

Living with Uncertainty and Stigma: Self-Experimentation and Support-Seeking around Polycystic Ovary Syndrome

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ABSTRACT

Polycystic Ovary Syndrome (PCOS) is a condition that causes hormonal imbalance and infertility in women and people with female reproductive organs. PCOS causes different symptoms for different people, with no singular or universal cure. Being a stigmatized and enigmatic condition, it is challenging to discover, diagnose, and manage PCOS. This work aims to inform the design of inclusive health technologies through an understanding of people's lived experiences and challenges with PCOS. We conducted semi-structured interviews with 10 women diagnosed with PCOS and analyzed a PCOS-specific subreddit forum. We report people's support-seeking, sense-making, and self-experimentation practices, and find uncertainty and stigma to be key in shaping their unique experiences of the condition. We further identify potential avenues for designing technology to support their diverse needs, such as personalized and contextual tracking, accelerated self-discovery, and co-management, contributing to a growing body of HCI literature on stigmatized topics in women's health and well-being.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; • **Applied computing** → **Health informatics**; • **Social and professional topics** → **Women**.

KEYWORDS

PCOS, Women's Health, Enigmatic, Chronic Condition, Self-Tracking, Self-Management, Self-Experimentation, Support, Stigma

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1 INTRODUCTION

Polycystic Ovary Syndrome (PCOS)¹ is a condition of hormonal imbalance—often a disorder of the endocrine system—that causes infertility and irregular menstruation in women [87]. PCOS is prevalent, affecting 1 in every 10 women [87], a rate similar to that of diabetes in the United States [9]. Notably, many women do not discover that they have the condition until they encounter issues with pregnancy, since almost 30% of women with PCOS have infertility issues [16]. Along with being a chronic health condition, PCOS is also enigmatic in nature [68], that is, not only is it part of a lifelong journey but symptoms, causes, and treatments of PCOS are not well-understood and vary across individuals. There is also uncertainty in discovering and diagnosing the condition which is further complicated by the lack of clear benchmarks across different medical councils [16, 107]. Medical research, too, acknowledges the uncertainty around PCOS as “*all the dimensions of PCOS have not been completely explored*” [95]. Moreover, PCOS plays an important role in shaping people's experiences and self-image as it is “*as much about social stigmas around the female body and femininity, as it is about its physiological manifestations*” [94]. Ashley describes in her article that women with PCOS face difficulties accepting their condition because “*they feel different, ashamed and set apart from what is considered to be normal due to the physical symptoms such as acne and excess facial hair*” [51].

While there are a significant number of commercial technologies for managing and educating about menstrual health and fertility (e.g. Flo [43], Period Tracker [72], Ava Bracelet [10], Cycles [32], Glow [29], Clue [28], Period Tracker-Ovulation Calendar-&-Fertility app [47]), with some exploring the possibility of predicting health issues such as PCOS [21, 101], very few are able to support the diverse self-tracking needs of people with PCOS. Many of these menstrual tracking technologies consider “healthy” individuals as their target audience, often excluding people with varying health conditions such as PCOS. People with PCOS often have irregular menstrual cycles, reducing the effectiveness of current cycle

¹We use the term PCOS to collectively refer to both PCOS and PCOD or Polycystic Ovarian Disease. While PCOS is a metabolic disorder, PCOD is also caused by hormonal imbalance but is not considered to be a full-fledged disease as it can be managed with exercise and diet regulations. [54].

prediction functionality provided by such applications. Further, the enigmatic nature of PCOS makes it even more challenging to track as different individuals may experience the condition differently. This variability contributes to the uncertainty in identifying which symptoms or variables are relevant and how these variables can be taken into account while designing self-tracking technologies that cater to PCOS as well.

On the research side, an emerging focus within the field of women's health in HCI has been fertility, sexual, and menstrual health—topics of critical importance which are often impacted by stigma and associated cultural taboos [58, 83, 114–116]. Prior works about these topics have examined how technology can support varying self-tracking and management goals across a “healthy” individual's life, studying the use of existing menstrual tracking tools [37] and providing recommendations for holistic fertility tracking, shaped by people's highly personalized contexts [31, 40]. However, research has been sparse in the HCI community around chronic health conditions that are in close relation to menstrual and sexual health such as PCOS. That said, research from other disciplines has explored the challenges that people with PCOS face in identifying, accepting, and managing their condition [109, 125, 127], motivating our work to understand people's support-seeking and self-experimentation practices. In this light, PCOS becomes an important context to study, lying at the intersection of being an enigmatic condition with no universal cure and a women's health concern with associated stigma.

Through this research, we aim to uncover people's lived experiences with PCOS—from discovery and diagnosis to living with and managing the condition—based on which we identify avenues for technology design to better support people with PCOS. To this extent, we conducted semi-structured interviews with 10 women diagnosed with PCOS and presently living (but not born) in the U.S. to learn about their lived experiences. Additionally, we analyzed PCOS-related posts on a popular subreddit forum—including those by people who are not diagnosed with the condition—in order to build a deeper understanding of how they communicate about and assess their bodies and the condition. We acknowledge that while our study is based in the U.S. (Reddit, too, being a primarily U.S.-based platform), we continually draw upon the ethnic and cultural backgrounds of the participants (especially our interview participants who are all of Asian origin) to compare and contrast their experiences in the U.S. versus their country of origin.

In this paper, we make three contributions. First, we provide a detailed account of the aspects that shape PCOS experiences: *uncertainty* and *stigma*. In particular, people self-experimented with different variables of their health to deal with the uncertainty and used online communities to seek support from people with similar conditions as well as “seek a diagnosis” for their condition by sharing sensitive details, including menstrual flow and fertility-related information. We also note the impact of stigma on people's perception of their appearance, identity, and daily lives, and report on the ways they sought support and communicated around their condition. Second, drawing upon these findings, we provide recommendations for designing technologies that support personalized and contextual tracking, accelerated self-discovery, and co-management of PCOS. We also describe the potential of leveraging Reddit and improving patient-doctor communication to enhance support around

PCOS. Our discussion highlights how to design women's health technologies in an inclusive way [34], further accommodating the needs of people with PCOS while enhancing the general public's awareness of menstrual health and its related health conditions. Lastly, by contextualizing our findings in light of recent works on menstruation, fertility, and self-tracking, our work contributes to the growing body of HCI and CSCW research that seeks to design for stigmatized topics in women's health and well-being.

2 RELATED WORK

PCOS is a highly personalized, enigmatic chronic health condition where the goal is to manage rather than cure. While the most common symptoms of PCOS are irregular menses, excess androgen, and polycystic ovaries, treatment can be complicated due to co-existing health conditions such as insulin resistance and diabetes. As such, we ground our work at the intersection of women's health, stigma, and uncertainty in the diagnosis and management of enigmatic conditions. We further cover works on women's health in HCI, highlighting the difference in experiences of menstruation and fertility by Asian populations, and summarize how people converse, seek support, and self-manage such stigmatized health conditions.

