

# Quality of Life in The Community of Women with Polycystic Ovary Syndrome (PCOS): A Phenomenology Study

Neina Qonita Istiqomah<sup>1,2\*</sup>, Zainal Abidin<sup>1</sup>, Agit Candoruk<sup>3</sup>

<sup>1</sup>Faculty of Psychology, Universitas Padjadjaran, Sumedang, Indonesia

<sup>2</sup>Faculty of Psychology, UIN Sunan Gunung Djati Bandung, Indonesia

<sup>3</sup>Department of Psychological Counseling and Guidance, İstanbul Üniversitesi-Cerrahpaşa, Turkey

**Abstract.** Polycystic Ovary Syndrome (PCOS) is a hormonal, endocrine, and metabolic disorder in women of reproductive age. This is characterized by symptoms such as hirsutism, menstrual disorders and infertility, affecting almost 20% of women. In this context, the syndrome affects the physical and psychological disorders of women. Conditions that predominate in PCOS women cause depression and affect their quality of life. Using a phenomenological approach, in-depth interviews were conducted to determine quality of life in six PCOS women. The participants were recruited using purposive sampling from PCOS Fighter Indonesia community in the Bandung area. Furthermore, three themes were developed from the analysis, namely positive thinking, healthy behavior and social support. This research showed the favorable facets of the experiences of women coping with PCOS and showed the important role of the community in offering support to individuals affected by the syndrome. The identified themes emanated from interviews exploring quality of life among women with PCOS, providing insights into their daily lives and the challenges posed by the symptoms.

**Keywords:** Polycystic ovary syndrome, quality of life, PCOS

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\* Corresponding author: Faculty of Psychology, Padjadjaran University, Sumedang, Indonesia and Faculty of Psychology, UIN Sunan Gunung Djati Bandung, Jl. A. H. Nasution No. 105 Cibiru, Indonesia  
E-mail: [neinaqonita@gmail.com](mailto:neinaqonita@gmail.com)

## Introduction

Polycystic Ovary Syndrome (PCOS) is a hormonal disorder characterized by oligomenorrhea or abnormal menstrual cycles, anovulation or failure of eggs to mature, and hyperandrogenism (excess testosterone) in women (Rushinaidu & Eswari, 2023). These endocrine disorders occur in reproductive age (Williams et al., 2016), affecting 20% of the women population globally. Rushinaidu and Eswari (2023) mentioned that the main symptoms commonly experienced included disorders of the reproductive system when the woman's eggs fail to mature. This resulted in irregular menstrual cycles known as oligomenorrhea, acne, and excessive hair growth on the face and other limbs known as hirsutism.

PCOS is a reproductive health issue predominantly observed in women aged 15 to 49 years. Limitation of awareness regarding the syndrome often results in its diagnosis occurring after women reach the age range of 20 to 30 years. PCOS Women are often identified in adolescence or early adulthood with symptoms of oligomenorrhea (irregular menstrual

cycles), hirsutism (excessive hair growth), or when presenting for treatment related to infertility issues (Cooney & Dokras, 2018).

The cause of PCOS is unknown but some research suggested the inclusion of genetic factors. According to Joham et al. (2022), the effects are complex, including genetic and epigenetic susceptibility, hypothalamic and ovarian dysfunction, excess androgen exposure, insulin resistance, and mechanisms related to the accumulation of excess fat. Research conducted by Wahyuni et al. (2022) also mentioned a relationship between PCOS incidence and a family history of the complication. Giampaolino et al. (2021) stated that PCOS etiology is still unclear. However, the interaction between genetic and environmental factors as well as the changes in the microbiome can lead to the development of gynecological problems and systemic metabolic syndrome.

PCOS prevalence and its symptoms increase with age, stating the need for a multidisciplinary approach to catch the disorder at an early stage (Mehreen et al., 2021). Guidelines from the Endocrine Society

recommend using the 2003 Rotterdam criteria for the diagnosis (Dumesic et al., 2015). Diagnosis can generally be achieved by careful history taking, physical examination, and basic laboratory tests without requiring ultrasonography or other imaging. PCOS diagnosis is based on three criteria, namely hyperandrogenism, ovulatory dysfunction, and polycystic ovary features obtained from ultrasonographic examination (Williams et al., 2016).

PCOS has affected the lives of sufferers with a range of reproductive, metabolic, and psychological health consequences (Joham et al., 2022). Approximately 50%-70% affected women have symptoms of insulin resistance leading to comorbidities, including metabolic syndrome, hypertension, dyslipidemia, glucose intolerance, and diabetes (Sirmans & Pate, 2013). PCOS Women are also at risk of developing other diseases such as infertility, type 2 diabetes, heart disease, and endometrial cancer (Williams et al., 2015). The accompanying clinical symptoms and long-term complications affect various aspects of their quality of life (Elsenbruch et al., 2003).

