

Patient Journey Map for Health Management in Reproductive-Aged Patients with Polyendocrine metabolic ovarian syndrome

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Abstract

Background Polyendocrine metabolic ovarian syndrome (PMOS), formerly known as polycystic ovary syndrome (PCOS), is the most common endocrine disorder among reproductive-aged women and requires lifelong management. Despite advances in pharmacological and lifestyle interventions, long-term self-management remains challenging due to complex and evolving health management needs. Current care models often lack patient-centered insights into the full disease trajectory, limiting their capacity to address patients' dynamic needs. Therefore, exploring the disease management journey from the patient's perspective is essential to improving outcomes.

Objective This study aimed to delineate the health management journey of patients with PMOS, identify critical care transitions and unmet support needs, and ultimately inform targeted nursing interventions.

Methods A descriptive qualitative design integrated with patient journey mapping was employed. Fourteen reproductive-age women with PMOS were purposively recruited from a gynecology outpatient clinic in Shenzhen, China, between January and May 2026. Semi-structured interviews were analyzed using inductive qualitative content analysis. Patient journey maps were constructed using WPS Office software.

Results Three distinct phases were identified: pre-diagnosis, diagnostic, and long-term self-management. Across the dimensions of tasks, emotions, pain points, and stakeholder interactions, 33 subthemes and 12 core themes were identified. These included symptom normalization and delayed care-seeking in the pre-diagnosis phase, a "cognitive-emotional paradox" at the diagnostic phase, and work-life-health conflicts, inadequate family support, and sociocultural fertility pressure during long-term management. The patient journey map was ultimately developed based on these subthemes.

Conclusion The disease journey of patients with PMOS is lengthy, and their health management needs are complex, dynamic, and multidimensional. Our findings directly inform the development of targeted nursing interventions, such as structured diagnostic communication to address the cognitive-emotional paradox, nurse-led health navigation programs to provide continuous support across phases, and professionally guided peer support to address psychosocial needs. Implementing such a phase-specific, person-centered approach is essential to improving long-term outcomes. Future research could focus on developing and validating these phase-matched interventions and examining how sociodemographic factors influence illness perceptions and self-management behaviors over time.

Introduction

Polyendocrine metabolic ovarian syndrome (PMOS), formerly known as polycystic ovary syndrome (PCOS), is the most common endocrine disorder among reproductive-aged women worldwide [1]. It profoundly affects women's quality of life, reproductive capacity, and long-term health. A meta-analysis reported a global pooled prevalence of 12.1% according to the Rotterdam diagnostic criteria [2]. As a highly heterogeneous chronic condition requiring lifelong management, PMOS necessitates health

management that extends across the patient's entire lifespan [3]. Beyond reproductive endocrine manifestations such as hyperandrogenism, menstrual dysfunction, oligo-anovulation, and infertility, the condition is frequently accompanied by metabolic disturbances, cardiovascular disease, sleep-disordered breathing, mood disorders, and an increased risk of malignancy [4]. Given that the interviews for this study were conducted prior to the international consensus on the nomenclature change, all participants referred to their condition as "polycystic ovary syndrome" (PCOS) during the interviews.

For women with PMOS, health management is especially demanding during the reproductive years. In addition to reproductive health issues, they must navigate concerns regarding altered appearance, metabolic dysfunction, and psychosocial adjustment, among others [5]. Although lifestyle intervention is the recommended first-line treatment [6], its success relies on sustained self-management, an area where low adherence and high dropout rates remain pervasive, seriously limiting outcomes [7]. Hence, systematically capturing and responding to the multifaceted needs that arise throughout the patient journey is critical for enhancing both quality of life and long-term health.

The patient journey map is a visualization tool that systematically captures patients' interactions with the healthcare system. It reconstructs the full pathway of patients' behaviors and emotional changes, from symptom perception and diagnosis, through treatment decision-making, to recovery and management, and identifies pain points and unmet needs at key touch points. By placing the individual at the center of inquiry and capturing experiences across the entire care continuum rather than treating medical encounters in isolation, this method has gained increasingly widespread application in chronic disease health management in recent years [8–10]. Although previous studies have explored various aspects of PMOS management, including lifestyle interventions, medication adherence, and psychological distress [11–13], few have systematically mapped the full longitudinal trajectory of patients' health management needs across the reproductive years. Most research focuses on isolated clinical outcomes or single time points, leaving a gap in understanding how patients' needs evolve dynamically over time and across different health dimensions. Given the prolonged, multifaceted, and often fragmented care pathway in PMOS, patient journey mapping is particularly well suited to identifying gaps and unmet needs. Accordingly, the present study aims to construct a health management journey map for reproductive-age women with PMOS, systematically exploring their core needs and real-world challenges across the full disease trajectory and multiple health dimensions. In doing so, this research seeks to identify critical intervention points and provide an empirical foundation for building a patient-centered PMOS health management support system.

Methods

Study design

A descriptive qualitative design integrated with patient journey mapping was adopted to systematically explore the health management experiences and needs of reproductive-age women with polyendocrine metabolic ovarian syndrome (PMOS). The patient journey map was constructed through a multi-step

methodology: (1) a desktop review of clinical guidelines and care pathways for PMOS to establish a preliminary timeline of the disease trajectory [8, 14]; (2) semi-structured patient interviews to capture experiential details, emotional fluctuations, and unmet needs across the full care continuum; and (3) collaborative validation with key stakeholders to refine and finalize the map. Among these steps, the descriptive qualitative method served as the primary approach for exploring patients' health management issues. The epistemological underpinning of this approach is pragmatism, which prioritizes the research problem and values practical outcomes and solutions. Guided by this stance, we focused on capturing the complex, real-world experiences of women living with PMOS to generate actionable insights for clinical practice, rather than seeking to develop a new theoretical model. This approach is particularly well suited to exploring under-researched areas of chronic disease management where a direct, rich description of phenomena is needed [15]. To faithfully represent participants' lived experiences and the clinical terminology available to them at the time of data collection, we retained "PCOS" in all patient quotations.

PMOS management involves critical transitions, from symptom awareness and diagnostic confirmation to fertility planning, metabolic regulation, and long-term psychosocial adaptation, each shaped by unique physical, emotional, and social challenges. By conducting in-depth interviews and inductive qualitative content analysis, this design allows patients to narrate their experiences holistically, revealing nuanced insights into decision-making processes, barriers to lifestyle adherence, and evolving support needs across the reproductive lifespan. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used to ensure methodological rigor and transparency in reporting this study [16].

