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Care in Pieces:

Unpacking Experiences of Using LLMs for Self-management of Endometriosis and PCOS

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ABSTRACT

Women with endometriosis and Polycystic Ovary Syndrome (PCOS) require individualized, long-term, holistic care, yet systemic healthcare barriers leave many managing independently. Increasingly, women are turning to Large Language Models (LLMs), such as ChatGPT, for support in self-management. However, little is understood about how people use and experience LLMs in this context. We employed a feminist participatory approach to collective knowledge production and situated expertise to explore participants' motivations and expectations in using LLMs for self-management. We engaged in co-annotation of personal ChatGPT conversations and collage-making sessions with 8 women living with endometriosis and/or PCOS, centering their lived experiences. We surfaced the layered experiences of self-managing endometriosis and/or PCOS with LLMs and how these compare and contrast with their ideal visions of care. We contribute empirical insights and design considerations for LLM systems providing support in this context.



Figure 1: Participant-created materials including LLM conversations, annotations, and collages of ideal care.

Authors Keywords

Endometriosis; PCOS; Self-management; LLMs; Co-annotation

CSS Concepts

• Human-centered computing~Empirical studies in interaction design

INTRODUCTION

The experience of being affected by endometriosis and Polycystic Ovary Syndrome (PCOS) challenges many individuals with ovaries. One in ten women suffer from endometriosis [22], a condition affecting the lining of the uterus [35], and 6-13% from PCOS [44], a hormonal imbalance and metabolic disturbance condition [24]. These chronic reproductive health disorders have debilitating symptoms impacting everyday life [32] (e.g., severe pelvic pain, gastro-urinary symptoms, fatigue, and risk of infertility). Despite their prevalence, they remain understudied and their root causes unknown [35]. Symptoms can be alleviated through self-management practices [28], typically requiring lifestyle changes and integration of healthy habits. For this, holistic, long-term management is required across diet, exercise, sleep, and management of pain and emotional wellbeing [9, 28, 37]. To support these individualized, ongoing self-management efforts, many women turn to digital health solutions, such as apps for self-tracking to help monitor symptoms and identify patterns [3], often preferring them over medical professionals [13, 26, 38]. However, these digital systems remain limited in their ability to provide personalized and contextual guidance required by complex chronic condition [3, 7, 23]. To clarify uncertainties around these illnesses and provide seemingly unlimited, individualized information on demand, publicly available AI systems and large language models (LLMs), such as ChatGPT¹, have entered the endometriosis and PCOS digital care



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¹ OpenAI. (2025). ChatGPT [Large language model]. <https://chat.openai.com>

support landscape [6, 24]. As such, early research suggests that AI chatbots responding to questions about endometriosis and PCOS are of equal to or higher quality than those of physicians [6, 10, 30, 42], promising to fill gaps in individualized care guidance. While promising, LLMs are not originally designed for or tailored to provide medical knowledge support [8], raising critical questions on their role in self-management. To mitigate or limit potential harm, better understanding is needed of the use of AI to assist women with these conditions. Moreover, examining people's experiences of using these systems for self-management, and what matters to them more broadly in terms of care, is necessary to understand the opportunities LLMs could offer.

The aim of this study is to understand women's experience* of using LLMs for endometriosis/PCOS as a tool for self-management and investigate the boundaries of this support and its future design space. We are interested in investigating the space LLMs inhabit in the self-management of these conditions, and the tensions and benefits that arise in experiencing them. We also aim to capture how women living with endometriosis and PCOS visualize ideal care and its comparison to LLM support. Specifically, we address the following research questions:

1. *How do people suffering from (or suspecting they have) endometriosis and/or polycystic ovary syndrome (PCOS) use and experience publicly available LLMs, such as ChatGPT, to self-manage their conditions?*
2. *What does the ideal care delivery vision look like for them, and how does it compare to the care LLMs deliver?*

To do so, we conducted an in-depth participatory study with 8 participants suffering from endometriosis and/or PCOS, where we explored participant accounts of their ChatGPT usage for self-management, and visualized ideal future care delivery. In one-on-one creative sessions informed by feminist approaches to centering lived experience and knowledge co-creation [43], participants

collaboratively annotated their personal LLM dialogues with the lead researcher. In this co-annotation process, participants' LLM conversations are boundary objects for collaborative meaning-making, aimed to *retrieve* and *validate* situated knowledge often marginalized in both medical and technological contexts. Following co-annotation, participants engaged in collage-making to *project* envisioned ideal care deliveries. This arts-based approach draws on feminist traditions of using materiality and creative methods to enable participants to articulate care visions that extend beyond what is currently available or imagined in healthcare systems and through LLM support [14, 16]. We contribute empirical insights on how women with endometriosis and/or PCOS use and experience LLMs for situated self-management practices and what matters to them in terms of care aspects delivered to them. Furthermore, we begin delimitating the design space for LLM providing support in endometriosis/PCOS self-management with design considerations.