These women may experience comorbidities, including depressive symptoms (Williams et al., 2015) as the major complication (Mirghafourvand et al., 2018). PCOS affects an individual's quality of life due to physical, psychological, and metabolic disorders (Rushinaidu & Eswari, 2023). These women are 50% more likely to experience psychiatric disorders, including bulimia, schizophrenia, bipolar disorder, depression, anxiety, borderline personality disorder, autism spectrum disorder, and tics (Cesta et al., 2016). The complication is also associated with psychological comorbidity, increasing the risk of anxiety, depression, and chronic stress (Tay et al., 2019), with the resulting health burden having a detrimental effect on quality of life (QoL) (Podfigurna et al., 2015).

Previous research has reported that PCOS has a detrimental effect on health, affecting quality of life (Williams et al., 2018). According to Coffey and Mason (2003), symptoms reducing quality of life are hirsutism, acne, diabetes mellitus, and obstructive sleep apnea syndrome (OSAS), a sleep disorder due to airway obstruction causing intermittent cessation of breathing. Another research conducted on PCOS women in Iran showed that menstrual irregularities and infertility were the most common quality of life problems (Bazarganipour et al., 2013). Similarly, Tabassum et al. (2021) reported that infertility was the main predictor affecting HRQOL. In Turkey, irregular menstruation and hirsutism have the greatest effect on quality of life (Açmaz et al., 2013). The results of Sánchez-Ferrer et al. (2020) supported other research where quality of life decreased significantly in PCOS

women with anovulatory phenotypes or immature eggs disrupting the menstrual cycle.

Deeks et al. (2010) showed that psychological functioning was impaired in PCOS women, specifically those who reported infertility. Depression and bad moods such as stress and moody were felt. In addition, some reported low self-esteem and self-consciousness as a result of having PCOS. The results showed that psychological and psychosocial problems significantly affected the women's quality of life (Elsenbruch et al., 2003). According to Elsenbruch et al. (2003), one of the psychosocial problems experienced is related to physical symptoms, such as excess hair growth in the facial area, which causes a negative effect on their sexuality. Likewise, Authier et al. (2020) reported that the symptoms of PCOS experienced resulted in feelings of social isolation. According to Aliasghari et al. (2017), the relationship with a partner and sexual satisfaction are the predictors that affect quality of life. In addition, PCOS women also felt underestimated by others because of the symptoms such as infertility. Therefore, they have low self-esteem and are often talked about by others because of the necessity to get pregnant or have a baby (Taghavi et al., 2015).

Bazarganipour et al. (2014) and Williams et al. (2015) reported that PCOS symptoms affect women's physical health and emotional well-being, disrupting their quality of life. Affected women experience and live with their symptoms and other comorbidity such as Irritable Bowel Syndrome (IBS). Most of the participants were depressed, self-harmed, and suicidal (Williams et al., 2015).

Elsenbruch et al. (2003), Podfigurna et al. (2015), Aliasghari et al. (2017), Williams et al. (2018), Authier et al. (2020), and Bazarganipour et al. (2014) consistently reported poorer quality of life in the emotional health subscale in PCOS women. Quality of life is considered to be the level of life satisfaction positively or negatively affected by individuals' perceptions (Moons et al., 2006). Furthermore, health-related quality of life is a measure of an individual's health in physical, spiritual, emotional, and role functions in society (Bazarganipour et al., 2014). Therefore, individuals can be said to have a good quality of life with optimal life satisfaction despite the effect of health on physical, spiritual, emotional, and role functions in society.

In Indonesia, the number of PCOS women has not been documented optimally. The cases are not officially recorded due to the lack of clarity in reporting and recording. However, Dharmais Hospital sees approximately 30 patients each year and 47 people suffering from ovarian cysts are reported from research at Raden Mattaher General Hospital, Jambi, during 2009-2010. In the 2008-2009 research at H. Adam

Malik General Hospital, Medan, there were 47 patients with ovarian cysts in 2008-2009. In 2010, Dr. Pirngadi General Hospital in Medan treated 34 patients with ovarian cysts among women of childbearing age. Concurrently, at ST. Elisabeth Hospital in Medan, data from 2008 to 2012 showed a total of 116 patients diagnosed with ovarian cysts (Saftarina and Putri, 2016). PCOS diagnosis is often delayed, includes many health professionals, and leaves women with unmet information needs (Gibson-Helm et al., 2014). Women have expressed a desire for support through diverse channels, including the availability of widely accessible educational materials, participation in patient forums and workshops, and access to Internet-based information (Gibson-Helm et al., 2017). Therefore, PCOS women seek support and join a community to obtain various information about the complications (Chopra et al., 2021).

PCOS Fighter Indonesia Community was formed in 2017 for women struggling to manage the complications and this community is a place to share educational information (Uma, 2021). An affected woman often experiences depression due to the symptoms and lack of knowledge of lifestyle management, hence decided to join the community to obtain helpful information.

Even though some analyses on PCOS women's quality of life have been conducted in other countries such as Europe and the UK, the Middle East, America, India, and China, research related to PCOS women's quality of life is very limited. A research on quality of life was carried out using quantitative methods by Rahayu et al. (2022), where social support affected the variable. Qualitative research is motivated by the need to explore the effect of PCOS beyond the clinical setting. For example, Williams et al. (2016) showed the value of qualitative research in understanding its effect on quality of life and the experiences of women with the condition. Malik-Aslam et al. (2010) questioned quality of life scale used in many quantitative research and argued that the concept does not accurately measure the variable. Therefore, this research aimed to assess the psychological impact of PCOS to gain insights into quality of life experienced by affected women in Indonesia.