Participants

Participants were recruited using maximum variation purposive sampling from the gynecology outpatient clinic of Shenzhen People's Hospital, Guangdong Province, China, from January to May 2026. To capture the full spectrum of PMOS experiences, we sought variation in age, disease duration, treatment history, fertility status, and body mass index. Inclusion criteria were as follows: (1) confirmed diagnosis of PCOS (now PMOS) according to the Rotterdam criteria [1]; (2) age between 18 and 45 years; (3) absence of cognitive impairment or mental disorders, with adequate communication and verbal expression skills; and (4) voluntary participation with signed informed consent. Exclusion criteria included: (1) severe primary diseases involving the heart, brain, liver, or kidneys; (2) hearing or speech dysfunction that would impede effective communication; and (3) refusal to permit audio-recording of the interview. The sample size was determined based on the principle of data saturation. Data collection and analysis proceeded concurrently. After each interview, the research team immediately debriefed and began preliminary coding. Following the analysis of the 12th transcript, we observed that no new codes or themes were emerging from the data. To rigorously confirm that saturation had been achieved, we conducted two additional interviews (Participants 13 and 14). The data from these interviews were coded using the existing codebook; no new codes were required, and the experiences described were fully captured within the pre-existing thematic framework. This confirmed that thematic saturation had

been attained. Therefore, the final sample comprised 14 participants. Their demographic and clinical characteristics are summarized in Table 1.

Research team

We established a focused research team comprising two principal investigators (YF X and S F), four research assistants (W Z, CX OY, YL W, and YF W), and one supervisor (HJ K). All team members had completed formal training in qualitative research methodology and possessed relevant clinical knowledge in reproductive endocrinology. One principal investigator had over ten years of clinical nursing experience in gynecology and extensive experience in gynecological nursing research. The research workflow was structured as follows: the principal investigator conducted all interviews, while research assistants performed verbatim transcription and preliminary data processing. To ensure methodological rigor, the supervisor conducted periodic validity checks through peer debriefing sessions to resolve any ambiguous interpretations during data analysis.

Research method

Desktop review

The research team conducted a desktop review to aggregate available clinical evidence and care protocols for PMOS [8, 17]. National and international clinical guidelines, consensus statements, and relevant literature were reviewed to identify the standard disease trajectory and critical milestones in PMOS management. Through iterative discussions, the team developed a preliminary patient journey timeline identifying three critical stages: (1) Symptom Awareness and Diagnostic Phase; (2) Initial Treatment and Information Acquisition Phase; and (3) Sustained Self-Management, Long-Term Adaptation, and Psychosocial Integration Phase. Key decision points, care transitions, and common patient challenges reported in the literature were systematically annotated within this preliminary framework.

Semi-structured interviews

Interview guide The interview guide was developed based on the research objectives, the desktop review findings, and group discussions among the research team. It was subsequently revised and refined following a pilot interview with two patients who met the inclusion criteria but were not included in the final sample. One expert in qualitative research and one clinician specialized in reproductive endocrinology were invited to review the interview guide, and further revisions were made based on their feedback. The semi-structured interview guide was designed to explore key phases of the patient journey, from initial symptom perception to ongoing long-term adaptation. Each question targeted specific constructs critical to mapping the experiential dimensions of the PMOS journey (see Table 1).

Table 1 Semi-structured interview guide and its targeted constructs

Interview Question	Targeted Constructs
1. Could you walk me through the changes you noticed in your body before diagnosis, what you did about them, and what finally prompted you to seek medical help?	• Symptom recognition and timeline • Self-initiated coping • Triggers for help-seeking • First department visited and initial encounter experience
2. How was the diagnosis communicated to you, and what did you do to understand your condition afterward?	• Quality of diagnostic communication • Immediate emotional response and primary concerns • Perceived knowledge gap • Information-seeking channels and their emotional effect
3. What management plan were you given, and what has it been like trying to follow it while balancing work, social life, and personal plans?	• Initial treatment plan components • Ease and difficulty of adherence • Conflicts with daily life and life plans • Strategies for balancing competing demands
(4) In your ongoing care, what has your relationship with healthcare providers been like? What kind of communication best supports you?	• Feeling heard versus dismissed • Participation in decision-making • Memorable supportive or neglectful experiences • Preferences for optimal doctor–patient relationship
(5) Can you share moments of both success and struggle in your self-management? What has sustained you, and what support do you still need?	• Self-management successes and setbacks • Sources of resilience • Support from family, friends, and peers • Gaps in current support
6. Looking back on this whole journey, how has PCOS shaped the way you see yourself and plan for the future? Has it	• Evolution of illness perception • Identity integration

brought any unexpected growth?

- Adjustments in life and fertility planning
- Post-traumatic growth

Data collection process

Data were collected through face-to-face, semi-structured in-depth interviews. The investigators, who had completed formal training in qualitative research methodology, conducted all interviews. Prior permission was obtained from the director of the gynecology outpatient clinic. Eligible patients were identified by the clinic's nursing staff during routine visits and introduced to the study. The purpose and significance of the research were explained in person by the principal investigator, who provided contact information. Interested patients voluntarily contacted the researcher to arrange participation. All eligible participants received a detailed explanatory statement outlining the study objectives, procedures, and their unconditional right to withdraw at any time.

Confidentiality was guaranteed through anonymized data handling and secure information storage. Written informed consent, including explicit permission for audio-recording, was obtained prior to each interview. Interviews were scheduled at participants' preferred locations and times to ensure comfort and convenience; most were conducted in a private consultation room within the hospital. During the interviews, participants were encouraged to share their personal experiences freely. All sessions were conducted in the absence of any third parties, with only the participant and the principal investigator present. Each interview lasted approximately 30 to 60 minutes and was audio-recorded in its entirety. To minimize potential bias from perceived clinical authority, the interviewer consistently emphasized the focus on personal lived experience, reassured participants regarding confidentiality, and encouraged open, non-judgmental expression. Field notes documenting non-verbal cues, emotional responses, and contextual observations were written immediately after each interview.

Data analysis

Interview recordings were integrated with field notes and transcribed verbatim within 24 hours after each interview. Data analysis commenced concurrently with data collection and continued until thematic saturation was achieved. The inductive qualitative content analysis method, following the procedures outlined by Elo and Kyngäs [18], was used to analyze the interview data. The analytical steps included: (1) iterative reading of all transcripts to achieve immersion and obtain a sense of the whole; (2) open coding through line-by-line annotation to highlight significant statements relevant to health management experiences; (3) independent review and initial coding by two researchers, followed by comparison and consensus to form the final coding scheme; (4) grouping of codes into subthemes and themes, and organizing them along the chronological timeline derived from the preliminary journey framework while remaining open to new temporal patterns emerging from the data; (5) thematic clustering through constant comparative analysis, with particular attention to the three core dimensions of the journey map, tasks, emotional experiences, and pain points; and (6) cyclical refinement of themes until all data were

accounted for and the thematic structure was stable and coherent. By integrating the pre-established PMOS patient journey framework with interview-derived data, we systematically analyzed the evolving health management needs throughout the disease experience. Using WPS Office software, we constructed and visualized the journey map through a structured, multi-layered visual layout.

The patient journey map itself is not an analytical method but a synthesizing framework and visual tool used to organize and present our findings. The map was constructed after analysis by synthesizing the key themes and categories we identified and arranging them chronologically along the care continuum. Its purpose is to provide an intuitive, holistic representation of the multi-stage patient experience, highlighting critical touchpoints, challenges, and opportunities for intervention. Final content validation involved collaborative review sessions with two patient representatives and one attending gynecologist, in which thematic findings and the visual map were systematically discussed to ensure completeness, experiential resonance, and clinical relevance.