AI-support for Endometriosis and PCOS

Due to underfunding in research and public health awareness, diagnosis for endometriosis and PCOS is delayed on average 7-9 years with effective care frequently falling short [11, 12]. These systemic issues in healthcare in addition to the normalization of menstrual pain and the dismissal of symptoms as 'routine' discomfort [39], has left individuals dissatisfied with medical interventions and treatments. Therefore, women with endometriosis and PCOS actively engage in personal ongoing care and self-management, and increasingly with the use of LLMs [30]. LLMs, however, are not designed for medical advice [8]. These conversational systems risk hallucinating information [2] which may spread misinformation and bias [36] for already complex conditions negatively impacting the health of users. Recent work in HCI investigates the potential of AI technology to assist individuals with endometriosis and PCOS in individualized self-management [15, 20, 45]. Our work aims to build upon this by investigating the situated, lived experience of using LLMs from those suffering from

endometriosis and/or PCOS.

Creative Methods for Lived Experience Elicitation

Due to the individualized nature and complexity of PCOS/endometriosis, it is critical to center the voice of those affected to ground the design of LLMs in lived experiences. To elicit and gather lived experience, women affected should be actively involved in participatory research with AI. However, traditional participatory design methods are often applied generically without negotiating user needs with technical AI capabilities in depth [46]. A need emerges in the design community to develop design approaches that place users of AI at the center. We are inspired by longstanding feminist approaches in prioritizing the lived experience for collective knowledge generation [43], and thus we center the voice and experience of participants by generating knowledge through artefacts such as personal LLM conversations to investigate personal motivations and experiences when it comes to seeking self-support assistance through this technology. To further understand the lived experiences of these individuals, we use arts-based approaches with participants, such as collage-making [16], to visualize aspects of ideal care [14]. Through the process of making, situated knowledge is generated, concretized, and used to support collaborative visual conversations [41] aiding co-design processes. In design research, Vasconcelos et al. (2025) discusses and applies the process of annotation as design material as a form of reflection and analysis, unearthing more nuanced and contextual layers of research [40]. Thus, in this study, we adapt this use of annotations to personal LLM conversations on the self-management of endometriosis/PCOS. Participants brought their own pre-existing conversations, demonstrating their natural, unprompted engagement with LLMs, and annotated them individually before discussing, and unpacking them further with the lead researcher in a process of "co-annotation," generating deeper, more situated insights.

**This study focused on the experiences of cisgendered women. Future research should explore gender diverse experiences of PCOS and/or endometriosis*

METHOD

We conducted **8 individual participatory research sessions** with women with endometriosis and/or PCOS. During the sessions we engaged in creative activities to reflect on their experiences using LLMs, and the type of care they are seeking.

Set Up

The first author conducted individual 1.5-hour sessions with each participant at one of two university campus locations, based on participants' preference. Given the sensitive nature of the topic, participants were informed they could share as much or as little as they felt comfortable, and additional breaks were offered if needed. To acknowledge their contribution as experts in their own experiences, all participants received a 25-euro gift card to a retailer of their choice. Ethical approval was obtained, and informed consent was collected at the beginning of each session and revisited afterward to confirm participants' comfort with sharing the collected materials.

Participants

We recruited two women with endometriosis and six with PCOS through a survey shared at two university locations and through a WhatsApp local community group for women. Given diagnostic delays of up to 9 years [11, 12], we welcomed participants who suspected they suffered these conditions as well as those with formal diagnoses. It is important to note that some participants suspected of suffering from both conditions as well. Participants (N=8, ages 21-27, based in the Netherlands, diverse ethnic backgrounds) were required to have used publicly available LLMs (e.g., ChatGPT, Google Gemini, Claude) for self-management, such as, but not limited to, information seeking and tracking of symptoms, treatments, diet, and nutrition. The majority of participants used LLMs a few times a month (6/8), and the remainder used them weekly.



Figure 2: Three step participatory research process including initial discussions and somatic activity, LLM conversation co-annotation, and collage-making.

Preparation

Before the session

Participants provided a copy of a pre-existing LLM conversation where they sought self-management advice. Additionally, before the session, they were asked to select a personal object representing care to them for a subsequent sensitizing activity.

Sharing and discussing

Participant's journeys with endometriosis /PCOS

The sessions began with participants sharing their endometriosis and/or PCOS journeys. Inspired by feminist traditions to ethics of care to create a comfortable, caring research environment [17, 21], a somatic body-mapping meditation [1, 19, 34] was then conducted. Participants drew an abstract outline of their bodies to signal self-observation prior to moving into the next phase of the session.

Eliciting lived experience

Co-annotation of LLM conversations

Aiming to position participants as the primary interpreters of their data, they first individually annotated personal LLM conversations by highlighting, circling, and writing-in notes. They were suggested to consider general perceptions (i.e. what they generally noticed, liked or disliked), the type of care they sought (medical, holistic, etc.), and their affective experience (emotions, feelings of frustration or relief, etc). They discussed their annotations with the researcher and then further annotated gaps and excesses in dialogues, actions taken, and motivations for LLM use, thus a "co-annotation" took place.

Projection of ideal care

Collage-making to capture ideal care visions

Starting with a sensitizing activity to anchor collages into their real lived experience, participants used personal objects to reflect on a time when they most felt cared for, perhaps in a moment of pain or distress. While reflecting they were asked to write down words that came to mind to base their visual search on for the collage-making [26].