## Methods

### Research Design

The design used was a phenomenological approach to obtain a quality of life overview of PCOS women. Since quality of life was stated by the impact of both objective and subjective elements on well-being, this research recognized the significance of various life domains regarding the cultural and temporal context of individuals (Jones & Drummond, 2021). Consequently, women with PCOS might present distinct perspectives

depending on the varied samples considered. According to Williams et al. (2015), qualitative research could help the understanding of women's quality of life conditions resulting from the psychological effect of PCOS.

### Sampling Procedure

Subjects were recruited using purposive sampling from PCOS Fighter Indonesia community in the Bandung area, namely women diagnosed by a doctor, registered as members of the community, and willing to become participants. There was no exact number of the community group because many of the members felt cured after having children. The sample size was determined by data saturation, at which there were no new themes related to the subject's experience. Data collection was conducted using direct interviews at a time agreed between the team and the subject.

The subject characteristics explained several things, namely age, marriage age, and history of PCOS diagnosis. This research achieved saturation with the inclusion of six participants who willingly agreed to participate. A detailed explanation of the research objectives was provided before obtaining informed consent from the participants. The informed consent comprehensively covered participation, safeguarding participants' rights, ethical considerations, research integrity, and acknowledgment of potential discomfort. Subsequently, consent was obtained for the conduct of in-depth interviews at a mutually agreed-upon time within the specified date range from April 29 to May 29, 2023.

Interviews were conducted through Zoom meetings with an average duration of 60 to 90 minutes. Before starting the process, the subject was informed about the importance of privacy and safety in the interview process. Participants were apprised of the privacy agreement, ensuring an engagement in a tranquil and confidential setting. To uphold the accuracy of the data, several measures were implemented namely (1) adherence to the prepared interview guideline, (2) recording the process to prevent data loss, (3) verification and confirmation of the obtained information, and (4) supporting open communication with the interview subject.

The use of Zoom meetings was based on previous research on PCOS women described as socially isolated (Williams et al., 2015; Kitzinger and Willmott, 2002), and some had difficulty with physical gathering. These women felt insecure because of visible physical problems such as being overweight, having acne, having a mustache or beard, as well as feeling strange and abnormal (Samardzic et al., 2021). Conducting interviews through Zoom meetings provided a more comfortable environment, which might increase their focus and comfort in talking about their experiences.

**Table 1**  
Participant

No.	Initial	Age	Marriage Age	PCOS Diagnosis Duration	Occupation
1	A	29 years	4 years	3 years	Housewife
2	B	30 years	5 years	4 years	Admin Staff
3	C	30 years	5 years	4 years	Student
4	D	26 years	7 years	7 years	Cafe Finance
5	E	28 years	7 years	6 years	Kindergarten Teacher
6	F	32 years	8 years	7 years	Civil Servant

**Table 2**  
Themes and Sub-themes

Theme	Sub-theme
Positive thinking	Self-acceptance Gratitude Humor
Healthy behaviors in dealing with PCOS symptoms	Treatment motivation Symptom management Controller
Social support	Family support Community support

The feature of turning off the camera while the interview is in progress is an alternative for those who do not wish to show their faces. In addition, Williams et al. added that using interviews with online meeting media makes it easier for subjects to take part, including minimal time and financial costs.

All interviews were recorded based on the willingness and permission of all subjects. The guide used questions developed from a literature review exploring the experiences of PCOS women (Williams et al., 2016) as well as Williams' (2018) quality of life theory representing the aspects of daily life, infertility, hirsutism, and mood. The following questions were asked, "How does PCOS affect your life?" "What are your goals for PCOS treatment?" "How do you feel about the extra hair you have?" and questions such as "How do you get through your days with PCOS?".

To ensure the validity of the data, member-checking interpretation was used by analyzing the results with participants or parties included to ensure accurate interpretation (Cresswell, 2014).

**Ethics**

The research complied with the guidelines of the Research Ethics Committee of Padjadjaran University Bandung with approval number 845/UN6.KEP/EC/2023. The subjects were informed of their rights regarding participation in the research

and were referred to by initials during analysis to preserve their anonymity.

**Data Analysis**

The interviews were analyzed following the thematic guidelines proposed by Braun and Clarke (2006). The transcripts of each subject were read many times to familiarize with all aspects of the data before identifying codes related to the questions. Furthermore, the codes and related data were grouped into themes, and unsupported codes were ignored. Finally, the themes were defined and named in a detailed analysis of quality of life in women with PCOS without any overlapping results. The themes were used to focus the questions asked in the in-depth interviews of the subjects.

**Results and Discussion**

The three major themes from the data are: Positive thinking about PCOS condition experienced (sub-themes: Self-acceptance, gratitude, and humor), healthy behaviors in the process of coping with PCOS (sub-themes: treatment motivation, symptom management, and controller), and support (sub-themes: family support and community support).

**Positive thinking**

*Self-acceptance*

Before receiving a diagnosis of PCOS, the women were already aware of unusual symptoms. It was agreed that menstrual irregularities were the first symptom experienced.

