/aogs.13071>
- Kismini, E., Iswari, R., & Fajar, F. (2023). The role of education in preserving Javanese ethical values. *Komunitas*, 15(1), 99–107. <https://doi.org/10.15294/komunitas.v15i1.41691>
- Koentjaraningrat. (1985). *Javanese culture*. Oxford University Press.
- Kreager, P., & Schröder-Butterfill, E. (2007). Gaps in the family networks of older people in three Indonesian communities. *Journal of Cross-Cultural Gerontology*, 22(1), 1–25. <https://doi.org/10.1007/s10823-006-9013-3>
- Lailisna, N. N. (2022). Rekonstruksionisme-futuristik dalam modernitas perempuan jawa. *Marwah: Jurnal Perempuan, Agama dan Jender*, 21(2), 80. <https://doi.org/10.24014/marwah.v21i2.15625>
- Laksono, A. D., Wulandari, R. D., Oedojo Soedirham, & Pinky Saptandari. (2020). Treatment seeking behavior of Tengger tribe in Indonesia. *Indian Journal of Public Health Research & Development*, 11(3), 1300–1305. <https://doi.org/10.13140/RG.2.2.28281.29284>
- Lau, G. M., Elghobashy, M., Thanki, M., Ibegbulam, S., Latthe, P., Gillett, C. D. T., O'Reilly, M. W., Arlt, W., Lindenmeyer, A., Kempegowda, P., & PCOS SEva Working Group. (2022). A systematic review of lived experiences of people with polycystic ovary syndrome highlights the need for holistic care and co-creation of educational resources. *Frontiers in Endocrinology*, 13, 1064937. <https://doi.org/10.3389/fendo.2022.1064937>
- Lin, A. W., Dollahite, J. S., Sobal, J., & Lujan, M. E. (2018). Health-related knowledge, beliefs and self-efficacy in women with polycystic ovary syndrome. *Human Reproduction*, 33(1), 91–100. <https://doi.org/10.1093/humrep/dex351>
- Marston, C., Renedo, A., & Nyaaba, G. N. (2018). Fertility regulation as identity maintenance: Understanding the social aspects of birth control. *Journal of Health Psychology*, 23(2), 240–251. <https://doi.org/10.1177/1359105317726367>
- Matsumoto, D., & Juang, L. (2017). *Culture and psychology* (6th ed.). Cengage Learning.

- Milyan, Idaman, & Sahili, L. O. (2021). Analisis sosial budaya terhadap partisipasi angkatan kerja wanita dalam meningkatkan kesejahteraan keluarga. *Intelektiva: Jurnal Ekonomi, Sosial & Humaniora*, 03(01).
- Mousa, S., Brady, Mousa, S., & Mousa. (2009). Polycystic ovary syndrome and its impact on women's quality of life: More than just an endocrine disorder. *Drug, Healthcare and Patient Safety*, 9, 9–14. <https://doi.org/10.2147/DHPS.S4388>
- Mulder, N. (2005). *Inside Indonesian society: Cultural change in Java*. Kanisius.
- Nurhayati, S. R., Setiawati, F. A., Amelia, R. N., & Fridani, L. (2023). Psychometric properties of dyadic data from the Marital Quality Scale of Indonesian Javanese couples. *Psicologia: Reflexão e Crítica*, 36(1). <https://doi.org/10.1186/s41155-023-00279-7>
- Ogden, J. (2023). *Health psychology* (7th ed.). McGraw Hill.
- Pelupessy, D. T. E., Retnoningtias, D. W., & Hardika, I. R. (2023). Self-acceptance dan infertility-related stress. *Journal of Psychological Science and Profession*, 7(1), 69. <https://doi.org/10.24198/jpsp.v7i1.42843>
- Percy, C. A., Gibbs, T., Potter, L., & Boardman, S. (2009). Nurse-led peer support group: Experiences of women with polycystic ovary syndrome. *Journal of Advanced Nursing*, 65(10), 2046–2055. <https://doi.org/10.1111/j.1365-2648.2009.05061.x>
- Puspitasari, D., Pudjibudojo, J. K., & Hartanti. (2022). Decision making on divorce for Javanese women in Indonesia. *International Journal of Environmental Sustainability and Social Science*, 3(3), 702–712. <https://doi.org/10.38142/ijesss.v3i3.276>
- Romero, M., Vivas-Consuelo, D., & Alvis-Guzman, N. (2013). Is Health Related Quality of Life (HRQoL) a valid indicator for health systems evaluation? *SpringerPlus*, 2(1), 664. <https://doi.org/10.1186/2193-1801-2-664>
- Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly*, 44(3), 94. <https://doi.org/10.2307/3348967>
- Rushinaidu, T., & Eswari, G. (2023). A review article on pcos and its impact on quality of life in women correlation with age, basal metabolic index and various factors. *International Journal of Health Care and Biological Science*, 4(1).