2.1 Stigma and Women's Health in HCI

Women's health has become an area of growing interest within the CSCW and HCI communities, obtaining a special ground when a workshop dedicated to “hacking women's health” was hosted at CHI 2017 [13]. Prior work in this space has covered a wide range of topics such as menstruation [22, 23, 37, 42, 44, 52, 58, 83, 112, 114–116], sexual well-being [36, 59], pelvic fitness [2, 3], pregnancy loss [6, 7], breastfeeding [12, 35, 123], maternal health [17, 48, 66, 90], motherhood [91, 108], abortion [80], and menopause [14, 53, 69, 70, 117]. A key portion of these works tends to technology design for tracking, engagement, and self-management. Epstein and colleagues examined menstrual tracking practices in the U.S. and found that some women track their cycles to be prepared for their periods and inform conversations with healthcare providers [37]. They noted that to be useful, cycle predictions must be accurate and commented on the non-inclusive nature of menstrual tracking apps. While cycle predictions may be accurate for people with regular and trackable periods meeting the needs of “healthy” individuals, people with PCOS often experience irregular and unpredictable periods. Commercially available solutions for PCOS (e.g., My PCOS Team [82], PCOS Guide [30], PCOS Tracker [113]) also fall short of offering the granular and diverse tracking options required by people with PCOS (e.g., hair loss, hormone levels). In addition to menstruation, fertility management is also important to consider when designing for PCOS. Figueiredo and colleagues explored the possibility of supporting holistic tracking for fertility [40] and discussed how design implications can be shaped by highly personalized contexts and experiences of individuals [31]. They also found that collaboration played an important role in reflecting and reaching conclusions based on tracked data [41]. On the other hand, Schneider and colleagues attempted to communicate infertility without spiking negative emotions by creating uncertainty visualizations for fertility tracking applications [96]. Our work situates findings from past work on menstruation and fertility management, highlighting

opportunities for more inclusive technology design, that is, creating technologies that include and address the needs of diverse individuals [34], including those with health conditions such as PCOS.

Other studies call attention to the stigma associated with designing intimate care and tracking technology for women's health [1, 3, 23, 110]. The role of stigma in women's health is critical to address as people with PCOS may struggle to obtain a diagnosis or seek support due to stigma surrounding menstruation, infertility, and chronic health conditions. More recent research has also explored menstrual tracking using ambient light and smart mirrors [42, 52], a potential way to counter stigma by embedding tracking practices into daily lives. Kumar et al.'s recent panel on "women's health, well-being, and empowerment" at CSCW 2019 [67] takes into account the affective and social aspects of health to extend the conversation around "holistic engagement" with women's health. Further, Tuli and colleagues shared how experiences of menstruation differ based on cultural context as they situated their work in India, where societal norms around menstruation are more limiting as compared to the Global North (e.g., not being able to enter temples if menstruating) [114, 116]. They emphasized the need for designing more culturally-responsive solutions for providing menstrual health education [114, 116], as well as for creating a safe space where women can manage their menstrual hygiene needs without being stigmatized [115]. Other researchers also proposed theories about stigma and "social construction" of PCOS, examining its socio-cultural impact on Indian women, especially those coming from economically weaker backgrounds [100].

Studies have leveraged anonymous and pseudo-anonymous platforms (e.g., Reddit) to study conversations around stigmatized experiences such as mental health illnesses [33] and menopause [69], as well as sensitive topics such as parenting [5]. The pseudonymity of a platform like Reddit "*both conceals information and encourages disclosure*" by protecting users' personally identifiable information, thus safeguarding them from the repercussions that might occur from using their real identities [106]. In contrast, social network sites such as Facebook might inhibit the discussion of stigmatized conditions [121]. Researchers have further examined online patient forums (e.g., Patientslikeme [89], PsychCentral [93], Caretogether [24]) which provide a dedicated space for people with chronic conditions, such as diabetes [56], arthritis [128], and heart disease [77], to share their experiences, exchange knowledge, and increase disease-specific expertise [119], as well as to seek support from peers with the same condition [126]. Depending on their preference, people share varying levels of personal medical information to reap the maximum benefit of being part of such online communities. In line with previous work on stigmatized experiences, we use Reddit to develop an understanding of the sensitive issues faced by people with PCOS, which participants may not feel comfortable sharing through an in-person interview. Furthermore, we are able to uncover deeper and aggregated insights into what people with PCOS seek support for and how they use the platform to assess and experiment with their bodies.

2.2 Enigmatic Conditions

Despite this strengthening focus on menstruation, intimate care, and fertility in the HCI community, closely associated chronic and enigmatic health conditions, such as PCOS, are less explored. While researchers have extensively studied the self-tracking practices and needs of patients with a wide range of chronic illnesses (e.g., [11, 81, 97]), understanding and managing enigmatic health conditions is a challenge given that their symptoms, causes, and treatments are not well-understood. Nettleton and colleagues revealed that patients who do not get medically diagnosed for their physical symptoms find it difficult to "make sense" of and in turn ill-manage their illness due to the lack of any "medical theory" to engage with [84]. However, previous HCI research has demonstrated the feasibility of self-experimentation technology in helping users identify and track variables relevant to their unique experience of enigmatic conditions, such as in the case of identifying triggers for Irritable Bowel Syndrome (IBS) [60–62, 98, 118, 132]. Researchers have also explored the use of self-experimentation technology for enigmatic conditions that are specific to women's health. For example, Young and Miller suggested that self-tracking can support women with Vulvodynia—a condition causing chronic pain in the vulva—in making sense about what causes the pain and how to self-manage the condition [130]. Similarly, McKillop and colleagues drew attention to the use of self-tracking technologies for endometriosis—an enigmatic chronic condition of abnormal tissue growth outside the uterus which causes swelling and pain during menstrual bleeding—wherein there is uncertainty about which symptoms or data is relevant to understand and track [78]. They further attested to using data aggregation across user groups to provide novel views of particular enigmatic conditions and bridge the gap between patients' experiences of these conditions and their medical understanding [78].

PCOS is enigmatic in nature [68] due to the uncertainty that arises in diagnosing and managing it. Diagnosis of PCOS follows an "exclusion" approach, which means that physicians have to first rule out common diseases that have similar symptoms [104], and there is a lack of clear benchmarks across different medical councils [16, 107]. Moreover, symptoms, triggers, and treatments vary across individuals, that is, PCOS may manifest in different ways in different individuals. There is no singular or universal treatment for the condition and the goal becomes more to manage than to cure [124]. Outside of HCI, researchers have explored the diverse lived experiences of people with PCOS, a condition which involves "much more than symptom management alone" [109]. For example, Williams and colleagues point out the frustration encountered by women with PCOS over the lack of support that they received from their doctors, leading some participants to online support groups [127]. Our work builds off previous research from HCI and other disciplines by highlighting the potential for technology to assist people in diagnosing and managing their condition, as well as in supporting collaboration around PCOS with doctors and people's close social circles. Previous studies have also noted ethnic differences in clinical, hormonal, and metabolic characteristics of PCOS, particularly in Asians as compared to western world populations [55, 63, 86]. For these reasons, those affected by PCOS shoulder the responsibility of understanding, discovering, and self-managing

their specific health-related variables. Thus, we ground our work at the intersection of enigmatic diseases and women’s health, investigating self-discovery, self-management, and communication opportunities around PCOS, moving towards more inclusive design of health technologies, also addressing the stigma aspect.