The following quote was stated by subject C regarding her psychological condition:

*..ngalamin kan mood swing nya parah ya PCOS tuh, mood swing parah, depresi, jadi kayak pemicu dikit tuh pikirannya overthinkingnya.. (C, P1)*

*..I experience severe mood swings with PCOS. Severe mood swings, depression, and it is like a little trigger for overthinking. (C, P1)*

In line with C, subject D also expressed the same thing:

*Ya sih kalau misalnya secara euu apa secara fisik kayak agak gemukan. Kayak asa bareurat gituu, gitu kan terus euu apa sih apalagi yah gimana yah emang aku stress meureun yaa. Ini teh berawal dari stress jadi kayak dikit-dikit kepikiran, dikit-dikit kepikiran apa aja kayak gitu. (D, P1)*

Yes, if, for example, physically, I am a bit fat. It is like I am desperate, and what is more, I might be stressed. This starts from stress so it is like I think of anything like that (D, P1)

Even though the women are in a depressed condition, their level of positive thoughts is not affected. This was stated by several subjects who finally accepted their condition. The following quote is submitted by subject A regarding the symptoms of infertility that make it difficult to become pregnant.

*Mau bagaimana lagi? Kalau saya sih cukup menjalani aja deh gitu, mungkin apa yang harus kita lakukan ya udah kerjain aja gitu (A, P1)*  
What else can we do? For me, I have to go through it, what we have to do, let us just do it. (A, P1)

*...dan saya juga kan gak diem ibaratnya, saya berprogram hamil, berproses setiap harinya. berpikir positif aja sama apa yang harus dilakukan ya udah kita lakuin aja gitu. (A, P1)*  
...and I also have efforts, I joined a pregnancy program and am always being processed every day. Just think positively about what to do, we just do it. (A, P1)

Similar to subject B, the marriage age is entering its 3rd year.

*...cuman ya selama ini berusaha nerima apa yang udah Allah kasih. Bersyukur jalanin ya udah gitu kan kita mau ngapain sih mau bikin rencana kayak gimanaapun kan tetep aja kan yang nentuin mah bukan kita gitu... secara fisik kita bisa ikhtiar olahraga makan teratur biar sehat biar tetep hidup gitu (B, P1)*

...just so far, we have been trying to accept what Allah has given us. Be grateful, we want to make plans like whatever, it's still not us who decide, physically we can make efforts to exercise, eat regularly to be healthy so that we can stay alive. (B, P1)

*...ikhtiar semaksimal mungkin yang bisa ngerubah cuman ikhtiar sama doa, bikin rencana ya boleh tapi gak usah berekspektasi tinggi biar gak terlalu kecewa (B, P1)*

...make every effort as much as possible. Because the only things that can change destiny are effort and prayer. You can make plans but don't have high expectations so you will not be disappointed. (B, P1)

#### Grateful

It is not easy being a woman with PCOS, which has various effects, both physical and psychological. In the interview, subject A stated how she came to suffer from PCOS.

*...sempet sih berpikir seperti itu gitu, maksudnya kok orang lain nggak PCOS? kok saya PCOS gitu (A)*

...I used to think like that, how come other people do not have PCOS? How come I have PCOS? (A)

There were negative feelings when she found out why she was one of the less fortunate women stating that:

*Ini baru Allah kasih gangguan yang gak bikin fisik saki-sakit banget. Yang lain ada yang fisiknya lebih sakit dari saya. Jadi harus bersyukur Allah masih kasih kita rezeki yang lain (A, P2)*

This is the first time Allah has given me a disturbance that does not make me physically very sick. Others are physically sicker than me, so we must be grateful that Allah still gives us other sustenance (A, P2).

The gratitude that arose in subject A was also felt by subject B as stated below:

*...jadi ya udah lah mencoba menerima apa yang Allah kasih aja, bersyukur masih banyak kok orang yang sebenarnya gak seberuntung kita (B, P2)*

... So, let us just try to accept what Allah gives, and be grateful that there are still many people who are not as lucky as we are (B, P2).

#### Humor

One of the coping strategies used by PCOS women who have symptoms of hirsutism is humor. This was stated by subject B who has a mustache and a little beard in her facial area,

*...gak terlalu ngurusin omongan orang gitu jadi ya udah lah gitu. Atau paling ya udah dibecandain aja, misal ih ini teh yang bikin aku menarik kaya gitu (B, P3).*

... I do not care what people say, so that is fine. Or I just make fun of it, because this interests me (B, P3).

The following is an excerpt from subject D, who uses the same approach when hearing questions, comments, or even scorn from others regarding the hair in her facial area.

*...kalau sekarang mah biar gak pusing ya dibecandain aja, misal ada yang bilang ih kenapa ada kumisnya, bilangnya pasti iya nih dicium suami, jadi nempel (D, P3).*

...For now, so that it does not become a thought, it's just considered a joke, for example, someone says why is there a mustache, I just answer yes, this is because my husband kissed me, so the mustache sticks. (D, P3).