Rigour

Prior to formal data collection, a pilot interview phase with two participants validated the interview guide's relevance and feasibility while calibrating the interviewer's technique. Throughout the study period, the interviewer maintained a reflexive journal to document personal assumptions, emotional responses, and methodological decisions, thereby enhancing self-awareness and reducing researcher bias. Interviews were conducted in participant-selected environments that ensured privacy and comfort. The interviewer consistently maintained methodological neutrality, refraining from offering clinical advice or expressing judgment. Transcript verification was performed via member checking: a summarized account of key findings and a draft of the individual's journey trajectory were shared with three participants to confirm interpretive accuracy and experiential fidelity. An audit trail was maintained throughout data collection and analysis, documenting raw data, coding decisions, theme development, and map iterations to ensure transparency and dependability of the findings.

Ethical considerations

This study received ethical approval from the Institutional Review Board of Shenzhen People's Hospital (approval number: LXBA-20260109-455-3). Written informed consent, including explicit permission for audio-recording, was obtained from all participants prior to data collection. Participants retained the right to withdraw from the study at any time without penalty or impact on their clinical care; no withdrawals occurred. To ensure participants' privacy and data confidentiality throughout the research process, the following measures were implemented: (1) contact information was used solely for initial scheduling and was stored separately from research data, accessible only to the principal investigator; (2) all participant-identifiable information was removed and replaced with a unique study code (e.g., N1, N2) during transcription and data analysis; (3) all digital records (audio recordings, transcripts, and field notes) were stored on encrypted, password-protected devices; and (4) only aggregated, de-identified data are presented in publications and reports, ensuring that no individual participant can be identified.

Results

Demographic characteristics of participants

- A total of 14 eligible patients with PMOS participated in this study, all of whom were female. Participants ranged in age from 19 to 47 years, with a mean age of 30.8 years (SD = 7.1). Regarding educational attainment, 71.4% of participants had received tertiary education. Half of the participants were married. A total of 18 interviews were conducted, with four participants being interviewed twice (N3, N6, N7, N12). Detailed participant characteristics are presented in Table 2.

Table 2
General characteristic of the patients (n = 14)

Variable	Age	Occupation	Educational level	Marital status	Course of disease (Months)
N1	30	Employed	Junior middle school	Unmarried	14
N2	19	Employed	College / Diploma	Unmarried	16
N3	24	Unemployed	Bachelor's degree	Unmarried	8
N4	28	Employed	College / Diploma	Married	52
N5	30	Employed	College / Diploma	Unmarried	10
N6	37	Employed	Bachelor's degree	Married	60
N7	25	Employed	College / Diploma	Married	34
N8	38	Employed	College / Diploma	Unmarried	71
N9	41	Unemployed	Bachelor's degree	Married	12
N10	44	Unemployed	Senior secondary education	Married	6
N11	23	Employed	Master's degree	Unmarried	29
N12	22	Unemployed	Bachelor's degree	Unmarried	11
N13	28	Employed	Senior secondary education	Married	9
N14	47	Unemployed	Junior high school	Married	37

Construction of the journey framework

- The patient journey map employed a dual-axis structure, with time progression on the horizontal axis and functional dimensions on the vertical axis. Guided by clinical expert consensus, the temporal axis was divided into three sequential phases: the pre-diagnosis phase, the diagnostic phase, and the long-term self-management phase. The vertical axis comprised four key functional

domains: health management tasks, emotional experiences, pain points, and stakeholder interactions. This framework was designed to capture patients' action goals, emotional responses, primary barriers, and support networks across different disease stages. Using this framework as an analytical matrix, the research team conducted thematic analysis of the interview data, distilling the core content of each functional domain within each phase and characterizing its evolution across phases.

- Through rigorous coding, 232 initial codes were consolidated into 33 subthemes, which were subsequently integrated into 12 core themes. These themes systematically documented behavioral adaptations, emotional transitions, and care barriers across all health management stages. This process enabled the construction of a multidimensional narrative, culminating in a comprehensive PMOS health management journey map (Fig. 1), which visually integrates patients' health management trajectories at each disease stage.

The Pre-diagnosis Phase

Task

1. Early symptom recognition. The early symptoms of PMOS typically manifest as oligomenorrhea or amenorrhea, progressive weight gain, acne, and hirsutism. For example, N1 reported: "I suddenly noticed that I was losing a lot of hair, and then my periods became irregular, I would go a long time without having one." N2 stated: "In high school, my periods often came only once every two or three months. I found it strange because all my classmates had theirs every month."
2. Non-professional healthcare seeking. Before seeking formal medical care, some patients attempted to manage their symptoms through over-the-counter medications, traditional Chinese patent medicines, or self-directed lifestyle adjustments. N2 revealed: "I bought medicine for my irregular periods on my own, following my mother's advice. I took Wuji Baifeng Wan, a traditional Chinese herbal medicine pill, but it didn't really work." N4 noted: "I did go to see a traditional Chinese medicine practitioner at one point, but he couldn't tell me what was actually wrong, he just said it might be due to my irregular lifestyle. After that, I started taking some supplements on my own, like fish oil, hoping to boost my immunity."
3. Health information seeking and help-seeking. Some patients initiated online searches for their symptoms after they persisted, but these efforts did not translate into a clear motivation to seek medical care. N7 said: "I searched online for some methods, but the information I found was mixed, some accurate and some not." N9 mentioned: "I asked some netizens with similar symptoms online, and they said I should go to a professional clinic promptly, otherwise the symptoms would get worse."

Emotions

1. Health indifference and confusion. During the pre-diagnosis period, patients generally lacked a sense of urgency regarding their symptoms and remained in a state of “health indifference.” N10 stated: “I didn’t think much of it at the time, I just didn’t see delayed menstruation as a serious problem.” N5 echoed: “It didn’t really affect my mood that much; I was still young and thought irregular periods were common.” Some patients experienced transient confusion when amenorrhea became prolonged. N2 recalled: “I was curious about why my classmates all got their periods every month while mine were always delayed.”
2. Body image distress and psycho-social burden. For adolescent and young adult patients, weight gain and acne posed notable body image concerns. N1 expressed: “I used to be thin and pretty. After gaining weight, I felt very self-conscious and didn’t dare to wear nice clothes anymore. I kept blaming myself for eating too much.” N10 shared: “I started losing hair, it was awful. My scalp was showing, and I even grew facial hair. I felt like I was becoming a man.” When the metabolic disturbances of PMOS became linked to fertility concerns, anxiety extended to domains of feminine identity and intimate relationships, triggering deeper emotional crises. N6 noted: “I was trying to conceive during that time but kept failing. It was particularly hard when my colleagues would talk about how they got pregnant right away.” N9 added: “My mood swings were intense, I’d feel the urge to cry every few days just to release the emotions.”
3. Concerns triggered by symptom exacerbation. When amenorrhea extended significantly or overt metabolic abnormalities such as acanthosis nigricans appeared, patients began to develop medical alertness. N3 described: “It was frightening, one day I noticed the skin on the back of my neck had turned dark. The symptoms had become severe enough that I’d fall asleep right after meals, and I felt a tingling, electric-like sensation in my hands.” N5 said: “My periods had never been regular, but this time I didn’t have one for six months. It scared me, I realized I must be sick and needed to see a doctor as soon as possible.”