3 METHODOLOGY

Our IRB-approved study took place from September 2019 to May 2020 in eastern U.S. Our goal was to develop a deeper understanding of different aspects that shaped people’s experiences with PCOS and identify avenues for technology design to better support their needs. To this extent, we studied both online and offline realms—collecting data using semi-structured interviews and analyzing posts on a popular PCOS subreddit. While the interview data were aimed at understanding individual journeys with discovering, diagnosing, and living with PCOS, Reddit diversified our dataset and further enriched our analysis by introducing dimensions such as understanding the ways people use online mediums to converse and seek support around stigmatized topics such as PCOS, in a pseudonymous setting [88], and experiment with their bodies. We present our methodology below, referring to the quotes by interview participants using P# and posts from Reddit using R#. We acknowledge that not all people who have PCOS identify as woman/female and thus use the phrase “people with PCOS.” This is to emphasize that the group we are studying might not be homogeneous in terms of gender identity.

3.1 Interviews

3.1.1 Data Collection. We conducted 10 semi-structured interviews with people officially diagnosed with PCOS (see Table 1 for demographics). Participants were recruited using a combination of snowball [49] and purposive sampling [111], using both electronic means (e.g., listserv, Facebook groups) and word-of-mouth. The goal of our interview was to learn about lived experiences of people officially diagnosed with PCOS and understand their technology use in discovering, diagnosing, and managing their condition. Before the interview, each participant filled out a demographic form, including their age of menarche (when they had their first period) and official diagnosis of PCOS. We began by querying participants about their reproductive health history, including how they discovered and got diagnosed with PCOS and what challenges they faced during the process. Participants were then asked to detail their specific symptoms and co-existing health conditions (e.g., insulin resistance, thyroid) associated with PCOS and how those affect their daily lives. Next, we sought to understand their management practices. We questioned them about a variety of management techniques, including non-medical lifestyle changes (such as maintaining physical fitness, following a healthy diet) and medical treatments (including both allopathic and non-allopathic treatments), and also asked them to gauge how strictly they followed their healthcare procedures. Finally, we learned about their current and previous practices of tracking, managing, and communicating about PCOS, including their experiences of using technology for the same. We focused on identifying opportunities for technology design to better support the needs of people with PCOS (e.g., “What kind of support do you feel is lacking in terms of managing your own health alongside

PCOS?” “Can you tell me about a time your tracking technique or tool did not work the way you wanted it to?”).

All the interviews were conducted either on the phone or in-person at locations convenient to the participants. Informed consent was obtained, including permission to audio-record, from each participant before the interview. All audio recordings were transcribed word-for-word for the analysis.

3.1.2 Analysis. We subjected the data to inductive thematic analysis [122]. We read and open-coded each interview transcript line-by-line and then clustered codes, such as *Difficulty and long time in diagnosis* and *Early indicators and self-noticed symptoms of PCOS*, based on emerging patterns in the data. We further grouped conceptually similar codes into higher-level themes such as *Procedures and challenges in discovering PCOS*. We performed this process iteratively, using a combination of open and axial coding [105], to formulate higher-level themes that structured our findings. While the first author performed the majority of the analysis, the co-authors remained in constant touch with the data through the collection and analysis stages, providing regular feedback.

3.2 Reddit Data

To further understand the communication and self-management practices of people with PCOS, we chose an online forum with high user engagement [74]. This online dataset also complements our interview data, as sharing information on stigmatized topics is preferred in anonymous settings [88]. We decided on Reddit as our online forum because it prioritizes pseudonymity, promoting users to converse freely about stigmatized topics [120]. Apart from getting a larger dataset, this approach also helped us identify new topics that are not influenced or centered around interviewers’ questions but emerge from the users’ own thoughts and experiences [76].

3.2.1 Data Collection. We used a Python-based Reddit API Wrapper (PRAW²) to scrape all posts from the r/PCOS subreddit, the largest PCOS-related community on the site with 46.4K members (as of May 2020), which describes itself as “A Place to discuss Polycystic Ovarian Syndrome and all that comes along with it.” All posts from the establishment of the subreddit on July 21, 2010 till November 30, 2019 are considered in our analysis.

3.2.2 Analysis. Our initial dataset consisted of 996 posts (with $M = 8.48$, $SD = 31.48$ comments) by 779 uniquely identified authors. Out of these, 22 irrelevant posts (advertisements, recruitment, etc) were discarded, leaving 974 posts for analysis. We subjected this data to iterative, thematic analysis [122] wherein the first-author performed a combination of open and axial coding [105], grouping conceptually similar interactions under codes (e.g., *Assessing effects of medication*, *Self-experimenting with PCOS management techniques*) and then further, into higher-level themes (e.g., *Assessing and experimenting with body and PCOS management*) [105]. The co-authors met regularly to discuss the themes and provide feedback. We followed this iterative coding process for the entire dataset to come up with our higher-level themes. While we started with themes that came out of the interview analysis, we modified and created new ones where necessary. For example, interview codes

²<https://praw.readthedocs.io/en/v2.1.21/>

Participant Code	Gender	Interview Type	Current Age	Racial Background	Age of First Period	Age of Diagnosis	Menopause Occurred?
P1	Female	In-person	23	Asian	12	16	No
P2	Female	In-person	24	Asian	11	15	No
P3	Female	Remote	22	Asian	12	17	No
P4	Female	Remote	25	Asian	13	20	No
P5	Female	In-person	23	Asian	12	17	No
P6	Female	Remote	22	Asian	12	19	No
P7	Female	In-person	23	Asian	16	17	No
P8	Female	In-person	55	Asian-American	13	26	Yes
P9	Female	In-person	23	Asian	14	17	No
P10	Female	Remote	24	Asian	13	23	No

Table 1: Demographic details of our interview participants. We conducted semi-structured interviews with 10 people officially diagnosed with PCOS. We acknowledge that all our participants are of Asian origin, and 9 out of 10 were university students at the time of the interview, thus shaping their experiences and needs in accordance with their cultural background.

such as *Non-medical changes in lifestyle and environment* were split into *Maintaining Physical Fitness* and *Healthy Eating & Diet* based on the granular details provided about the same in the Reddit posts. New codes such as *Correlating PCOS with other habits and contexts* also rose from our analysis and were added to the Reddit codebook. Thus, the Reddit data analysis was heavily informed by the interview analysis codebook, showing how our analysis of both datasets interacted with each other to inform our findings.

We also coded the Reddit data using inductive and deductive coding methods to classify (1) the user type—*who* is making the post and (2) the nature of the post—*how* certain topics are being spoken about. For the first category (user type), the first-author performed a combination of open and axial coding [19] on the first 100 posts to come up with a coding scheme (see Table 2) to distinguish between users who were diagnosed vs not diagnosed with PCOS. The coding was done by asking two questions: (1) was an attempt made to diagnose PCOS, and (2) what was the result of the diagnosis. This scheme was then used by the other two researchers (second and third authors) to deductively code the data. To achieve minimum inter-rater reliability (IRR) score of 80%, an iterative process was followed in which the two researchers started by coding the same set of posts. After each set of 100 posts, all the researchers came together to discuss and come to a consensus, resolving any discrepancies and revising the code definitions wherever necessary. This process was followed until an IRR of 93% was obtained on the third set of 100 posts. The remaining posts were then divided among the two researchers and coded independently. This rigorous process of coding and discussing to come to consensus ensured the quality of the coding.