## Healthy behavior

### Treatment motivation

Women with PCOS prefer to obtain medical evaluation for their concerns. However, when approaching doctors before marriage, their requests for examinations were declined, with the recommendation to marry first. This was because the common diagnostic procedure to assess ovarian features includes a transvaginal ultrasound. Cultural and religious constraints, coupled with the necessity for symptoms to be evident post-sexual activity, contribute to the delay in conducting such examinations. Almost all participants encountered a delay in obtaining a definitive diagnosis since these examinations were typically conducted post-marriage in line with the participants' intentions to start a family. The treatment process unfolded and was motivated by various considerations. As quoted by subject D regarding the treatment carried out:

*Program hamil. Baru-baru sih baru baru, pas setelah nikah mau program hamil terus ya didiagnosis PCOS gitu dan euu ya sekarang bingung harus gimana, ngapain, sekarang sih kayak ngejalanin aja kayak healthy life, jauhin junkfood nya kayak makanan seblak apa segala macem dihindarin (D, S1)*

Pregnancy program. Recently, after marriage, I wanted to get pregnant and then I was diagnosed with PCOS and I am confused about what to do. It is like living a healthy life, avoiding junk food like seblak and all similar foods are avoided (D, S1).

In line with D, subject E also focused on treatment to have children.

*Nah itu sih yang memacu saya buat program hamil itu salah satunya kan saya itu guru dulunya, guru anak usia dini jadi terpancing di sana kayak aduh kayak pengen banget, pengen banget nganterin anak-anak sekolah juga kayak orang tua yang lain kayak gitu (E, S1).*

Well, that is what spurred me to make the pregnancy program, one of which is that I was a teacher before, an early childhood teacher. So I was hooked there like I want it, I want to take my children to school too like other parents (E, S1).

Likewise with subject F who wants to have children:

*Memang tidak ada kewajiban kalua setelah menikah itu harus punya anak. Tapi saya nikah udah 8 tahun, ingin sekali rumah dipenuhi ketawa anak, tangis anak. Meskipun punya anak bukan satu-satunya tujuan pernikahan, angger weh teh saya ingin sekali ounya keturunan. Dalam Islam kan emang gitu kan, sok menikah dan punya keturunan. Makanya saya ngejar banget target turun berat badan sama haid biar lancer, minum*

*obat dokter terapi terapi alternatif saya lakuin (F, S1).*

There is no obligation to have children after marriage. But I've been married for eight years, and I want my home to be filled with my children's laughter and cries. Although having children is not the only goal of marriage, I want to have them. In Islam, that is what it is, to get married and have children. That is why I am chasing the target of losing weight and letting my period run smoothly, taking medicine from doctors, and practicing alternative therapy (F, S1).

Besides the motivation to get pregnant, subjects C and A stated that their focus was to live a healthy life.

*..kalau fokusnya pengen punya anak yang ngerawat siapa, yang backup siapa yang sama anakku nanti siapa, gitu kan. Yang penting fokus sehat dulu (C, S1).*

..If the focus is to have children, who will take care of them, who will backup them, who will be with my child, right? The important thing is to focus on being healthy first (C, S1).

*... Oh itu mah (hamil) bonus, kalo saya mah sekarang sehat dulu hehe, karena memang ngerasakan banget kalau udah diatur pola makannya, olahraga, kayak gitu tuh udah ngerasain banget gitu (C, S1).*

... Oh that is (pregnant) a bonus if I am healthy now first. It is because I feel healthy if I have a regulated diet, and exercise, like that, I feel it. (C, S1).

### Symptom management

All participants in the research engaged in discussions about symptoms including hirsutism, androgen hormone excess, menstrual irregularities, and infertility. Each individual outlined distinct strategies for managing their symptoms. Different details were shared about treatment regimens to address hirsutism, daily skincare routines targeting acne control, and specific diet or exercise plans aimed at weight management. The six subjects elaborated on the necessity of medication to regulate blood sugar levels and treat type 2 diabetes. This approach served as an alternative to metformin, which lowers testosterone levels to improve menstrual cycles and reduce clinical symptoms associated with hyperandrogenism.

As in the following quote from Subject D who recounted the drug therapy taken for her menstrual irregularities:

*Iya pengen ngobatin aja sih dulu, yang penting mah lancar aja dulu sih. Intinya gitu doang obatnya, lagian aku pas aku ke dokter kandungan juga cuman dikasih dua jenis obat doang. Kalau*

*aku sih dikasihnya methformin sama trimolus gitu kalau gak salah (D, S2).*

Yes, I just want to treat it first, the important thing is that it goes well first. That's the point of the medicine, after all, when I went to the gynecologist, I was only given two types of medicine. For me, I was given methformin and trimolus if I am not mistaken (D, S2).

Another addition from subject E was becoming burdened to constantly take medicine or vitamins even for the loss she was experiencing:

*...Awalnya sih begitu, cuman karena memang saya pengennya hidup sehat ya mbak ya, jadi enggak ngerasa terbebani aja, cuman saya terbebannya ke minum obat aja tuh tiap hari, saya kan harus itu obat-obatan terus setiap hari untuk penunjang itu apa sih, vitamin D kan vitaminnya perlu. Ya perlu banget supaya rambutnya gak rontok yang kek gitu gitu jadi lebih capenya sih minum obat gitu (E, S2).*

...At first, it was like that, but because I wanted to live a healthy life, yes, so I did not feel burdened. But I was burdened by taking medicine every day, I have to take medicine every day to support vitamin D which is a necessary vitamin. Yes, it is really necessary hence the hair does not fall out (E, S2).