Pain points

1. Barriers to early symptom recognition. Participants consistently reported that their early symptoms, irregular menstruation, progressive weight gain, acne, and hirsutism, were not recognized as potential signals of underlying gynecological-endocrine pathology. This recognition failure occurred across multiple levels: patients themselves lacked the health literacy to interpret bodily changes and often dismissed them as normal or inconsequential; family members failed to provide timely reminders; and primary care providers did not offer referrals or raise suspicion. N7 said: “I gained 10 kilograms in one semester, but my parents just said I ate too much and didn’t exercise. I went to the community health center for acne, but the doctor never connected it to my endocrine system.”
2. Health literacy deficit and illness-related stigma. Patients generally lacked a basic understanding of what constitutes a normal menstrual cycle and were therefore unable to recognize prolonged menstrual intervals as pathological signals. N2 recounted: “When my period didn’t come for a long time, I didn’t know who to ask, so I went to my mother. She told me I was still young and shouldn’t bring it up all the time, she said it’s not proper for a girl to talk about these things with outsiders.” N3

noted: “I searched my symptoms online, but the information was all over the place. After reading it, I still couldn’t figure out what was wrong. Eventually I thought it was probably just a minor issue that would resolve on its own, so I didn’t pay much attention to it.” N12 added: “People around me said my waist was getting too big and asked whether it was because I wasn’t exercising and had gained weight. None of us knew anything about PCOS.”

3. Symptom attribution bias and delayed healthcare seeking. Although some patients perceived physical discomfort, they attributed their symptoms to external factors, stress, late nights, or medication, rather than an underlying pathological condition, thereby postponing medical consultation. N9 admitted: “I was focused on work at that time, working late every night. I felt I had no time to go to the hospital.” Meanwhile, patients subjectively inflated the time costs and infection risks associated with hospital visits, forming a judgment that “it’s not worth the trip.” N10 said: “I found it too troublesome and was afraid of going to the hospital. There were always so many people waiting in line, and I worried about catching something there.”

The diagnostic Phase

Task

- ☒ Care-seeking decision and diagnostic examinations. Patients were typically triggered to seek medical care by significant symptom exacerbation or life events such as pregnancy planning or job transitions, after which they completed the diagnostic workup. N5 said: “The doctor ordered hormone tests, an ultrasound, and a glucose tolerance test.” N3 said: “After my job transfer, I had more free time, so I decided to come to the hospital for a checkup.” N11 said: “I hadn’t had my period for six months, and the skin on the back of my neck had turned dark. I looked it up online and saw it might be acanthosis nigricans related to diabetes, I got scared and booked an appointment immediately.” N10 described the examination process: “I went in for a pre-pregnancy checkup. The doctor drew several vials of blood and had me drink a large cup of sugary water, then drew blood again an hour later. I had no idea what all these tests were for.”
- ☒ Passive acceptance of pharmacological treatment. Patients received medication regimens including dydrogesterone, combined oral contraceptives, and metformin, but lacked a clear understanding of the mechanisms of action and long-term treatment plans. N4 said: “The medication the doctor prescribed brought my period when I took it, but it stopped when I didn’t, I can’t even remember if it was estrogen or progesterone.” N13 said: “The doctor just told me to take the pills and get injections, without explaining what else I should be doing.” N6 confessed: “The doctor prescribed Yaz (a contraceptive pill) for me. At the time, I thought it was just a regular menstrual regulator. I took it for three months, and it wasn’t until later when I read some health posts that I realized it was a contraceptive pill. I felt quite uncomfortable that the doctor hadn’t made that clear to me.” N9 said: “Metformin gave me diarrhea, so I stopped taking it on my own without consulting the doctor. It wasn’t until my follow-up visit that I was told I shouldn’t have discontinued it without advice.”

☒ Passive reception of digital health education. During the diagnostic consultation, patients primarily received basic disease information through means such as scanning QR codes to follow official accounts, collecting printed brochures, or watching educational videos in the waiting area. Some patients were directed to the hospital's nutrition department or case management clinic for follow-up counseling. N1 said: "After reviewing my report, the doctor told me I had PCOS and asked me to scan the QR code on the desk, saying there was an introduction there." N8 said: "He gave me a pamphlet and told me to read it at home." N11 said: "The nurse asked me to follow the hospital's official account, which posts regular health education articles." N13 said: "The doctor told me to visit the nutrition department before my next follow-up, as they would teach me how to manage my lifestyle."

Emotions

- ☒ Diagnostic shock and unfamiliarity-induced fear. Upon first hearing the unfamiliar term "polycystic ovary syndrome," patients generally experienced a strong sense of shock. N4 said: "I was completely stunned at the time, I'd never heard of this condition. How could an endocrine disorder be related to gynecology?" N3 said: "The moment of diagnosis was terrifying. Knowing that I was sick, I felt absolutely awful." N12 said: "I just froze when the doctor finished speaking. My mind went blank. All I remembered was the word 'syndrome', it sounded so serious." N5 said: "I sat in the corridor for a long time holding my ultrasound report. It said 'polycystic ovarian morphology.' I thought it meant I had ovarian cysts, I even worried it might be a tumor."
- ☒ Anxiety over physical changes and altered body image. The interpretation of hyperandrogenism results triggered deep-seated fears of masculinization and loss of attractiveness. N8 said: "When I heard my androgen levels were high, I panicked, I was afraid I'd turn into a man and become ugly." N11 said: "When the doctor mentioned elevated androgens, I unconsciously touched my upper lip, afraid that my beard would grow out and be seen by others." N14 said: "After diagnosis, I stared at myself in the mirror for a long time afterward. The more I looked, the more I felt my face had become squarer and my shoulders broader. Since then, I've avoided having my photo taken."
- ☒ Fertility concerns and intimate relationship strain. Uncertainty regarding fertility constituted the most profound emotional impact, extending into intimate relationships. N6 said: "The doctor said it could affect my ability to conceive. I was terrified that I might lose my chance to become a mother, it felt like my world was falling apart." N4 said: "During the period when I was just diagnosed, I was in a really bad mood. My husband and I fought constantly, and our sex life faded. I felt us growing apart, and I knew it was hurting him too." N9 said: "I'm not even married yet, but I kept thinking, would my future boyfriend look down on me for this? Would he leave me because of it?" N2 said: "My mother kept sighing beside me. The more she sighed, the worse I felt, as if I'd already been sentenced."