For the second category (nature of the post), a similar methodology was followed to derive the two-tier coding scheme described in Table 3. The codes fall under the high-level categories of *Seeking support* and *Expressing emotions and sharing experiences*, each of which are further divided into subcategories as shown in Table 3. The second and third authors performed deductive coding using the derived scheme, following the same iterative process as before to ensure a high IRR score. On the first set of 100 posts itself, an

IRR score of 93% was achieved and the remaining posts were divided among the two researchers to code independently. While the subreddit had “flairs” (e.g., general/advice, rant/venting, fertility, meds/supplements) to help filter posts based on their nature and content topics, we did not use those to inform our analysis.

3.3 Ethical Concerns and Study Limitations

All the interview and Reddit data management procedures were constructed based on the approval of our university’s institutional review board (IRB). We made sure to maintain the privacy of participants while reporting quotes and posts by anonymizing any personal data [20] or pseudonymous identities [46], quoting only relevant excerpts, and assigning post identifiers in a shuffled order. We further paraphrased all post from the online forum and did not attempt to correlate multiple posts made by the same user. However, we acknowledge that since posts on r/PCOS are public and by a small number of identifiable users, it might be possible for readers to trace back posts to individual users.

A major limitation of our study lies in the generalizability of our findings from the interviews. While we recruited using various means and tried to ensure a diverse group, given the limited resources and difficulty in accessing a rather specific target population, all of our interview participants were Asians or Asian-American. We believe that our findings are heavily shaped by their cultural backgrounds (e.g., high social stigma around menstruation and fertility in Asian countries such as India, use of traditional medications and home remedies) even though they are currently based in the U.S. All of our participants identified as women/females and lived in the U.S., an important consideration given that understanding accounts with the U.S. healthcare system is a key to contextualizing PCOS experiences. The time for which they have been in the U.S. (given that 9 out of 10 are international students) is another factor that can affect their experiences and adoption of different management and support-seeking practices. Further, 9 out of 10 participants belong to the age bracket of 21 to 26 years, which means that they may have very different lived-experiences as compared to someone who is older and living with the condition for a longer time. For example, the one participant (P8), who

does not belong to the 21 to 26 years age range, reported that she was diagnosed with PCOS when she had difficulties trying to get pregnant—an experience that none of the other participants had as they got diagnosed earlier and had not reached that stage in life yet. Further, P8 talked about the difficulties she faced “back in the day” when PCOS was not common knowledge, again speaking to the time component and how practices have evolved from the time she was younger. We also acknowledge that all authors, though currently US-based, are of Asian origin and three out of four authors are university students. We believe the authors’ background to be a possible reason for the skew in demographics of the participants recruited for the interviews as we used snowball [49] and purposive sampling [111]. To recruit more diversely for future studies, we identify the potential of tapping into online support groups (e.g., social media groups, mailing lists), health-specific workshops and events, and collaborations with organizations.

We strove to balance out this limitation by analyzing data on Reddit, an online forum, which we expect to be possibly more diverse in terms of its participants. Being U.S.-based researchers and English-speakers, we study an English-only subreddit on PCOS. Previous research has shown that people prefer anonymous settings to share information on stigmatized topics [88] as it safeguards their real identities [106], encouraging disclosure and promoting them to freely converse [120]. Thus, studies have leveraged platforms such as Reddit to analyze conversations around mental health [33], menopause [69], and parenting [5], among other sensitive topics. Moreover, studying such an online platform helped us identify themes, which were purely based on people’s own experiences, not centered around interviewers’ questions [76]. However, Reddit as a forum that allows pseudonymity has other limitations, such as not being able to identify demographic, ethnic and racial, or economic characteristics of users. While certain users may reveal some of this information in their post content (e.g., “I am a 30 year-old female” (R682)), it is difficult to comment on the exact nature of the population. Additionally, there might be a skew in certain characteristics (e.g., high technology literacy skills, better access to online resources, open to sharing online) of participants who frequent online forums. Other researchers also highlight that those who write on such forums, may be inclined to share more intense or negative experiences of their condition [69].

4 FINDINGS

We now present our findings, highlighting the two aspects we found to be most important in shaping PCOS experiences—uncertainty and stigma. We take a consolidated view of the interview and Reddit data. While our interviews detail individual PCOS journeys (from discovering and diagnosing to living with the condition), the Reddit data provides deeper insight into how people communicate and seek support online around PCOS, as well as how they experiment with their bodies and various management techniques.

4.1 Uncertainty in Discovery, Diagnosis, and Management

4.1.1 Difficulties in Discovery and Diagnosis. Discovery and diagnosis of PCOS tends to be a long process. All interview participants reported facing challenges and taking a long time (at least 3 to

7 months) to obtain a diagnosis for PCOS. While missed periods and infertility were the most common prompts for people to visit doctors and get diagnosed, several other early indicators such as sudden weight gain, excessive acne, hair fall, and hirsutism also appeared at the dawn of the condition.

“I used to have pretty bad hair fall and also I never really gained weight but then I saw this tendency to put on weight sometime around that time. I didn’t realize that at that time that these are all...manifestations of PCOS” (P4)

The presence of other health conditions and diseases further complicated diagnosis, making it difficult to ascribe particular symptoms to PCOS. As P6 explained:

“because of my thyroid, a lot of my symptoms are similar... hair fall happens due to thyroid... erratic acne can happen due to thyroid, but it wasn’t that, as I’ve discovered. I didn’t experience massive weight gain all of a sudden but I’d always had difficulty losing weight and that was also because of thyroid but it’s also because of this PCOS... It was compounding.” (P6)

Other factors such as age (e.g., near menarche), stress, and being on birth control could complicate the process of discovering PCOS, often resulting in symptoms being dismissed as a “natural” fluctuation. Furthermore, the effects of PCOS such as hormonal imbalance might take time to develop and appear in diagnosis results.

“When I got my first test done a few years back, everything was normal and I was still not having a period for 2-3 months... knowing that my hormones are fine I would not really pay heed to it... it became worse when I came to the States... I had to get the blood test done and then my androgen levels came high” (P10)

Additionally, as PCOS follows a diagnosis of exclusion approach [104], challenges also arose in interpreting results and finalizing a PCOS diagnosis:

“[the doctor] says it may not be PCOS so he wants to run tests for high prolactin and thyroid (even though it’s been tested multiple times). The only reason he doesn’t think it’s PCOS is because my periods have become more regular...” (R67)

Other factors such as being on birth control could cause hormone level fluctuations affecting blood work results and clinical diagnosis³. High variability and inconsistency in diagnostic criteria in different geographical locations [129] further complicates the diagnosis process.