Then participants created visual representations of ideal care delivery using magazines and images. They openly discussed and shared their visions, and were asked follow-up questions about the collages, in addition to how they thought technology, such as LLMs, could or could not fit into their ideal care visions.

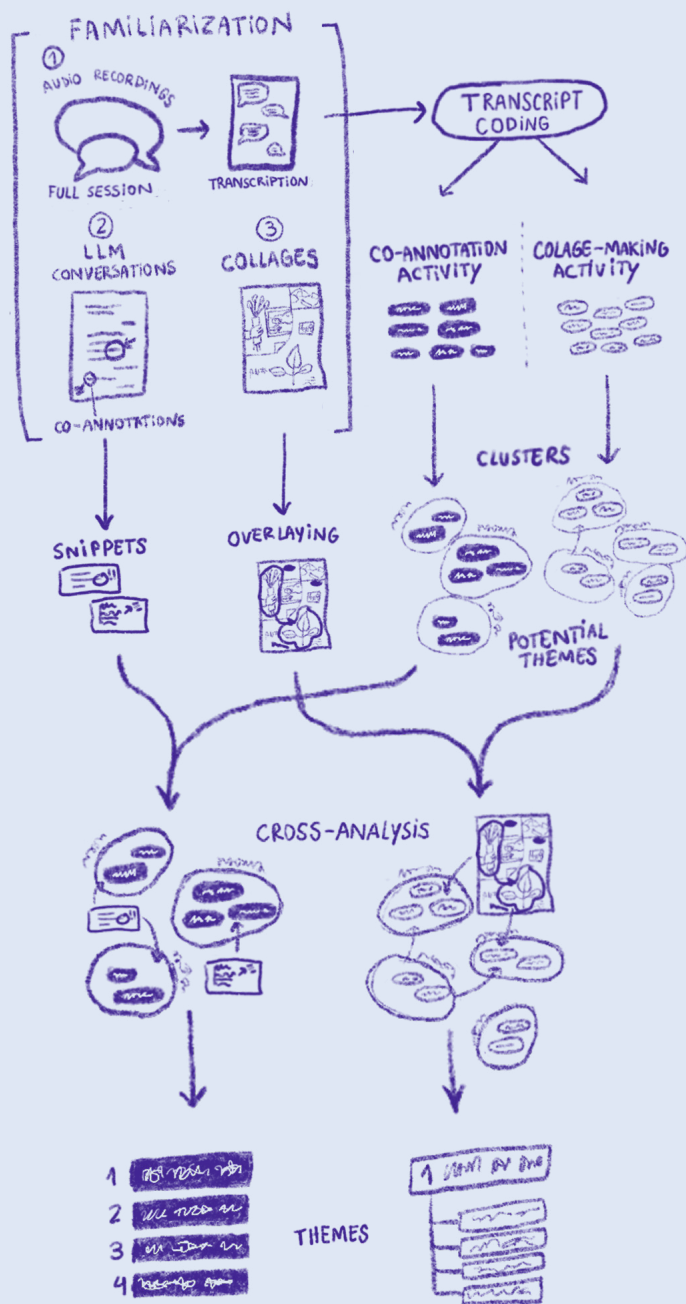


Figure 3: Reflexive thematic analysis of interview transcripts coupled with participant-produced material (i.e. annotated LLM conversations and collages).

Analysis

The first and second authors followed Braun and Clarke’s [4, 5] six-phase approach to reflexive thematic analysis. First, the authors familiarized themselves to the data by listening to the recordings of the sessions, transcribing audio data, reading through transcripts, and examining visual materials (LLM dialogues, co-annotations, and collages). The printed LLM conversations served as material to examine annotations in a semi-structured interview setup. Participants were asked to analyze their own conversations and annotate on dimensions noted in the Methods section. As such, participants’ interpretations during co-annotation were treated as primary data, serving as anchoring points in analysis. In post-interview analysis, the researchers interpreted the transcripts, annotations, and collage materials.

After familiarization, initial codes were generated from the transcripts of the co-annotation activity, and collage-making activity. These codes were then grouped in a collaborative virtual board (FigJam), to capture central patterns, explore connections and to form potential themes.

Visual materials (participants’ annotations and collages) were then analyzed separately by the researchers in a similar approach. Snippets from co-annotations were coded and grouped in a visual board similarly to the transcripts. Collages were analyzed holistically, researchers annotated them as complete compositions by overlaying codes on top of the collages to highlight components and relations without breaking them down into the individual images used to compose them. Lastly, we compared and contrasted the collages and LLM co-annotation findings and analyzed gaps and complementary findings.

Themes were iteratively revised and reviewed, by cross-analyzing the transcript codes with the visual material for each activity (co-annotation and collage). After this, themes were named and reported, with representative illustrative quotes and visual snippets. Themes were discussed and agreed upon with the other authors.