Pain points

- ☒ Inefficient communication and fragmented information delivery. Limited consultation time led to rushed information delivery; even when physicians were friendly, patients struggled to retain information and frequently faced a psychological barrier of “not daring to ask further questions.” N14 said: “The doctor was very nice, but she spoke too fast. I couldn’t remember what she said, and I felt too embarrassed to ask her to repeat it.” N8 said: “He barely responded to any of my questions, which made me so nervous that I forgot everything I wanted to ask.” N10 said: “The doctor told me a lot, and I just nodded along, but I honestly didn’t understand most of it. There was still a long line of patients waiting outside, so I didn’t dare take up any more time.” N3 said: “I wanted to ask whether this disease could ever be cured, but the doctor was already calling in the next patient. I had to swallow my words.”
- ☒ Non-individualized health education and cognitive overload. Standardized educational materials were poorly absorbed by patients in a state of high anxiety, lacking specificity and engagement. N1 said: “There was too much content for me to read on my own, and it was too complex. I left the hospital still only half-understanding.” N3 said: “Who has the time to read that much text? The information was too general, it didn’t feel relevant to my situation.” N8 said: “My mind was blank at the time. I had no energy to read it when I got home.” N5 said: “The nurse gave me a diet sheet that said ‘reduce oil and sugar, eat more whole grains’, but it didn’t specify how much I should eat or how to balance my meals.” N13 said: “I scanned the QR code and it led to a long popular science article. I scrolled through a bit and gave up, there were terms I couldn’t understand, like ‘insulin resistance,’ and reading it just made me more anxious.”
- ☒ Deficits in chronic illness communication and catastrophic interpretation. When the message of “long-term management” and “incurable” was delivered without a phased action plan or specific goals, patients tended to interpret “chronic” as “untreatable” and “long-term” as “a lifelong sentence.” N3 said: “The doctor told me this condition basically can’t be cured, I could only manage it slowly on my own.” N7 said: “The doctor said it’s difficult to treat and told me to prepare myself mentally. Hearing that was really hard.” N11 said: “The doctor just said ‘this is something you’ll have to manage for life’ and didn’t elaborate. I cried for a long time afterward, feeling like my life was over.”
- ☒ Post-diagnostic information vacuum and self-navigation dilemma. After leaving the hospital with limited understanding, patients turned to the internet to fill the information gap, but the task of discerning information quality placed a heavy burden on non-professionals. N7 said: “I felt so lost after I got home. I searched online, but there was so much information that it only made me more anxious.” N12 said: “The internet says all sorts of things, I couldn’t tell which ones were true.” N9 said: “I got even more scared after looking things up. Some sources said it could lead to endometrial cancer, others said I’d never lose weight. The more I read, the more hopeless I felt.” N4 said: “I joined several patient groups. Some people were selling supplements, others claimed a ketogenic diet could cure it. I didn’t know who to trust.” N1 said: “I found a post online from someone who also had PCOS and got pregnant after just three months of treatment. Reading that made me feel even worse, it seemed like everyone else could get better except me.”

- ☒ Socio-cultural fertility pressure. Fertility expectations from family, particularly the husband's family, constituted a persistent psychological stressor. Some participants internalized the perceived link between reproductive capacity and their worth within marriage. N8 recounted: "What I dread most is returning to my in-laws' house for the holidays. Relatives always ask when we're having children, and even though my mother-in-law doesn't say it directly, I can feel her waiting for a grandchild." N7 stated: "My mother calls every time to ask whether my periods are regular and when I can get pregnant, as if I'm not a complete woman if I can't have a child." N11 shared: "My husband is an only child. He says it doesn't matter, but I know his family values this deeply. Some nights I can't sleep just thinking about it."

Long-term self-management phase

Task

- ☒ Medication adherence and dependence management. Patients were required to take long-term hormonal medications to regulate menstrual cycles, yet commonly faced a "withdrawal bleeding upon medication, amenorrhea upon discontinuation" dependency dilemma, along with challenges in maintaining adherence. N1 stated: "After taking the progesterone, my period came every month like clockwork, but if I stopped, it wouldn't come, it was really frustrating." N6 noted: "The timing of the medication is tricky; there was a period when I had to take it every day, and I kept forgetting."
- ☒ Structured lifestyle modification. Guided by case managers or nutritionists, patients implemented structured regimens including low-glycemic-index diets, caloric control, and combined aerobic and resistance exercise. Some developed precise self-quantification habits. N12 said: "The healthcare staff made a plan for me, daily exercise, dietary control, avoiding high-calorie foods, and I haven't touched them since." N10 explained: "When I eat, I weigh things out to the gram and control my portions." N3 reported: "I have to do a body composition analysis every month; based on changes in body fat and other indicators, they adjust my exercise targets." N9 had a similarly positive experience: "The doctor drew me a diagram, showing me which stage I was at and what to do next. Even though I knew this condition required long-term management, at least I knew where to start."
- ☒ Regular follow-up and comorbidity monitoring. Patients maintained routine follow-up visits to monitor sex hormones, glucolipid metabolic markers, and comorbid conditions. N12 said: "The doctor told me I was vitamin D deficient and told me to get more sun." N3 mentioned: "Every follow-up involves blood tests to check if there's any improvement." N5 stated: "The doctor asked me to recheck my insulin every three months, saying this indicator is crucial."

Emotions

- ☒ Oscillation between achievement and frustration. During self-management, patients' emotions fluctuated intensely between positive reinforcement and self-blame. N10 stated: "When I see my body weight and body fat percentage drop, I feel a real sense of accomplishment. Every time my

friends see me, they say I look different, and that keeps me motivated.” N7 admitted: “When I go out and realize I should have exercised that day but didn’t, or when I eat something I know I shouldn’t, I feel this wave of guilt and start blaming myself.” N13 described: “After every binge eating episode, I’m filled with regret. I just think, how could I lose control again?” N4 added: “I can stick to the plan perfectly for a whole week, and then one meal ruins everything. That feeling of all your efforts going to waste is devastating.”

- ☒ Fear of complications and health anxiety. After gaining a certain understanding of the disease, patients developed intense anticipatory anxiety about long-term complications, particularly diabetes, endometrial cancer, and cardiovascular disease, often amplified by anecdotal stories on social media. N2 said: “I’m worried about developing diabetes in the future. I have relatives with diabetes who can’t eat properly and have lost their eyesight. Online, they say cardiovascular problems can occur too, it feels very serious.” N5 expressed: “My main anxiety is that insulin resistance will progress to diabetes.” N9 stated: “What forces me to shut my mouth and start exercising immediately is the fear of insulin resistance; I cannot accept becoming diabetic.”
- ☒ Medication safety and dependence anxiety. Patients consistently expressed doubts about the long-term safety of hormonal medications, accompanied by distress over the prospect of lifelong pharmacotherapy. N9 stated: “I worry about the side effects, taking these drugs for a long time will inevitably make me concerned about my liver and kidney function.” N14 expressed: “As soon as I heard I had to take medication long-term, I felt scared. I don’t know if my body will develop other problems after taking this for a decade or two.”
- ☒ Restructuring of reproductive plans and shifting life priorities. After a period of disease management, patients began to reframe fertility concerns from “Can I ever have children?” to “When and how can I have children?” Some actively advanced their original reproductive timelines, some re-evaluated possible pathways after consulting fertility specialists, and others gradually shifted their life focus toward career development or self-fulfillment. N5 shared: “We originally planned to have kids after 30, but now my husband and I have decided to start trying next year; we don’t want to delay any longer.” N11 said: “I saw a reproductive specialist, and they said there’s hope with IVF. I felt less hopeless after hearing that, at least there’s a direction.” N13 admitted: “I’m now focusing more on my career. As for having children, I’ll leave it to fate; I don’t want it to hold my life hostage.”