So while the set of clinical diagnostic procedures appeared to be straightforward, the challenge remained for individuals to recognize signs and symptoms of the condition and obtain enough information to finalize a PCOS diagnosis through a process of exclusion:

“...I don’t have much acne, I am not overweight... In an ultrasound, the doctor noticed the “ring of pearls” or cysts around my ovaries....this makes him think that I

³There is also a form of PCOS called pill-induced PCOS [38] which develops due to the consumption of birth control pills that suppress ovulation.

have PCOS even though I don't fit into any of the other diagnosis criteria (except hair loss)." (R49)

As a result of the difficulty in obtaining a diagnosis, users on Reddit seemed to turn to the platform to not just seek support, but “seek a diagnosis” by sharing their symptoms and medical information:

“high AMH levels (approximately 51)... dheia and SHBG levels were normal... presence of a 5.3 cm ovarian cyst...the doctor now feels that my AMH levels could high be due to this large cyst on my ovary...Without high levels of other hormones, could one still have PCOS?” (R468)

Further, Table 2 shows that around 6% of the posts on r/PCOS are by users who are either undiagnosed or in process of diagnosis, and 3.8% of Reddit posters shared inconclusive diagnosis results or lacked information from their doctors about their diagnosis. Thus, Reddit played a role in supporting self-discovery and self-diagnosis of this enigmatic condition. In summary, discovering PCOS can take time due to absence, complications, or lack of realization about certain symptoms. Further, there is uncertainty associated with interpreting diagnosis results due to the enigmatic nature of the condition, even though the diagnostic procedures are well-defined (USG, bloodworks, and/or physical exam).

4.1.2 Fluctuations and Frustrations in Management. People were seen using various ways—natural and medical—to manage or treat their PCOS. Given the cultural background of our interview participants, 3 out of 10 also used non-allopathic (non-conventional) medications or “*more natural remedies*” which have medical benefits, such as Ayurvedic, Homeopathic, and traditional Chinese medicine. However, all interview participants and a significant portion of posts on Reddit reported one or more personal and/or structural challenges while managing PCOS. Personal issues included difficulty and weariness in following meticulous treatment plans, medication side-effects, fluctuations in symptoms, and complexities with co-existing health conditions. For example, P5 explained that her doctor prescribed four medications that were “*really hard to keep track of*” and “*really hard to follow*.” Moreover, given the complicated nature of PCOS, people often needed to consult with multiple different healthcare practitioners including specialists such as endocrinologists, gynecologists, dermatologists, nutritionists, and therapists to deal with different issues (e.g., skin, hair, diet, mental health) related to their condition.

Structural challenges were related to cost, insurance, quality of available treatment, and access to healthcare facilities, doctors, and/or healthy food. P7 described the dilemma of postponing treatment for financial reasons:

“I did want to start my medication here [in the U.S.] but it was so expensive. And I'm on loans so I didn't want to start... once I get a proper job- once I get everything sorted, I can start on medication.” (P7)

Similarly, R190 explained that complications with insurance hindered their ability to access treatment:

“to use the full benefits of my insurance coverage, I need to stay within a certain network of doctors. So my appointment with an gyne is 3 months away!” (R190)

Medical providers may also be inaccessible due to their location (e.g., “*I am far away from my OBGYN because I am at school. She refuses to change my prescription unless I physically see her but I go to school 8 hours away from where she is!*” (R751)).

While personal issues appeared to be more closely tied to bodily aspects of different individuals, structural challenges were common for different groups based on external factors such as geographic location and socioeconomic background. Studies have also shown differences in the prevalence and characteristics of PCOS based on region and ethnicity [129]. For example, in some countries like India, PCOS is considered a “lifestyle disorder” [92] which can only be controlled (or prevented) by fixing one's lifestyle (e.g., food habits, exercise, sleep schedule). Furthermore, as international students, many of our interview participants encountered shared difficulties in navigating the U.S. healthcare system. These difficulties included obtaining insurance and finding providers, and they were compounded by other issues such as arranging transportation in an area that has limited public transit options. Thus, the management of PCOS is strongly shaped by individual and systemic factors, and some groups are disproportionately affected by structural challenges. Moreover, the lack of a universal treatment for PCOS added to the uncertainty accompanying the condition.

4.1.3 Dealing with Uncertainty through Experimentation and Assessment. Due to the lack of a clear universal treatment for PCOS, people often assessed and experimented with their bodies and different management techniques to find what worked best for them. In both the interviews and Reddit posts, we observed people assessing the effects of and experimenting with a range of techniques including medications, birth control, food supplements, natural remedies, diets, and workout plans. For example, R369 tried to assess and correlate the effects of Metformin on their body:

“Since Metformin is supposed to help lower blood sugar, can it also make you dizzy? Recently, I have been getting these weird hearing changes and experiencing dizziness and spotted vision when I stand up... I have been taking Metformin for several months...” (R369)

We observed that people tried to triangulate their understanding and experiment accordingly based on insights gained from experts (i.e., different kinds of doctors, nutritionists, or other people living with the same condition), their intuition about their bodies, and/or from reading online sources of information, including information shared within Reddit communities:

“Is metformin a cause of liver issues?... While my endo said that metformin can cause liver issues, I read online that metformin, if anything, helps one's liver...I know PCOS can cause fatty liver...My endo does my blood tests at least twice a year but she has never mentioned it.” (R58)

Further, they tried to correlate other habits and factors (e.g., stress, smoking, sexual activity, age, and genetics) with symptoms (e.g., irregularity in menstruation) to explain or justify what they are experiencing. For example, one poster attempted to understand the combined effects of birth control, a supplement, and stress on her menstrual cycle:

Type (%)	Definition	Example
Diagnosed - Explicit (41.99%)	Explicit mention about being diagnosed with PCOS	<i>"I was officially diagnosed with PCOS today." (R218)</i>
Diagnosed - Implicit (12.42%)	Implicitly deductible that diagnosed with PCOS	<i>"A neurologist said that me having neuropathy is a mystery as there is no reason why I should have it. However, I can't help but think it is because of PCOS..." (R51)</i>
Unmentioned or Unclear (35.73%)	No mention of PCOS or diagnosis in the content, unclear whether symptoms related to PCOS at all	<i>"Do you notice nostril hairs come out really fast? I have to wax mine every six days." (R25)</i>
Undiagnosed (6.06%)	No attempt at getting tested yet or in process or awaiting diagnosis results	<i>"I'm undiagnosed and I haven't been to a doctor in over two years" (R125)</i>
Inconclusive Diagnosis (3.80%)	Not diagnosed as PCOS or unsure about PCOS despite a diagnosis	<i>"He says it may not be PCOS so he wants to run tests for high prolactin and thyroid (even though it's been tested multiple times)... The only reason he doesn't think it's PCOS is because my periods have become more regular..." (R67)</i>

Table 2: Classification of the nature of the user —who is making the post, using inductive and deductive coding on the Reddit data.