Subject B expressed a sense of exhaustion in recounting her experience while being aware of the initial steps required to manage their PCOS symptoms:

*langsung diikutkan euu apa namanya euu fitness member gitu ya biar olahraganya teratur karena emang secara apa tuh namanya berat badan emang over, dari pernikahan dari sebelum nikah sampe sekarang tuh naiknya hampir 15 kilo jadi emang ya udah lah sekalian nurunin juga gitu kan sekalian hidup sehat juga cuman kan lama-lama ya namanya orang ada capenya ya, akhirnya berhenti gitu kan ya ngilang (B, S2).*

..I immediately joined a fitness member so that I could exercise regularly because I was overweight. From before marriage until now I've gained almost 15 kilos so it is okay to lose it as well as live a healthy life. But after a while, yes, sometimes it was tiring, so I finally stopped. (B, S2).

The main interest for PCOS women was to control their symptoms, through self-medication for hirsutism, acne, and weight control (Brennan et al., 2017).

#### Controller

Another sub-theme from the interviews was PCOS as a controller. In the excerpt below, subject C recounted

how she could not consume sweets to prevent increasing her symptoms,

*.. jadi aku mikirnya yang ya yang positif aja deh, jadi lebih memilih makanan, makanan yang dikonsumsi jadi kayak oh ini bisa oh ini gak bisa gitu kan (C, S3)*

... so I just think positively. I can be more choosy about the food I consume. So this can be eaten and this can not be (C, S3)

*...aku gak pernah minum manis sama sekali sampe sekarang (C, S3).*

...I never drank sweets at all until now. (C, S3).

Subject B also stated the same thing regarding how she could not lose the weight recommended by the doctor.

*...diet yang seimbang tuh memang seperti itu harus diikutin katanya ini tuh pasti katanya ada yang Enggakk sesuai makanya naik, makan buahnya kemarin yang manis ya? terus sayurinya dikit ya? apa dan segala macem, nasinya kebanyakan kali sampe fotonya diliatin.. Enggakk tuh saya makan tuh ini ini tapii kok gak turun (B, S3).*

...a balanced diet must be followed. According to the doctor, there must be something inappropriate so the weight has increased. He asked me if yesterday I ate sweet fruit. Did you eat less vegetables? and all kinds of things, was the rice too much? Even the photo was seen. The fact I did not, I also ate accordingly but how come I did not lose weight? (B, S3).

Likewise with subject D,

*..emang harus bener bener di jaga betul-betul sih, gitu kan. Agak nyesel juga kayak misalnya makan makanan instant junkfood, gitu, kan...aku mikirin makanan gitu ya soalnya aku ngerasa bersalah juga kayak misalkan makan sembarangan (D, S3).*

...You have to take care of it, right? It is a bit regretful too like for example eating instant junk food, I think about food so much because I feel guilty too like for example eating carelessly (D, S3).

#### Support

Almost all subjects expressed confusion over the lack of information and support from health professionals. However, in the interviews conducted, PCOS women could build more positive relationships with their families and communities.

#### Family support

Subject F said that her husband's support was very influential in all the efforts she made for treatment.

*Alhamdulillah, suami support banget. Jadi lebih intim sekarang mah. Olah raga berdua, beneran diperhatiin banget saya teh. Biar program hamilnya sukses (F, D1).*

Alhamdulillah, my husband supports me and it is more intimate now. Exercise together, I pay attention to my tea. So that the pregnancy program is successful (F, D1).

In addition to subject F, B also said the same thing:

*...apapun yang saya pengen lakuin beliau selalu support gitu misalnya saya pengen ke dokter ini ya udah kita ke dokter itu gitu euuu, pengen olahraga ini pengen punya plan ini diikuti lah pokonya disupport lah (B, D1).*

...whatever I want to do, he always supports it, for example, I want to see this doctor, let's go to that doctor, I want to do this sport, I want to have this plan, he follows it, the point is to be supported (B, D1).

In addition to the support from their partners, women with PCOS receive assistance from their parents who actively strive to achieve desired outcomes. Subject B also disclosed facing external pressure from the surroundings concerning issues related to infertility.

*...satu satunya yang ngebelain ya cuman papah, yang selalu ngomong kalau ya udah sih gak apa-apa gitu emang kenapa euuu kebahagiaan itu kan gak selalu dari anak, kesempurnaan juga bukan berarti ketika dia harus punya anak dulu baru sempurna.. yaa intinya sih yaa kalau dari keluarga pribadi gak ada, gak ada masalah gak ada tekanan, support aja gitu (B, D1).*

...the only one who defends me is my father, he always says that it is okay. Happiness is not always from children, perfection also does not mean that you have to have children first to be perfect. Yes, the point is that in my family there are no problems or pressure (B, D1).