☒ Gradual acceptance and cultivation of equanimity. After prolonged management, some patients transitioned from pursuing a “cure” to “living with the condition,” developing a more sustainable mindset. N1 said: “I’ve accepted it and am treating it seriously.” N9 remarked: “Mindset is everything; there’s no use being anxious.” N6 reflected: “I told myself to lower my expectations and not expect a complete reversal. I evaluate progress every six months instead of worrying about changes after just a few days of medication. I’ve integrated the principles of healthy living into my daily routine.”

Pain points

- ☒ Time conflict among work, life, and health. Overtime work interfered with timely meals and exercise, and night shifts disrupted circadian rhythms and medication schedules, constituting the

most prominent structural barrier to long-term management. N7 said: “If I’m supposed to eat dinner before 7 p.m. but have to work late, I can’t control my meal timing. When I’m exhausted from work, I have no energy to exercise.” N4 noted: “Exercise is recommended earlier in the day, but I don’t have a suitable time during the daytime because of work.”

- ☒ Dietary interference and lack of family support. Uncooperative family eating habits and spouses’ unhealthy dietary behaviors continuously eroded patients’ self-control resources. Some patients also faced body-shaming from family members. N8 said: “I eat whatever my parents cook; I have no control over it.” N9 described: “My husband has a habit of bringing home midnight snacks around one or two in the morning, and that’s when I get strong cravings, it’s really hard to resist.” N3 recounted: “My family’s first reaction was to think I was too fat and needed to lose weight immediately; they started to look down on me a bit.”
- ☒ The “cognition-behavior gap” in self-management. Patients consistently reported that “appetite” rather than “physical hunger” constituted the greatest barrier to dietary control, with the immediate temptation of high-calorie foods continuously conflicting with long-term health goals. Stressful situations further eroded self-regulatory capacity. N10 explained: “The hardest part isn’t hunger, it’s craving, especially at night.” N13 noted: “When I’m stressed, I find it especially hard to resist. I just want to eat snacks and chocolate to cope.” N9 reflected: “I understand the logic, I know eating too much will make me gain weight and worsen my insulin resistance, but the moment that craving hits, all that reasoning just vanishes.”
- ☒ Social media information overload and discernment difficulties. Confronted with vast and contradictory disease management information on social media platforms, patients commonly found themselves trapped in anxiety over being unable to distinguish credible information from misinformation, imposing a heavy cognitive burden on those without professional backgrounds. N5 stated: “Every influencer says something different, some claim you must absolutely avoid carbs with PCOS, while others insist you have to eat them. I don’t know who to listen to.” N7 explained: “I follow several accounts that talk about PCOS and have watched tons of videos, but the information is so fragmented that I end up feeling more confused about what I’m actually supposed to do.” N12 recounted: “Some article headlines are really alarming, saying if you don’t control PCOS you’ll get cancer. After reading them, I felt terrified, but I had no way of knowing if it was actually true.” N10 added: “A lot of information seems very convincing, but I can’t tell which advice is science-based and which is just someone trying to sell products. It feels like the internet is full of traps.”
- ☒ Economic burden and insufficient health insurance coverage. Some patients reported considerable out-of-pocket medication costs, and non-pharmacological treatments such as laser hair removal added to the financial strain. N2 stated: “The medications prescribed by the doctor didn’t seem to be covered by health insurance, it was all self-paid, and the process was painful and expensive.” N12 said: “As a student, I don’t have much money for treatment; each laser hair removal session costs a lot.” N3 added: “To reduce my hair loss, I’ve spent a lot of money on various topical and oral treatments.”

Discussion

This study employed patient journey mapping to systematically delineate the health management needs of reproductive-age women with polyendocrine metabolic ovarian syndrome (PMOS) across the full disease trajectory. By structuring the analysis along four functional domains, tasks, emotions, pain points, and stakeholder interactions, and across three temporal phases, the findings reveal a complex and dynamic picture of patient experiences that extends well beyond the traditional biomedical focus on menstrual regulation and metabolic control. The visual integration of these dimensions into a comprehensive journey map (Fig. 1) not only captures the multidimensionality of living with PMOS but also identifies critical intervention windows that have been largely overlooked in current care models. Moreover, this analysis helps to delineate patterns of human resource allocation along the patient journey, providing a basis for delivering personalized, dynamic, and precise support to patients.

A central finding of this study is the persistent yet phase-specific nature of symptom burden. Consistent with previous studies, menstrual irregularities and metabolic disturbances were the most prominent and distressing symptoms reported by participants [19–21]. However, the journey map provides a longitudinal perspective, revealing that these symptoms are not static. In the pre-diagnosis phase, oligomenorrhea was frequently normalized or misattributed to benign causes, contributing directly to diagnostic delay. By the long-term management phase, symptom burden had shifted to medication-withdrawal bleeding, ongoing weight management challenges, and insulin resistance–related manifestations. This phase-specific pattern underscores the necessity of stage-matched symptom management strategies. Although not directly examined in this qualitative study, a plausible mechanism proposed in the literature is that unresolved menstrual issues may perpetuate a vicious cycle of psychological distress and endocrine deterioration via hypothalamic–pituitary–adrenal axis activation [22]. This hypothesis, however, requires testing in future longitudinal and physiological studies. Given that suboptimal symptom control directly impairs quality of life, our findings nonetheless highlight the importance of maintaining both menstrual regularization and metabolic optimization as dual therapeutic priorities throughout the care continuum.

One pattern identified in this study was what we describe as a “cognitive-emotional paradox” during the diagnostic phase: patients reported high information needs, yet their capacity to absorb information appeared limited. This pattern seemed to arise from the simultaneous presence of an unfamiliar diagnosis, unfamiliar medical terminology, and emotional arousal related to fertility concerns and body image. Structural constraints, such as limited consultation time and one-way health education delivery, likely further compounded this situation. This finding aligns with previous qualitative evidence on PMOS diagnostic experiences. Tomlinson et al. [23] found that women with PMOS frequently reported delays and barriers to diagnosis, alongside a general lack of empathy from healthcare professionals and significant discrepancies between patients’ illness beliefs and providers’ attitudes. Similarly, a scoping review of patient perspectives on PMOS diagnosis identified that poor clinician–patient communication negatively affects patient trust, with diagnostic experiences often characterized as emotional, negotiated, and incomplete [24]. Moreover, recent evidence indicates that providers frequently downplay

PMOS-related symptoms, contributing to diagnostic delays of up to 15 years [25]. This mechanistic explanation is supported by experimental evidence from van Osch et al. [26], who demonstrated that affective communication during bad news delivery significantly reduces anxiety and uncertainty while improving patients' recall of medical information, particularly prognostic details and treatment options.