"I went off of birth control in Jan and so far my periods have been irregular... I decided to start taking inositol, which seemed to help regulate my periods for around 3 months, but suddenly my periods have stopped. It's been 54 days since I had my period. I've also had the most stressful month. I am not sure if stress has anything to do with my irregular periods." (R54)

However, at times it became difficult to differentiate between the symptoms of PCOS and the effects of different treatments or medications (e.g. *"I'm not sure whether this bleeding is normal or caused by imbalanced hormones or if it is an infection caused by my IUD or something else..." (R156)*). Further, the possibility of PCOS being pill-induced made this differentiation even more complex. PCOS may go unnoticed if a person has been on birth control pills for a long time, and they may end up discovering it only at later stages in life such as when trying to get pregnant.

We also observed that individuals made choices and trade-offs between different management techniques and treatment plans. The most basic choice they made was between taking medications and incorporating lifestyle modifications because they faced challenges in following both or did not wish to follow certain treatments (e.g., *"I was told my periods would be irregular so the doctor wanted to put me on BC. But I didn't want to do that as that would only mask my issue." (R540)*). Some individuals chose to compromise on lifestyle measures, such as keeping active and eating healthy, and believed that medications could keep PCOS under control:

"I was having medicines and I believed it's supposed to get my period regular." (P2)

Others chose between different lifestyle measures, depending on what is feasible:

"So right now I just make sure that my protein diet is fine, like milk and all that. Exercise... it's not something like I've been avoiding [it]... just I did not get time." (P1)

Trade-offs were also made between following rigorous management regimes (*"doctor had given me medicines...I had to take them before and after dinner...some four medicines" (P5)*) and taking measures only when needed (*"every time I switch to a new medicine I'm like I'll do everything... it never works for me so I just gave up after a point and I'm in that phase like I'll deal with that later" (P7)*). These trade-offs were often made as a result of weariness in following meticulous management regimes, making people depend on a few practices more than others and were also a result of experimentation—what the individual felt worked best for their body—due to the absence of a universal cure for PCOS.

To further support self-experimentation and assessment, participants expressed interest in obtaining information about the impact of diet and lifestyle changes on their PCOS, including the effects of medications, to facilitate self-management. Throughout the process of self-experimentation and self-management, people struggled to decipher whether their treatment plans were working (*"Do you think that Inositol stopped working for me or was stress a cause of this flare up in my symptoms?" (R950)*), as well as to identify the specific outcomes of different lifestyle changes (*"I eat 1300 calories a day, burn at least 700 calories by exercising for an hour every day but I don't lose weight. I'm gaining weight around my belly and torso and I barely get periods. I also have some chin hair and front hair loss." (R89)*). One participant (P5) indicated a desire to track "very specific" diet changes to understand if her diet modifications were making an impact, as well as rule out the influence of "random things" such as other foods or vitamins. Diet changes were more complicated than inclusion/exclusion and some participants wanted detailed

information about the properties of the foods they consumed in order to support their self-management process. For example, P2 expressed interest in understanding the hormonal impact of meat and dairy products she consumes:

"I think there should be more information about the right kind of food to have specifically... All milk, eggs, meat, they're treated with antibiotics and hormones, and that can create a lot of hormonal imbalance in women. I think there should be more information about that..." (P2)

At times, information found on credible online sources (e.g., American Pregnancy Association, Mayo Clinic) felt inadequate as they provided mostly medical details but were unable to answer experience or context-based questions (e.g., *"Is it safe to take antidepressants with Spiro?"* (R71)), resulting in people turning to online forums such as Reddit to learn from experiences of people with similar conditions and fill in their information gap:

"I had this brilliant idea of scrolling through Reddit to search for a remedy for my skin condition & that is where I found about the existence of Spiro" (R16)

4.1.4 Tracking Needs for PCOS Management. As part of the self-experimentation process, many people expressed interest in tracking different parameters related to the condition (e.g., menstrual information, diet, exercise, weight, sleep, medications, co-existing conditions). Eight out of ten interview participants tracked (or used to track) their periods and PCOS-related variables in different ways, such as using a self-tracking application (3/10), writing in a paper-based calendar (2/10) or diary (1/10), memorizing (1/10), or simply by sharing details regularly with someone close to them (1/10). P2 and P4 consumed birth control pills to regulate their periods and indicated how the 28-day pack of pills acted as a tracker for them. P6 indicated that she shifted from paper-based diary tracking to using a period tracking application as it provided a *"good range of things you can track"*, such as mood, water-intake, heaviness of flow, and pain, which were common variables *"for 90% of women to track when they had their period."* However, she discussed additional metrics that she would want to track that were specific to PCOS:

"did I have any acne outbursts? Hmm, did my upper lip go back much faster than normal? Hmm, and I started sprouting hair in places I never had it before?" (P6)

By tracking acne and hair growth, two common symptoms of PCOS, this participant argued that she would be able to assess the impact of birth control on her body and decide whether to adjust her medication. We also noted some participants' frustration with existing tracking applications and desire for tools that integrated more with their lifestyle. P9 said that she tried to use a tracking tool, but found it *"too complicated to maintain"* because the tool was *"not personal"* and did not match her needs. A common complaint was that tracking tools were unable to accurately predict periods of people with PCOS due to irregularity in their cycles. P5 expressed the need for an integrated tool that allowed her to understand diet, exercise, and periods *"in context of each other."* P10 migrated to a more general health tracking application from a period-specific one and further criticized current period tracking apps for being *"one-layered"* and

expressed the need for *"something more centric towards a person having PCOS or a person having endometriosis or a person nearing their menopause."* Thus, we see the need for highly-customizable tracking tools, which incorporate co-existent conditions and lifestyle information along with menstruation-specific parameters, for supporting the experimentation process.

4.2 Social Implications, Stigma, and Support

4.2.1 Impact on Daily Activities, Social Life, and Perception of Self. PCOS significantly affected the daily lives of individuals (both students and professionals), physically and mentally restricting them from various activities. For example, P1 noted *"I [she] had to miss a lot of my [her] classes at times because of the medication... it was just not a very good time."* At times, individuals self-doubted their capabilities, such as being able to work and dealing with non-understanding peers:

"I am very open with my boss about my health problems so she knows what's going on. Part of me though gets worried that employers think that it is not a valid reason to take time off work." (R7)

On the other hand, people also reported social limitations and embarrassments that accompanied PCOS. For example, P7 narrated an incident when she had to shorten a vacation with her friends due to excess bleeding that resulted in her fainting. She also discussed other social limitations that accompanied her PCOS and management techniques:

"In homeopathy, you cannot eat certain food, so you have to restrict... that was the biggest issue because I couldn't go out with friends. Even if I went out with friends, I couldn't eat food which everyone ate. I had to ask them to make specially for me." (P7)

Such incidents often made individuals uncomfortable and afraid of being stigmatized due to their limitations in being able to perform professionally or socially as per other people's expectations.