Subject E conveyed aspects associated with parental support in the context of her infertility:

*Ibu saya, ya mungkin karena kalau di kampung teh banyak, kalau gak punya anak nanti ditinggalin suami gitu, tapi kita tahu kan suami kita tuh seperti apa gitu kan. Terus ya saya meyakinkan pada ibu, kalo saya lagi promil dia semangat banget support banget (E, D1).* My mother always supports me. Yes, maybe because in the village there is a thought that if you don't have children, your husband will leave you, but I know what my husband is like. Then I convinced my mother that I was in a pregnancy program and she was very excited and supportive (E, D1).

### *Community Support*

Several participants expressed a sense of injustice regarding their PCOS diagnosis in comparison to women without the condition. The women voiced frustration about the lack of information available regarding the treatment of symptoms. However, some interviewees were part of the communities that served as valuable platforms for sharing knowledge and experiences. Online support communities played a crucial role for some participants in result support and information from fellow PCOS women. For instance, subject F discovered support from other women in online communities, stating that these individuals possessed 'more knowledge' and were 'more understanding'. The following quote shows how Subject F perceived a disparity in understanding between her family and other women, despite the former's support. This shows the unique and beneficial support networks formed within online communities, where shared experiences enhance a deeper understanding among individuals facing similar challenges.

*...bersyukur banget bisa gabung sama komunitas PCOS fighter. Karena mereka beneran peduli sesama. Kasih saran bahkan kalau kita gak tahu ya dikasih tahu sama mereka. Beneran saling share aja (F, D2).*

...I am grateful to be able to join PCOS fighter community since they care about each other. They give advice, even when we do not know, they tell us (F, D2).

Subject C also mentioned how she also wanted to be useful to other PCOS women:

*Ku buktikan dengan diriku sendiri dan dengan penelitianku berikutnya bahwa itu bukan cuman abal-abal dan bukan efek jangka panjang bahkan bisa jangka pendek sekalipun kita gak ngerti terjadinya bisa kapan aja gitu. Jadi jangan sepelein jangan ya jangan juga dipikir berat ya tapi jangan juga nyepelein makanya aku pengen bawa itu ke edukasi ke masyarakat gitu loh banyak yang belum aware dan lain-lain bukan maksud untuk ditakuti tapi kalau bisa dihindari gitu kan (C, D2).*

I proved to myself and with my next research that it is not just fake and does not have a long-term effect and can even be short-term even though we do not understand that it can happen at any time. So do not think about it too hard but do not trivialize it either, that is why I want to bring it to education to the community, so many are not aware and others are not meant to be feared but if it can be avoided, right? (C, D2).



*...depresinya banyak, insecuranya banyak, stressfullnya banyak, kalau berbagi tuh bisa ngurangin banget, curhat gitu gitu menurutku. Kayak apa ya kayak berbagi berbagi sebagian yang dirasain bisa ngurangin bangetlah stressfull yang ada (C, D2).*

..there is a lot of depression, a lot of insecurity, a lot of stress, sharing can reduce it, I think. It is like sharing some of what you feel can reduce the stressful things that exist (C, D2).

The theme's link to quality of life was conveyed by subject B:

*...masih ada banyak hal yang perlu kita syukuri meskipun dengan segala gejala yang dirasain. Masih banyak hal positif yang bisa dilakuin biar gak stress (B, QoL).*

... there are still many things we need to be grateful for even with all our symptoms. Many positive things can still be performed to avoid stress (B, QoL).

Subject F said something similar:

*.. meskipun saya belum punya anak, tapi bukan berarti hidup saya tidak berkualitas. Saya masih bisa berbuat baik. Betul saya stress, saya merasa hidup gak berkualitas. Tapi kalau saya terpuruk gimana saya mau berhasil program hamil? Mungkin iya dulu usia pernikahan di bawah 5 tahun saya merasa hidup saya gak ada artinya. Tapi kalau begitu terus ya, masa aja (F, QoL).*

... even though I do not have children yet, it does not mean my life is not quality. I can still do good. I am indeed stressed, I feel that my life has no quality. But if I'm down, how can I succeed in my pregnancy program? Maybe yes, when I was married under 5 years old I felt my life was meaningless. But do I want to be like that forever? (F, QoL).

## Discussion

This research explored PCOS effect on quality of life from the perspective of women and found three major themes. As described in [Table 1](#), these themes include positive thinking about the condition (sub-themes: Self-acceptance, gratitude, and humor), healthy behaviors in the process of coping (sub-themes: treatment motivation, symptom management, and controller), and support (sub-themes: family support and community support).

This research agrees that PCOS can reduce women's quality of life ([Authier et al., 2020](#); [Williams et al., 2018](#); [Aliasghari et al., 2017](#); [Podfigurna et al., 2015](#); [Bazarganipour et al., 2014](#); [Elsenbruch et al., 2003](#)). The complication is seen as a problem of physical and psychological disorders, affecting

psychosocial life. Poor health-related quality of life and high levels of psychological distress are found in a large group of PCOS women ([Gonzales-Blanch et al., 2018](#)).