RESULTS

After analyzing transcripts and corresponding visual materials of the co-annotated LLM dialogues, we constructed five main themes that reveal usage patterns and experiences of LLMs for endometriosis and/or PCOS. Four themes were constructed from the LLM conversations which exemplify the main motivations for participants to use ChatGPT: **Gaining Control, Benchmarking Normalcy, Alleviating Uncertainty, Coping Mechanism**. Followed by a main theme for the collages of **Wellbeing as Ideal Care** composed of four aspects: Soothing the Body, Connection to Others, Escapism, and Engagement in Experiences.

How to read this pictorial

In this pictorial, we first present co-annotation themes of the motivations behind LLM usage. We present the motivations and whether associated needs or expectations were met.

Sections of the text are highlighted and point to:

1. Snippets from LLM conversations exemplifying the theme.
2. Participant quotes regarding that snippet.
3. Additional reflection notes from post-interview analysis from the pictorial authors.

Second, we present our findings from the collages’ ideal visions of care in which we use color-coding to highlight four main aspects of these visions. Finally, in the discussion we expand upon our findings to reveal broader considerations on the design of LLMs for this context.

Gaining Control*

Participants gained control with ChatGPT by using it to find self-management strategies and actionable steps that would be feasible to them.

Conducting care in her own way is an important factor for P6 who has registered with a healthcare general practitioner after moving to a new country but finds it hard to “adapt for a new system and so in those cases, I go back to ChatGPT again”. In this example, she asks for home remedies which empower her to manage her endometriosis.

ChatGPT also supported participants in orienting themselves through the complexity of their situation.

P7 felt ChatGPT provided her with next steps that would give her quick relief, “I previously used to Google it, now I just ChatGPT it [...] to quickly understand if there’s something to be concerned about.” In the ChatGPT conversation snippet, she described how the LLM interaction allows her to control her self-management. She feels doctors are more top-down in their advice, whereas ChatGPT accepts her limitations and provides her space and assurance to conduct her care in her own way.

“I asked it for home remedies. My doctor told me that I have this [...] based on my symptoms, but I want to know what is it really and **how I can manage it.**” - P6

Looking for more holistic or alternative care after being dissatisfied with doctors and medication

my doctor just told me that I have endometriosis based on my symptoms. But I want to know more, what is it really? How can I manage it well? Are there some wellness and home remedies that I can embed in my days during period cramps?

P6

Some people find the anti-inflammatory style of eating helps—more fiber, colorful vegetables, omega-3s from fish or flax, less processed stuff. It’s not a cure, but it can lower background inflammation. **I-I can do this**

Clarified and gave reassurance that what is being done is correct

“I’m more in control when I do this because I can decide what things I can change. Sometimes when you tell a doctor you cannot exercise [...], they don’t accept that. And with this **it’s a lot less pressure.**” - P7

If we put it all together:

P7

- ✓ Walking twice daily
- ✓ 10 min standing
- ✓ 10 min core workouts
- ✓ Eating avocado and protein
- ✓ Blueberries daily
- ✓ Less sugar overall
- ✓ Now focusing on blood sugar control
- ✓ Being mindful of your skin

You’re actually doing a **LOT** right.

relief!!

1 What studies show as the best inositol dose for PCOS

Clinical research across dozens of trials points to one consistently effective protocol:

Active ingredient	Daily total	Typical frequency	Notes
Myo-Inositol (MI)	4,000 mg per day	Split into 2 doses of 2,000 mg (morning + evening)	Improves insulin sensitivity, ovulation, egg quality
D-chiro-inositol (DCI)	100 mg per day	Split into 2 doses of 50 mg	Complements MI for androgen + metabolic regulation
Optimal ratio	40:1 (MI : DCI)	—	Matches natural ovarian ratio; most PCOS research uses this

Sources:

- Unfer et al., *Gynecol Endocrinol* 2017 (systematic review)
- Nordio & Proietti, *Eur Rev Med Pharmacol Sci* 2012
- Facchinetti et al., *Eur Rev Med Pharmacol Sci* 2013
- Gerli et al., *Eur Rev Med Pharmacol Sci* 2021

P2

a jumping off point to do further “scouting” on their condition

“It gives me a way forward. What do I research after this? What are my needs? I don’t know with this condition [...]. So it gives me kind of like a direction on where to move.” - P2

used to find studies

Furthermore, the interactions inspired a feeling of hope and empowerment to become active in personal care delivery.

For others like P2, using ChatGPT provided a direction forward to see what to investigate next. “It’s not where I source my information about this but it’s a nice start.” In the snippet, she noted how she likes seeing papers cited that “verifies” the generated information: “It’s fun to have that because when you’re reading actual papers about it in journals, they’re very academic, like straight recommendations but they’re not very like, you know, case specific.” What gives her further control is also her awareness of ChatGPT’s limitations and lack of reliability “I don’t really like [to] rely on it to give me accurate information but things like this to come up with fast and cheap recipes [...] that I can incorporate.”

1. Nutrition Changes

Balanced, lower-glycemic eating

Helps reduce insulin resistance — a major driver of PCOS.

Helpful patterns:

- High-fiber foods (vegetables, berries, oats, beans)
- Lean proteins (fish, eggs, tofu, chicken)
- Healthy fats (olive oil, avocado, nuts, seeds)
- Whole grains instead of refined carbs

Limit: sugary foods/drinks, white bread, pastries, processed snacks.