Moreover, symptoms of PCOS such as weight gain, acne, hair fall, and hirsutism have major effects on an individual's appearance and body, making people with PCOS feel *"set apart from what is considered to be normal"* [51]. These in turn significantly impacted their self-confidence, body image, and social image:

"I think that putting on weight is a very, you know... because nowadays everyone is super conscious about not putting on weight and I know PCOD has been linked with obesity in many ways. So yeah, that's like a social image that you have to maintain." (P4)

Some individuals also felt *"ugly"* and expressed a desire to be more *"womanly and beautiful"* (e.g., *"Last week I got my hair done and eyebrows waxed for the first time in years and I feel like a new woman. I feel much prettier than I have in a long time. I now want to find more such ways to 'feminise' and pamper myself"* (R50)). On the other hand, in some cases, PCOS helped people recognize their individuality and psychological gender [65]. R755 accepted their *"masculinity"* and acted upon their *"gender dysphoria"*.

"In the last few years I have purchased a lot of male clothing and I have been cutting my hair very short. I have stopped faking my voice to be higher pitched and

cuter than what it is. I have moments when I don't hide my acne or my five o'clock shadow. This weekend, I've finally decided to get a very short men's haircut and will buy a binder this year. I'm pretty excited to finally feel like my real self and not someone I'm not." (R755)

Many individuals also reported that PCOS took a toll on their mental and emotional health, at times causing depression, anxiety and even enhancing premenstrual syndrome (PMS). Compounding factors such as pain, fluctuations, stress, accompanying menstrual issues (e.g., endometriosis, premenstrual dysphoric disorder or PMDD), and failed treatments or medication side-effects further worsened the situation.

"This latest period is the worst...it is getting progressively heavier and I am in SO. MUCH. PAIN... I am exhausted, my face is broken out, and my mood is terrible." (R66)

In other cases, hormonal treatments such as birth control pills were the cause for mood and emotional fluctuations similar to PMS:

"I have been put on the pill to help with these dreaded PCOS periods and my mental health has plummeted since being on it for around 3 months. I'm short tempered, sad and sensitive all the time and assume that this is because of the pill..." (R101)

Thus, PCOS appeared to substantially affect people physically, mentally, and emotionally, and their experiences were shaped by not just the condition itself but also their highly personalized contexts and their perception of people's definitions of "normal".

4.2.2 Social Stigma and Lack of Understanding. As a condition that causes infertility and hormonal imbalance, PCOS carries a certain stigma. This perception often arises due to the lack of awareness about the condition and conversations around it, despite its prevalence. P6, who comes from India, shared the conversational taboo around *periods and stuff* in society, saying that she could not talk to her school friends who also had PCOS because "social factors" prevented her from asking multiple questions about how and why they got PCOS. While a major source of stigma around PCOS was difficulty in getting pregnant (or future infertility scare) as individuals with PCOS were instilled with the fear of "disappointing" their partners and family by not being able to conceive "naturally", both interview participants and Reddit posters noted experiences they had with other people who only seemed to care about their outer appearance and effects PCOS had on it:

"When it was found that I have PCOS, people around me were way more concerned about my appearance rather than my inward health. To them, the biggest downside was that I had hirsutism and not my hormones or insulin levels. Because a woman should be most upset by facial hair growth and not by the havoc PCOS wreaks inside her body" (R42)

On the other hand, P1 noted that:

"it becomes very difficult for you [her] to explain why you're [she is] skipping classes for the whole week. Nobody is able to understand, nobody is able to get you have a condition but it's not serious. People will be like, 'oh for a whole week what happened?' They would like to know and you can't tell them. You can't tell them

that you're not in a condition to be hospitalized, you just need to be left alone or just given like-treat you normally. You just need some rest and some care." (P1)

Similarly, P9 shared how "it creates kind of a pressure" on her when people were insensitive or lacked awareness about her condition, making her feel "as if I [she] have some big disease". R374 further highlighted the difficulties in "acceptance" that arose as her boyfriend's parents treated her as being "terminally ill".

We also observed repeated criticism related to the lack of understanding and proper communication by doctors regarding the condition. P9 expressed frustration about how her doctor did not give detailed information about what she should do to manage her condition:

"every time I used to go, she [the doctor] used to have the same opinion like improve your lifestyle, improve your lifestyle. Like what kind of lifestyle changes does an 11th-grade girl need to do. You need to tell that!" (P9)

On the other hand, P7 reported trying out five different doctors and how each one of them followed a "my way will work" approach, not paying attention to her past medication records:

"I would go to every doctor and say 'this is what I've been taking and this hasn't worked for me'... she [a doctor] prescribed me a medicine similar to that... It was under a different company name... again it didn't work for me... I told her 'it's the same thing! I told you it didn't work for me, it has adverse effects for me, so why did you prescribe it?' She's like, 'oh I missed that'..." (P7)

Similar to Reddit posters, P7 also noted her preference of going to "female doctors over men" as she found going to the latter to be "awkward" especially for matters related to PCOS.

4.2.3 Social Support and Sharing of Responsibility. People with PCOS sought social support in some form or another from their family members, friends, or people experiencing the same condition. Interview participants such as P1, P7, and P9 lived with their families for many years and reported feeling well-supported by them. P7 and P9 also shared the responsibility of managing their PCOS with female family members such as their mothers and aunts:

"it is my mom who does most of the tracking for this [PCOS]. She finds out most of the stuff and she makes me drink like all these kind of weird things like putting ginger in water and drinking..." (P9)

However, in some cases this co-management resulted in the person with PCOS not knowing exactly what was followed to manage their condition:

"I don't remember anything [name of a medicine] now because my mom was handling that." (P7)

Participants also saw value in seeking support from close friends and significant others. P10 disclosed her condition to her boyfriend and her friends, who would "raise her spirits" and "lift [her] emotions" when she felt depressed. In other cases, people shared their struggles of not being supported by their close circle and how that impacted their treatments and emotions:

Type (%)	Subtype (%)	Example
Seeking support (82.96%)	Seeking conversational opportunities (12.75%)	<i>“Just curious on what were your symptoms or red flags that indicated something was wrong” (R185)</i>
	Seeking advice, clarifications, and recommendations (70.30%)	<i>“Any suggestions of alternative ways for getting pregnant (besides IVF)... ways that are natural or medicines that will not prevent pregnancy but will also help with my symptoms?” (R234)</i>
	Checking for normalcy (16.95%)	<i>“Is this normal - can periods gradually come back or do they just come back out of nowhere?” (R792)</i>
Expressing emotions & sharing experiences - including giving advice based on experiences (17.04%)	Sharing positive experiences - achievements, positive outcomes, expressing relief (36.14%)	<i>“I feel my bloating is gone and my face isn’t as round. I have more energy and my brain fog is gone! I’m actually able to get things done and I’m in a way better mood (something very important to me due to my depression) and my face actually looks better, it isn’t as red and inflamed as before...” (R782)</i>
	Sharing negative experiences - negative outcomes, failures, disappointments (63.86%)	<i>“I still find myself as unattractive, unworthy, not confident, and have serious body image issues. Some nights, I get anxious, feeling that I’m never going to lose weight and will remain fat forever. I’m TIRED of feeling like this, I’m TIRED.” (R149)</i>

Table 3: Classification of the nature/type of the posts—how certain topics are being spoken about, using inductive and deductive coding on the Reddit data.