Other results have shown that there is a positive effect on certain quality of life domains, such as positive thinking through self-acceptance. [Jersild \(1963\)](#) stated that self-acceptance was a willingness to accept the self, which included the physical, psychological, social, and achievement conditions, as well as advantages and disadvantages. According to [Chen et al., \(2017\)](#), self-acceptance is an important aspect that has an effect on self-adjustment in fighting the disease. To achieve normalization, women go through crisis, compromise, and impression management stages ([Chen et al., 2020](#)). In line with these results, [Williams et al. \(2015\)](#) reported positive aspects in PCOS women such as control, relationship and support themes. The theme of relationship control and support can improve quality of life ([Williams et al., 2016: 2015](#)). PCOS is seen as a control and their symptoms do not get worse and one of the first controls suggested by doctors is exercise as well as a healthy and regular diet ([Cowan et al., 2023](#)).

In addition to self-acceptance, the use of humor as a coping strategy is a reaction used consciously to master stressors by creating distance and new perspectives on the self and environment, as well as managing negative emotions ([Laudza & Dinardinata, 2019](#)). According to [Stieger et al. \(2023\)](#), humor shows the potential of adaptive coping strategies that are easily accessible, mostly free, and can be widely used.

PCOS Women often feel confused due to the lack of information and support received from health professionals ([Kitzinger & Willmott, 2002](#); [Williams et al., 2015](#)). Previous research has shown that one of the consequences of lack of support and information is social isolation/resignation ([Taghavi et al., 2015](#)). However, PCOS women can also build relationships with others with the same condition through social networking. This result is in line with [Holbrey and Coulson \(2013\)](#) and [Williams et al. \(2015; 2016\)](#), where participation in online support groups can help women feel empowered.

This research found that women who were aware of abnormality symptoms received delayed diagnosis due to being unmarried. As discussed in previous literature ([Williams et al., 2015](#); [Kitzinger and Willmott, 2002](#); [Snyder, 2006](#)), this may lead women to educate themselves using books and the internet through Instagram to gain information and connect with others. They tend to have discussions and seek answers through the use of online resources and books, supporting the results of this research ([Avery et al., 2020](#)). The positive aspects of PCOS women and the

community's role in providing support for other women with this syndrome were described.

The research showed how women used online media and social networks to gain support. According to Williams et al. (2015), this could have led to PCOS women encountering misinformation. However, the community often created activities including healthcare professionals. The themes described PCOS women's quality of life to understand the relationships and influences between factors contributing to the variable.

Quality of life concept is broad and consists of physical, psychological, social, family, and environmental domains (González-Blanch et al., 2018). Jones and Drummond (2021) identified ten domains, namely relationships, work, money, health, leisure, care, self-esteem, resolution of past life events, mental style, and life management skills. According to Fallowfield (2009), quality of life is seen from the point of view related to disease and its treatment. This affects the psychological, social, and economic well-being aspects of the individual. Therefore, it is crucial to comprehend quality of life experienced by women from their perspectives. The participants' accounts shows that the variable is not uniformly perceived as negative due to the symptoms. However, understanding the intricacies of the process through which a positive quality of life is attained leads to further research and exploration.

The research also shows how PCOS women maintain a positive outlook despite living with the condition and its symptoms. Therefore, the women remain hopeful about their future lives in the face of uncertainty, specifically about future fertility. Previous research has shown that optimism significantly predicts positive health outcomes (Lu et al., 2002; Rasmussen et al., 2009). This suggests that being optimistic may be psychologically beneficial for women suffering from infertility and implies interventions to increase hope.

Results from several quantitative research exploring the relationship between quality of life and general distress show that PCOS women tend to have high depression (Abdelaziz et al. 2023; Bahadori et al. 2020; Deeks et al. 2010). However, there is a realization that life must go on by developing positive aspects in their lives (Williams et al., 2015). The effect of the condition on quality of life can be very diverse. In this research, the negative and positive aspects of the condition were stated by participants due to the effect of demographic variables. Duration of diagnosis and marriage can be one of the factors improving quality of life. Women with a longer duration of diagnosis may be familiar with PCOS control procedures.

This is the first research to explore quality of life in PCOS women. The selected methodology represents a strength to gain a more profound understanding of

quality of life experienced by women. According to Williams et al. (2015), the subjects were also not given a quality of life definition. Therefore, PCOS women serve as valuable narrators, offering insights into their experiences and daily challenges with symptoms. The dynamic nature of the definition, influenced by individual contexts, may be perceived as a limitation. This variability allows subjects the freedom to conceptualize and articulate the meaning of quality of life. The diversity in perspectives adds depth and richness to the understanding of the multifaceted concept in the context of PCOS (Williams et al., 2015). The subjects were limited to PCOS women who did not have children. Therefore, future research is expected to explore PCOS women's quality of life with various effects on their health.

### Conclusion

In conclusion, this research was conducted to explore PCOS effects on quality of life from the perspective of affected women. The three major themes reported were positive thinking about the condition (sub-themes: Self-acceptance, gratitude, and humor), healthy behaviors in the process of coping (sub-themes: treatment motivation, symptom management, and controller), and support (sub-themes: family support and community support). The research showed that PCOS women had positive aspects developed to achieve the desired life.

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