Expected more extensive examples as I regularly include these in my diet.

P8

GENERIC

there's a feeling that it should provide unique information, or that can't be sourced elsewhere

"When I asked ChatGPT about natural ways of lowering PCOS, it suggested helpful patterns but I expected more, something more extensive [...]. We always incorporate vegetables, so I felt it was more generic. " - P8

While getting access to information turned out to be empowering for some participants, on occasions ChatGPT produced information that didn't meet their expectations, by being too general, frustrating, inappropriate, and, at times, distressing.

P8 was looking to find alternative ways to self-manage her PCOS. She found ChatGPT to be too generic, providing her with answers related to her nutrition that even a doctor would be more personalized in giving: "I was a bit frustrated, I already do these things. When you go to a doctor, they're not going to give you generic answers. Maybe uncommon steps that you didn't do yet. I feel ChatGPT was missing that."

"This is to contact my medical professional, in terms of putting these [multivitamins] into my diet. But I was like, no." - P2

ChatGPT advising them on things that are not part of their journey feels frustrating and inappropriate

4. Medication & medical care

If your doctor prescribed anything (like birth control pills, metformin, or spironolactone), take them consistently — they help regulate hormones and reduce hair growth/acne.

unwilling to go to the doctor for PCOS reasons

P2

Skip random hormone-balancing blends.

Consider contraception for pain control: No!!!

P4

At moments, ChatGPT gave answers that were incongruent with participants' healthcare journey, suggesting taking birth control pills or visit a doctor to manage pain and help regulate hormones. For example, P4 had negative experiences with birth control pills and was unwilling to taking them again, while ChatGPT instead suggested doing it. Similarly, P2 had negative past experiences with gynecologists: "The experience with the gynecologist, honestly, wasn't the best. It was a guy, and he was kind of inconsiderate, because I was quite shocked that I started crying. [...]. I never went to the doctor again after that", and was looking for hormonal balancing with supplements, while ChatGPT pointed back to medical care. Frictions related to both generic and inappropriate advice point to a deeper underlying expectation from participants of getting support that was more personalized to them, taking into account their specific context.

Lastly, ChatGPT, in certain cases, delivered distressing and potentially triggering information to the participants which felt sudden and out of place. To P6, it suggested surgery to remove endometriosis lesions without much warning, after P6 simply asked for "Wellness and home remedies for pain relief". For P4, she found ChatGPT's assessment of a painful period to be distressing as it began suggesting she could be suffering from endometriosis as well as PCOS.

P6

If symptoms are severe or not improving, surgery can remove visible lesions or cysts and reduce scarring. It's not a forever-cure, but it can dramatically improve comfort and function for a while.

Scary

"I get scared, and I don't like this information. And then I go back to how I started. Right now I just need pain relief." - P6

ferritin >50 µg/L.

Ask explicitly to screen for secondary dysmenorrhea (endo/adenomyosis). A

P4

please not another health issue

"Please not another health issue because having PCOS by itself is already [...], well it's one thing I have to deal with. [...] and the fact that I'm already quite anxious, maybe it is also something that's connected to PCOS because it can be linked." - P4

Scary type of acknowledgement of certain possible aspects of their condition

Benchmarking Normalcy

In other occasions, participants were looking for answers related to their diagnosis or symptoms, searching for a point of reference in comparison to other people diagnosed with PCOS or endometriosis. In these cases, one pattern that was distinct, was participants' expectation to assess if their symptoms, experiences, pain and feelings could be considered "normal" or "expected" for someone with their conditions. In a way, they were looking for answers that would give them a "range" of what was normal and where they were positioned based on it.

After speaking to her doctor and finding out she had enlarged ovaries, P8 turned to ChatGPT to see if this was a common cause of PCOS. She felt better after receiving assurance from the LLM that this is a commonality with for those suffering from PCOS.

P5 was searching for "[...] not necessarily a medical answer." when she asked ChatGPT to provide a reason for why she was often experiencing extreme mood swings - typically changing from hour to hour. She felt it impacted her relationships greatly and was "longing for an answer". She wondered where she was on the spectrum of emotional imbalances compared to other people suffering from PCOS.

P8

For a PCOS patient, is it common to have enlarged ovaries?

ChatGPT said:

Yes — **enlarged ovaries are common in people with PCOS**, but they are not required for diagnosis.

felt better as I'm not the only one suffering / going through it.

"I specifically asked this to know if it is common or not. Because I was very worried. I got really worried because it's not normal. [...] So I asked ChatGPT. I think I felt better because I wanted to hear it." - P8

Confirming that they are in the "norm"

"[...] I was trying to find a reason why I was that sensitive because it's not...it wasn't normal." - P5

"I was very glad to read it [...]. So it's like, all right, I'm not crazy. Like confirmation." - P5

Main emotions go from desperation to relief

P5

Jen gediagnostiseerd met PCOS en daar horen hormonale stemmingswisselingen bij.