- Rzońca, E., Bień, A., Wdowiak, A., Szymański, R., & Iwanowicz-Palus, G. (2018). Determinants of quality of life and satisfaction with life in women with polycystic ovary syndrome. *International Journal of Environmental Research and Public Health*, 15(2), 376. <https://doi.org/10.3390/ijerph15020376>
- Samardzic, T., Soucie, K., Schramer, K., & Katzman, R. (2021). “I didn’t feel normal”: Young Canadian women’s experiences with polycystic ovary syndrome. *Feminism & Psychology*, 31(4), 571–590. <https://doi.org/10.1177/09593535211030748>
- Sarbaini, W. (2021). Nilai-nilai pendidikan dalam tradisi tingkeban budaya masyarakat suku Jawa ditinjau dari perspektif filosofis. *Ability: Journal of Education and Social Analysis*, 2(4), 77–88. <https://doi.org/10.51178/jesa.v2i4.292>
- Simarmata, O. Y., & Lestari, M. D. (2021). Harga diri dan penerimaan diri pasangan menikah tidak memiliki anak di Bali. *Jurnal Psikologi Udayana*, 8(1), 112–121.
- Situmorang, A. S. W., Tesselonika, T., Yunita, C. M., & Lubis, D. F. A. (2024). Pola pengasuhan anak usia dini berbasis budaya jawa. *Buletin Antropologi Indonesia*, 1(2), 10. <https://doi.org/10.47134/bai.v1i2.2724>
- Suzanna, S., Abdul Majid, Y., & Tanda Bela, L. G. (2022). Identifikasi pengalaman istri mendapatkan stigma negatif dengan kondisi infertilitas. *Jurnal Keperawatan Silampari*, 6(1), 183–191. <https://doi.org/10.31539/jks.v6i1.4107>
- Tabassum, F., Jyoti, C., Sinha, H. H., Dhar, K., & Akhtar, M. S. (2021). Impact of polycystic ovary syndrome on quality of life of women in correlation to age, basal metabolic index, education and marriage. *PLOS ONE*, 16(3), e0247486. <https://doi.org/10.1371/journal.pone.0247486>
- Taghavi, S. A., Bazarganipour, F., Hugh-Jones, S., & Hosseini, N. (2015). Health-related quality of life in Iranian women with polycystic ovary syndrome: A qualitative study. *BMC Women's Health*, 15(1), 111. <https://doi.org/10.1186/s12905-015-0272-4>
- Thorpe, C., Arbeau, K. J., & Budlong, B. (2019). ‘I drew the parts of my body in proportion to how much PCOS ruined them’: Experiences of polycystic ovary syndrome through

- drawings. *Health Psychology Open*, 6(2), 205510291989623.
<https://doi.org/10.1177/2055102919896238>
- Tumanggor, R. (2010). Masalah-masalah sosial budaya dalam pembangunan kesehatan di Indonesia. *Jurnal Masyarakat & Budaya*, 12(2).
- Wahyuni, A., Supriyatiningsih, Kusumawati, W., Sedah Kirana, K., & Mayayustika, C. D. (2022). Family history of PCOS, obesity, low fiber diet, and low physical activity increase the risk of PCOS. *Jurnal Kedokteran Dan Kesehatan Indonesia*, 13(1), 59–69.
<https://doi.org/10.20885/JKKI.Vol13.Iss1.art8>
- Wicaksono, H. (2013). Dongke dalam Masyarakat Desa Tanggulangin: Pemahaman Konsep Sehat-Sakit dan Penyakit dalam Kajian Etnosains Terhadap Sistem Medis. *Jurnal Masyarakat & Budaya*, 5(2).
- Widyaningrum, N. D. (2017). Tradisi adat Jawa dalam menyambut kelahiran bayi: studi tentang tradisi jagongan pada sepasaran bayi di Desa Ngentak, Kecamatan Temon, Kabupaten Kulon Progo. *Jurnal Penelitian Budaya*, 8(2), 112-124.
- Widiyanti, E. (2024). Tepa Selira sebagai Solusi untuk Bullying Pendidikan. *JSSH (Jurnal Sains Sosio Humaniora)*, 8(2).
<https://doi.org/10.22437/jssh.v8i2.39273>
- Williams, S., Sheffield, D., & Knibb, R. C. (2015). ‘Everything’s from the inside out with PCOS’: Exploring women’s experiences of living with polycystic ovary syndrome and co-morbidities through Skype™ interviews. *Health Psychology Open*, 2(2), 205510291560305.
<https://doi.org/10.1177/2055102915603051>
- Williams, S., Sheffield, D., & Knibb, R. C. (2016). A snapshot of the lives of women with polycystic ovary syndrome: A photovoice investigation. *Journal of Health Psychology*, 21(6), 1170–1182.
<https://doi.org/10.1177/1359105314547941>
- Williams, T., Mortada, R., & Porter, S. (2016). Diagnosis and treatment of polycystic ovary syndrome. *American Family Physician*, 94(2), 106–113.
- Zimmer, Z., Rojo, F., Ofstedal, M. B., Chiu, C.-T., Saito, Y., & Jagger, C. (2019). Religiosity and health: A global comparative study. *SSM - Population Health*, 7, 100322.
<https://doi.org/10.1016/j.ssmph.2018.11.006>