Given the chronic and multi-system nature of PMOS, expert consensus recommends phased, individualized management based on comprehensive multidisciplinary assessment involving gynecology, endocrinology, nutrition, and psychology [27]. However, our data suggest that without structured communication and education at the point of diagnosis, even the best-designed multidisciplinary pathways may fail to engage patients effectively. Diagnostic communication is therefore not merely the transmission of information; it represents the foundation upon which illness understanding, treatment trust, and long-term self-management commitment are built.

The psychological trajectory identified in this study progressed from health indifference to diagnostic shock and, eventually, to varying degrees of meaning reconstruction. In the pre-diagnosis phase, most patients remained in a state of "health indifference," lacking the knowledge framework to interpret early symptoms as pathological, a pattern described in other chronic conditions where symptom normalization delays care-seeking [28, 29]. Diagnosis marked a sharp rupture, with participants describing intense shock, fear, and a sense of bodily betrayal, a phenomenon previously characterized as a form of illness identity disruption [28]. A particularly salient temporal theme was the experience of "reproductive time freezing," in which patients felt their reproductive clock suspended in uncertainty, further intensifying psychological distress; this altered temporality has likewise been noted in prior qualitative work on PMOS [23]. With accumulated management experience, however, a subset of patients began to undergo "reproductive plan restructuring," reframing fertility concerns from existential threat to practical planning, whether by advancing their conception timeline, pursuing assisted reproductive technology, or shifting life priorities toward career and self-development. This transition from fertility fear to fertility planning represents a positive psychological adaptation. Nevertheless, not all patients achieved this shift; those with limited partner support, economic constraints, or intense family fertility pressure remained trapped in prolonged reproductive anxiety. These findings underscore the heterogeneity of psychological adaptation and the need for risk-stratified psychosocial support, particularly at critical junctures such as diagnosis disclosure and fertility decision-making.

Long-term self-management was characterized by a constellation of structural and sociocultural barriers extending beyond individual behavioral factors. Three salient dimensions emerged: a tripartite time conflict among work, life, and health demands; dietary interference and lack of support within the family environment; and sociocultural fertility pressure rooted in traditional lineage continuation expectations. These barriers suggest that PMOS self-management cannot be disentangled from its social-ecological context. Indeed, Lim et al. [20] also found that women with PMOS faced logistical barriers such as time and cost, relational barriers including unsupportive partners or prioritizing children's meal preferences, and environmental barriers such as lacking access to safe places to exercise. McGowan et al. [30] further identified weight stigma and an overemphasis on weight loss and fertility, rather than patients'

personal motivations, as pervasive barriers to sustained lifestyle change. Similarly, Garcia et al. [31] reported that scheduling conflicts and financial limitations were the most cited barriers to follow-up consultations among women with PMOS in the Philippines, while Bazarganipour et al. [32] identified financial status and lack of family support as key inhibiting factors to treatment adherence. Interventions focusing solely on individual knowledge and motivation are unlikely to suffice; rather, family-level engagement, workplace accommodations, and culturally sensitive counseling are needed to create an enabling environment for sustained self-management. Moreover, the economic burden associated with long-term medication and non-pharmacological treatments, including the cost of dietitians, personal training, and laser hair removal, further compounds these structural barriers, particularly for younger patients and students [31].

Another important finding concerns the gap between the abundance of PMOS-related information available to patients and their capacity to critically evaluate its quality. Most participants had no prior knowledge of PMOS before diagnosis, a finding consistent with previous research indicating that many patients lack prior awareness of their condition before diagnosis, contributing to delayed healthcare seeking [21]. Patients acquired preliminary understanding only through post-diagnosis interactions with healthcare providers or internet searches. However, social media functioned simultaneously as an information source and an anxiety amplifier: patients commonly found themselves trapped in discernment dilemmas, unable to distinguish credible from unreliable information, and peer support groups occasionally exposed them to unverified treatment regimens and commercial marketing. This finding aligns with the emerging concept of health information overload in chronic disease management [33]. Higher levels of disease knowledge were associated with greater self-efficacy [34–36], but merely increasing the volume of standardized educational materials is insufficient. Instead, healthcare systems should prioritize the cultivation of health information literacy, the capacity to critically appraise the credibility and relevance of health information. Transitional care platforms that provide professionally vetted, multi-format educational content, complemented by guided peer support [37], may effectively bridge this gap while mitigating the risks of misinformation exposure.

The findings of this study carry several implications for clinical practice and future research. Based on the unmet needs identified in the journey map, we propose, as a hypothesis-generating recommendation rather than an evidence-based conclusion, that nurse-led PMOS health navigation programs should be developed and rigorously evaluated. If implemented and tested, nurse navigators might serve as information buffers at diagnosis, self-management coaches during the vulnerable early adaptation period, and resource coordinators during fertility decision-making. Similarly, digital health tools such as AI-assisted dietary logging and symptom tracking could be explored as potential complements to these programs, providing real-time, accessible support between clinical encounters [38]. In addition, integrating professionally guided peer support into routine follow-up care is a promising strategy that warrants further investigation to address the social and emotional dimensions of living with PMOS, which are often neglected in biomedical consultations [7].

In summary, this journey map offers a comprehensive and dynamic portrait of health management needs among reproductive-age women with PMOS. It reveals that the challenges patients face are not confined to the clinical management of symptoms but are deeply embedded in psychological, social, and structural contexts that evolve over time. Addressing these multifaceted needs will require a shift from fragmented, disease-centered care to integrated, person-centered models that are phase-specific, emotionally intelligent, and ecologically sensitive. From a public health perspective, PMOS affects a substantial proportion of reproductive-age women, and delayed diagnosis, fragmented information, and inadequate long-term support impose a considerable burden on both individuals and health systems. The journey map developed in this study can inform population-level strategies, such as targeted screening programs, community-based health education, and the integration of PMOS management into primary care and maternal health services. By identifying stage-specific needs and barriers, the map provides a basis for allocating resources more efficiently and designing services that are responsive to the social and cultural contexts in which women live. Future research should focus on developing and validating phase-matched interventions, as well as examining how sociodemographic factors influence the evolution of illness perceptions and self-management behaviors over time.