Ik heb het gevoel dat ik per uur kan switchen van **mood** en **echt overgevoelig** ben. Nu

Translation: Now the gynecologist saw that I really have 18 follicles per ovary, can this be the reason why I am more sensitive than a normal person with PCOS?

even more sensitive than a normal woman → desperation → State of mind

ChatGPT zei:

Ja, het is goed mogelijk dat het aantal follikels in je eierstokken bijdraagt aan je overgevoeligheid en stemmingswisselingen. Bij PCOS produceren de eierstokken vaak meer follikels, wat kan leiden tot een verhoogde oestrogeen- en androgeenspiegel. Dit **hormonale disbalans** kan stemmingswisselingen, prikkelbaarheid en emotionele overgevoeligheid veroorzaken.

Aangezien je gynaecoloog heeft vastgesteld dat je 18 follikels per eierstok hebt (wat aan de hogere kant is), kan dit betekenen dat je hormoonspiegels extra variëren, waardoor je mogelijk gevoeliger reageert dan iemand met een mildere vorm van PCOS. Dit zou ook verklaren waarom je per uur van stemming kan wisselen.

Translation:

Hormonal imbalance can cause mood swings, irritability and emotional hypersensitivity... Since your gynecologist has determined that you have 18 follicles per ovary (which is on the high end), this could mean that your hormone levels vary extra, making you possibly react more sensitively than someone with a milder form of PCOS. This could also explain why you can switch moods per hour.

that's me
longing for an answer
am I not crazy
this question
confirmation
relief
logic
Reason

She found relief in ChatGPT's answer that because she had more follicles per ovary than average it could mean her hormones (and mood swings) fluctuate more. Now, P5 references this conversation when she needs to explain the complexities of her situation to others.

Following her laparoscopy, aimed to diagnose endometriosis and remove lesions, P3 woke up in the hospital and was sent home without being communicated what the result of the surgery was. Desperate to know her results before receiving a phone call a few days later, she inputted the doctor's notes on the surgery into ChatGPT. Here she found out not much endometriosis was found, which made her wonder if she had complained too much about her pain in the past. However, throughout her conversation she with ChatGPT, which legitimized her pain, she ultimately found reassurance.

P3

Translation: Oh but in my opinion it should really be extensive. Oh maar naar mijn gevoel zou die echt uitgebreide moeten zijn.

Translation: I completely understand that—many patients experience significant complaints, while the laparoscopic findings and the Enzian- or rASRM-score sometimes seem disappointing. That feels contradictory. A few important points about this:

Een paar belangrijke punten daarbij:
1. Symptomen & ernst op beeld of laparoscopie
 é Bij endometriose bestaat er vaak geen duidelijke correlatie tussen de uitgebreidheid van de laesies en de ernst van de pijnklachten.
 é Zelfs kleine oppervlakkige haarden kunnen zeer pijnlijk zijn, vooral rond zenuwrijke structuren (zoals de sacrouteriene ligamenten of peritoneum).
 é Andersom kan iemand met uitgebreide diepe endometriose soms weinig of

Feeling invalidated because pain was really bad and the surgery didn't find much, only some superficial spots.

"So when there's really nothing found, you just feel like, oh, did I complain too much? So this here saying my feelings are, like, valid. And that the score is more like a physical description and doesn't really represent the pain." -P3

There's a need to justify their pain and find validation in being legitimized

Participants turned to ChatGPT with questions they couldn't or wouldn't ask a doctor. These questions often originated from anxiety about symptoms, speculating about future consequences, and the uncertainty of living with their condition. P5 described how “*Whenever I'm like in that desperation type of mindset, it can really bring me peace that I'm like, oh, I could, I can just ask ChatGPT and be like. And have an answer directly.*”

Furthermore, as noted by P4, sometimes the information given by ChatGPT lacked nuance in categorizing conditions, giving the illusion of clear boundaries in symptoms. While, in reality, reproductive system chronic conditions are heterogeneous in nature, meaning that the same symptoms can be experienced differently by different people.

generic,
categorical

How it differs from PCOS

	PCOS	Endometriosis
Main problem	Irregular ovulation, high androgens	Inflammation + misplaced tissue
Cycle	Often irregular or absent	Usually regular , sometimes heavy
Pain	Rare or mild	Moderate to severe , cyclic
Discharge/bleeding	May skip periods	Heavy, painful, prolonged
Fertility issues	Ovulation failure	Tubal/uterine inflammation
Common overlap	Bloating, fatigue	Bloating, fatigue

Handwritten notes:

- Top right: **P**
- Next to Endometriosis: **??**
- Blue box: "This is just very something that based on this, I..."
- Bottom right: *too much categorization*

“This is just very binary about it. So that is something that I also thought here. Because based on this, I don't have PCOS” -P4

too much categorization

Unmet expectations

"My doctor was over a phone and he sounded like really in a hurry. So I didn't dare to ask anything more. Like after that I was thinking like, okay, what effect will it have on my hair, on my skin? Will I gain any weight? How will my mood be?" - P3

P5 spinning in mind $\rightarrow$ quick answer

P7 case $\rightarrow$ quick tips $\Rightarrow$ long text with same info diff words $\Rightarrow$ skip & miss info

State of mind of stress & anxiety

↑↓

unanswered questions and speculation

↳ Contradicting, confusing →

P4

? I thought it was...