Limitation

This study has several limitations. First, only PMOS patients who actively sought care at gynecology outpatient clinics and agreed to participate were included; those who had never sought care, had discontinued treatment, or were managed in primary care settings were not represented, which may have led to the omission of their unique experiences and unmet needs. In addition, the study relied solely on patients' self-reported narratives, without incorporating the perspectives of healthcare providers, spouses, or other family members, thereby limiting opportunities for multi-perspective triangulation. Second, all data were collected cross-sectionally and retrospectively, which may have introduced recall bias regarding pre-diagnosis and early diagnostic experiences, particularly symptom perception and healthcare-seeking decisions. Moreover, because the interval between diagnosis and interview was relatively short for some participants, long-term challenges may not have been fully captured. Third, the study was conducted in a single region of China, where family role expectations, fertility pressure, patient-provider communication patterns, and healthcare access are profoundly shaped by local culture and social structures. Therefore, the transferability of findings to other countries and healthcare systems should be approached with caution. Additionally, the study did not systematically examine how sociodemographic factors such as age, marital and reproductive status, education, and socioeconomic position may differentially shape illness perceptions and self-management behaviors. Future research should incorporate the perspectives of family members and healthcare providers, employ prospective longitudinal designs to track dynamic changes in patient needs and management behaviors, and conduct multicenter, cross-cultural comparative studies to generate richer and more complete evidence.

Conclusion

This study used patient journey mapping to systematically explore the full-cycle health management experiences of reproductive-age women with PMOS, from symptom perception to long-term self-management. The findings revealed that the pre-diagnosis phase was characterized by symptom normalization, limited health literacy, and delayed care-seeking; the diagnostic phase by diagnostic shock, information fragmentation, and communication discontinuity; and the long-term management phase by work–life–health conflicts, inadequate family support, and sociocultural fertility pressure. These multidimensional needs highlight a substantial gap between the current pharmacotherapy-centered care model and patients’ actual needs.

Based on the critical intervention points identified in the journey map, the following recommendations are proposed. For future research: (1) develop and validate phased, nurse-led health management interventions that provide differentiated support at key transition points such as diagnosis, early lifestyle modification, and fertility decision-making; and (2) conduct longitudinal mixed-methods studies to track how sociodemographic factors (e.g., age, education, marital status, and fertility intention) influence the evolution of illness perceptions and self-management behavior trajectories. For clinical practice: (1) integrate professionally guided peer support programs into routine follow-up care, pairing experienced patients with newly diagnosed individuals or those experiencing management difficulties to provide informational and emotional support; and (2) build co-designed digital health navigation systems that offer stage-matched educational content, symptom tracking tools, and direct patient–clinician communication channels, with timely professional responses at high-risk moments such as immediately after diagnosis and during fertility decision-making. Implementing these directions can help shift PMOS care from a disease-centered to a person-centered model, ultimately improving long-term health outcomes and quality of life.

Abbreviations

PMOS	
Polyendocrine metabolic ovarian syndrome	
PCOS	
Polycystic ovary syndrome	
COREQ	
Consolidated Criteria for Reporting Qualitative Research	
SD	
Standard deviation	
WPS	
Word Processing System	

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the Declaration of Helsinki and was approved by the Medical Research Ethics Review Committee of Shenzhen People's Hospital (Approval No. LXBA-20260109-455-3). Written informed consent, including explicit permission for audio-recording, was obtained from all participants prior to data collection. Participants retained the right to withdraw from the study at any time without penalty or impact on their clinical care; no withdrawals occurred.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due to privacy and ethical restrictions, but are available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests.

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Authors' contributions

Y.F.X. and S.F. conceptualized and designed the study, conducted all interviews, performed data analysis, and drafted the manuscript. W.Z. and C.X.O.Y. contributed to verbatim transcription, preliminary data processing, and coding, and critically revised the manuscript. Y.L.W. and Y.F.W. contributed to participant recruitment, data management, and data interpretation, and critically revised the manuscript. H.J.K. supervised the study, contributed to study design and data interpretation, and critically revised the manuscript. All authors read and approved the final manuscript.

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Figures

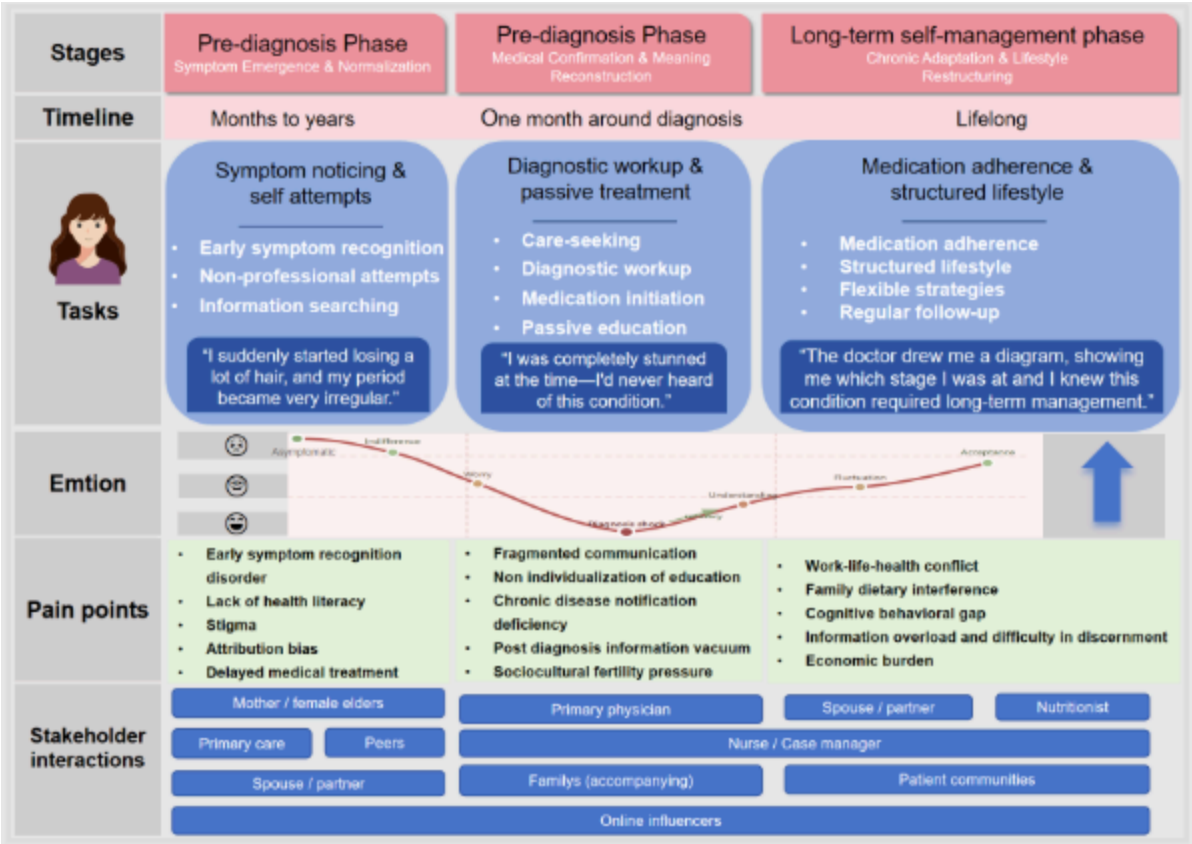


Figure 1

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