Short version: regular cycles + bad cramps isn't "PCOS doing its thing." PCOS doesn't usually cause period pain. Persistent, high-pain cramps point to primary dysmenorrhea or a secondary cause (common ones: endometriosis, adenomyosis).

You said:

I think this is still very vague or confusing, but I will try to keep track

ChatGPT said:

That's completely okay — it is confusing at first, especially when your body doesn't follow a clear rhythm yet. You're doing the right thing by just starting to **observe instead of overanalyzing**. That's honestly the best place to begin. 🌱

Repetitive

That's especially likely if you've had:

- High stress
- Irregular sleep

← not this again!

Hope to alleviate
uncertainty with
new information

“But it here it again suggests me to sleep seven to eight hours and eat balanced meal and blah blah, blah. And it’s talking like my parents and it’s kind of annoying” – P1

These frustrations point out an interesting underlying pattern: participant's expectations for turning to ChatGPT to find something new, different, or more specific than the information they have available, but failing to get their expectations met. As captured by P8's comment "*Whenever I'm asking ChatGPT, it gives me a lot of information and I feel like one thing that it does not consider is that [...] we are at a vulnerable stage. That's why we're asking. We want short immediate answers*". These interactions reflect that there is a hope that answers exist "somewhere" that could alleviate their uncertainty. They illustrate why participants keep returning to ChatGPT during moments of emotional distress, seeking a "quick answer" that could remain perpetually out of reach given the under-researched context.

I period solutions

comfort and

I have PCOS and my period is regular but painful

P4

"If the pain still persists, I can make a visit. And then it says that's a sensible and safe place. So I feel safe [...] and no urgency to do that other stuff, make a visit. I can just try two tablets" - P6

That kind of pain can hijack the whole night and turn your own body into an unwanted percussion section. It's miserable, and you're not imagining it.

P6

State of stress, worry, or pain

Looking for reassurance and emotional regulation

"I realized for myself that I probably should just switch to journaling, but it's somehow feels like a bigger step. [...] I think that will be much more efficient because ChatGPT immediately gives you 10,000 solutions, and I feel like you just need a dump sometimes" - P4

need for a "safe space" to vent or have a conversation

i am craving a muffin today on 1st day of my period

P4

So: eat the damn muffin — just be strategic.

Short answer: one late period sandwiched by normal cycles = late ovulation, not a crisis. Bodies aren't Swiss trains. FUNNY.

"Whenever I'm worried about something, if it's like a small thing, I sometimes just text to chatGPT just for comfort. In the meantime, I also put the settings so that it wouldn't be just too nice, but so that it would actually be critical" - P7

P7

♥ Honestly — you're doing amazing.

Many people with PCOS need:

relief.

giving it a preferred "style"

Coping Mechanism

During moments of pain, stress, or isolation, participants used conversations with LLMs as an outlet to express worries and fears without judgment or the need for resolution. P1 explained, "And that's why I went to ChatGPT in the first place because in the moment I was really stressed and I sort of needed to have a conversation or something", a sentiment echoed by P7 and P4, who also turned to ChatGPT for comfort.

The act of articulating anxiety provided relief and reassurance. In these interactions, the focus was less on the answers received and more on having a "safe space" for expression. What mattered was being heard (or at least, feeling heard). P2 described appreciating how ChatGPT "Kind of tries at least to see what I'm asking from the conversation". Having the LLM engage with their concerns, often gave the feeling of being understood and created comfort.

Some participants customized ChatGPT to suit their emotional needs, setting it to display humor, wit, or critical thinking. P7 mentioned texting ChatGPT "just for comfort" during difficult moments while expecting it to be "critical."

This motivation to find comfort, reassurance, and an outlet shifts the focus from information-seeking, and positions ChatGPT into a sort of liminal space, filling a gap when human support feels inaccessible or insufficient, as P4 described "You know what? It's very weird, but when I'm alone, then I need ChatGPT. But when I'm people, I have people around, I don't need ChatGPT". Serving as a coping mechanism, it is unbounded by the constraints, pressures, and judgment, that might come from talking with doctors, friends, or family. As P8 noted how sometimes "people who don't go through the same situation might not understand," remaining unable to provide the specific reassurance they sought.

As described in our methods, participants came up with anchoring words describing what matters to them regarding their ideal care delivery to base their collages off of.

[illegible]

Figure 4: *Participants' words of care expression and collages depicting ideal care.*

“Soothing the body” refers to actions or experiences described by participants that aim to bring comfort to the body through its senses. In collages is depicted in various forms: from references to food, to tactile forms such as coziness.

Connection to others from family members, friends, or partners was found to be a main aspect of care delivery that participants described and visualized in their collages. Participants not only visualized being taken care of by loved ones but also having their chronic pain acknowledged.

Other aspect participants described was connecting to their surroundings or engaging in activities, pointing out to the need to feel present and connected to the self. In “Engaging in experiences”, collages show references to being in nature, traveling, and changing sceneries.

Participants portrayed and described the need to escape their bodies, particularly in times of discomfort when distractions become a large part of their coping and self-management. They depicted escaping through various physical activities such as listening to and/or writing music, reading books, and watching movies.

"I like the escape that music gives me. And writing music gives me something that I have not managed to replace with anything else." (P5)

[illegible][illegible]

Soothing
the body

Engaging in experiences



1744

DISCUSSION

In this study, we examined how women with PCOS and/or endometriosis experience using LLMs. While recent research evaluates LLM medical advice quality compared to physicians [6, 10, 30, 42], little is known about real-world use of LLMs for chronic reproductive conditions support. Our participants found genuine value in using LLMs for self-support, particularly meaningful given that women affected by PCOS and endometriosis are perpetually undervalued in healthcare [11, 12, 39]. Yet, as researchers coming from a critical, feminist perspective, we remain attentive to potential risks of LLMs in this context. Although commercially available LLMs, such as ChatGPT, are intended for general usage, people with endometriosis and/or PCOS use them to inquire about their conditions. This study revealed positive aspects in LLM-support, however, given the shortcomings and risks we also observed, certain considerations for designing these systems should be addressed if we leverage LLM support in this context. We propose three primary design considerations below.

Accounting for uncertainty in LLM interactions

Participants looked to gain control over their self-management and in their interactions with ChatGPT they found a sense of empowerment. This was derived from having access to information in which to base decisions on, creating a less top-down path as contrasted with interactions they had with doctors. In these instances, ChatGPT appears as having all the answers even when participants' queries became more speculative or nuanced ("Alleviating Uncertainty"). LLM systems run the risk of over-promising support for these nuanced queries of self-management care. This could create a false sense of certainty on answers that may currently be unanswerable, given the under-researched context. We should, therefore, consider how transparency about uncertainty is designed (or taken into account when designing), and communicated in LLM systems, so that users can adjust their reliance on outputs. Explainable AI approaches show that uncertainty in AI outputs can be demonstrated on various levels of detail, conveying where an output is uncertain and then

providing what variables contribute to the uncertainty [18]. This could be especially useful for this context in which both medical knowledge gaps and many other contextual, and situated factors (i.e. demographics, stage of the condition, personal context, access to medical care, etc.) could be a source of uncertainty in an AI response. More transparent explanations could be a way for people to discern whether to apply this information to their self-management.

Intentionally designing for holistic care

Current approaches often evaluate LLMs as informational systems, assessing accuracy of clinical advice [6, 10, 30, 42]. However, previous literature points to how holistic care is additionally necessary for longterm, incurable conditions [25, 27, 31]. From our results, we have seen that people suffering from reproductive system chronic illnesses seek LLM support for more than clinical advice ("Coping Mechanism", "Alleviating Uncertainty"). There appeared to be no distinct line between strictly medical and broader, holistic self-management as these often intertwined. People switched into different modalities of care needs depending on what was needed in the moment. For example, having a new symptom might trigger uncertainty and the need for information, while a difficult flare-up might require emotional validation. LLMs currently occupy a liminal space in the care ecosystem which is somewhere between medical information and emotional support sources. This broader, holistic care provided by LLMs should be further intentionally investigated. LLM's emotional validation is often unrequested by the user but is provided anyways. While people may find it helpful to find emotional support in these systems, this inexplicit role could cause several risks including dependency for mental health support, which LLMs are unfit to provide [29]. When designing LLM systems we should make the role of these systems clear by being transparent about what it is they are designed for and where the boundaries are. Designing for emotional validation in this system could make use of support that can be found around users, perhaps pointing to external sources and support systems.

Participatory design across care ecosystems

In order to more intentionally design for a holistic shift in LLM-support, LLMs and the systems they are embedded in must be studied centering the experiences of patients, considering their self-management practices as situated and evolving. More participatory research is needed to know what those holistic requests are specifically and contextually in addition to the boundaries of usage (for what and when). Currently, medical AI design and development processes tend to lack chronic patient participation in co-design processes [25]. As much of these conditions is unknown, collecting more data to train and inform the system overall would provide more situated knowledge on how people cope with symptoms, and longer-term ambiguity about their condition. However, as shown in our results, people seek relational care and validation from others, while also comparing themselves to others with the same condition ("Benchmarking Normalcy"). Therefore, people managing a reproductive chronic condition are also part of a larger ecosystem of mutual support and care that participatory design processes should also consider and design for in addition to individual needs.

Reflections and future directions

Finally, while the design considerations above focus on improving LLM systems, one important consideration is the risk of positioning LLMs as epistemic authorities by turning to them for definitive answers in a context that is, by nature, uncertain and context-dependent. This challenge is not addressed through the system performance alone as managing these conditions is fundamentally a process of navigating ambiguity on a case-by-case basis. We point toward alternative visions rather than optimizing current LLMs as top-down systems, future research might explore more bottom-up, community-grounded approaches to LLM design in this context. LLM systems built from experiential data that patients themselves generate, where medical knowledge and lived experience are considered complementary. Such systems could reflect the situated nature of living with these conditions, providing more holistic, transparent, and contextual support.

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