“My family doesn’t support me at all. I’m tired of receiving comments about how fat and hairy (which forces me to shave!) I am. I did not ask to have PCOS!... I just want to feel self-confident again but hearing their horrible comments doesn’t let me feel so... Every time I try doing a diet, they say that I will give up. If I suggest a medicine that can help my condition, they just discourage me for asking for more medicines.” (R158)

This further resulted in people feeling frustrated as well as stigmatized due to their condition. On Reddit, around 83% posts sought support from fellow members of the PCOS community either in the form of advice, conversational opportunities, or checking for normalcy of their experiences (see Table 3). Thus, in line with previous studies [33, 69], this subreddit forum provided people with a space to seek different kinds of support and deal with social implications of their condition by conversing with others with the same condition (or similar ones as 36% of the posts did not mention or reveal if the person was diagnosed with PCOS, just hinted at symptoms that could be associated with it). Additionally, we note that nearly 10% of the posts were by people who were undiagnosed or struggled with an inconclusive diagnosis (see Table 2), highlighting that the platform was also used by individuals who were not diagnosed but doubted that they have the condition, to make sense of what is going on in their bodies. Our data also revealed the other way round, that is, people who did not have PCOS sought information on Reddit on how to support people close to them, such as their friends and significant others, who have PCOS:

“My wife was diagnosed with PCOS earlier this week...I am just curious about how I can best support my wife and be well-equipped to support her.” (R83)

Furthermore, participants expressed interest in “communicating and letting people know that you have this issue” (P10) to build understanding about their actions and behaviors (e.g., mood swings). Others believed technology, including communication platforms and applications, to be a good alternative to verbally explaining things to others (including doctors) and bypassing the accompanying social stigma. P7 reflected on sharing graphical data (or images of the same) about her menstrual cycles from a period tracking application with her doctor who “really likes the graph because it’s very easy to understand” and how that reduced the burden on her to explain various aspects of her condition. We also note the value of assisting users in communicating about their PCOS with other parties such as peers, bosses, and teachers. For example, R894 sought advice on how to navigate issues around having PCOS in the workplace:

“Does anyone else have such bad pain or nausea that it causes you to miss work? My boss is not happy but I’m not sure what to do other than just suffer through work when I can hardly even sit due to the pain.” (R894)

Lastly, we found that some participants were interested in meet-up groups to virtually as well as physically connect with other people with PCOS. P7 expressed her interest in having “a [physical] safe space to talk” about PCOS—a community where she “wouldn’t feel

so alienated all the time.” Moreover, Table 3 shows that support-seeking is not the only thing people used the subreddit for as around 17% of the posts shared positive (36.14%) and negative (63.86%) experiences people had with the condition. Thus, by talking openly about PCOS and connecting with others, people could affirm the normalcy of their experiences, seek support, and share their experiences with others.

5 DISCUSSION

Through our study, we found PCOS to be an important context given its dual nature of being an enigmatic chronic condition and a stigmatized topic in women’s health. In this section, we reflect on the findings and discuss opportunities for future research and design directions that can positively influence and support people with PCOS. We also take into account the social and cultural factors that inform our findings and recommendations.

5.1 Exploring the Value of Tracking

In section 4.1.3, we discussed participants’ desire, attempt, and failure in identifying potential triggers and effective treatment by assessing, experimenting, and reflecting on their bodies and practices to deal with the uncertainty of PCOS. This, along with section 4.1.4, makes the value of tracking personal health data related to PCOS—ranging from dietary requirements, exercise, and medications to menstrual flow, fertility, and sexual activity—evident as it can facilitate the self-discovery, self-experimentation, and reflection process and assist people in making more informed decisions in regards to their health. In the following, we discuss how to design more inclusive self-tracking technologies to support people’s experience with PCOS, acknowledging how as a chronic health condition it shapes the life experiences of an individual over a long period of time. While most current commercial technologies are designed to cater to the needs of “healthy” individuals looking for conception or contraception, our findings regarding the current practices for managing PCOS corroborate the need to support different tracking purposes (e.g., assessing effects of medications and managing comorbidities). We align with the works of Fox et al. [45] and Epstein et al. [37], both of which discuss many use cases of existing commercial tools that go beyond common usages (e.g., within the framing of usage of a lesbian couple). In particular, Fox and colleagues present the notion of *multiplicity* [45], that is, the need to support “different kinds of menstruating bodies” in design. We further emphasize the qualitative nature of tracking [73, 78], going beyond the typical misunderstanding that tracking is quantification. In Luo et al.’s work [73], for example, eating disorder patients are encouraged to track “what they did to honor their body” as a way to reflect on their body image and self-care act. Similarly, in the case of PCOS, designing to **reflect** on tracked data can help people understand their condition’s impact on their body, and devise strategies and form hypotheses that are worthwhile to be experimented, which we discuss further in the next section.

5.1.1 Accelerate Self-Discovery. We find that self-tracking tools have the potential to support users’ self-discovery process, going beyond their common use for self-management of enigmatic conditions (e.g., [78]). Early indicators of PCOS, which are often missed, such as P4’s case of bad hair fall and weight-related issues, could

have been tracked, possibly facilitating faster self-discovery. As shown in 4.1.1, most individuals faced challenges in recognizing signs and symptoms of PCOS, as well as patterns in their symptoms, often mistaking them as symptoms of other conditions (e.g., thyroid), side-effects of medicines or birth control pills, or manifestations of stress. To aid and accelerate the self-discovery of PCOS, we recommend that common symptoms of PCOS be listed as potential tracking items in mainstream period tracking apps—making them more inclusive—and users be made aware with necessary information. Such information could get people who experience symptoms which could be indicators of PCOS (e.g., missed periods), to be more aware of the possibility of having PCOS, prompt them to carefully observe their symptoms, and systematically collect evidence for further examination. For those who are not experiencing these symptoms, accessing such information from a period tracking app could still be helpful to broaden and deepen their understanding of PCOS. Existing period tracking apps, such as Clue and Flo, did explore the possibility of using machine learning to evaluate and predict the risk of PCOS by integrating a “pre-diagnostic” functionality in their tools [21, 85]. However, they received criticism for creating their health risk assessment without conducting proper clinical studies and without attempting to understand the context behind people’s symptoms before telling them that they might have PCOS [101]. For example, a user reported a health risk assessment on the Flo app to be very concerning as it claimed that she might have PCOS because of her acne and menstrual cycle changes, which were actually caused by her switching to birth control pills [101]. Thus, we reiterate on the opportunity of using self-tracking tools not as a replacement for clinical diagnostic procedures, but as a valuable way to accelerate the self-discovery process. Future research can explore the design of inclusive self-tracking tools that support self-discovery of PCOS and motivate vulnerable users to initiate careful observation of their body, navigating the slippery slope between keeping users well-aware of their bodily changes and potentially over-diagnosing their condition.

5.1.2 Support Personalized Tracking Experience. Due to the highly individualized nature of PCOS, we found the need to support personalized tracking experience, enabling each individual to configure tracking items that suit their PCOS journey. We further believe that participants’ little experience with tracking does not negate the proposition of technologies but suggests that current technological offerings are not meeting people’s needs. As shown in 4.1.4, people with PCOS desired extensive customization options to address their individual needs and symptoms. While existing menstruation and ovulation tracking tools support tracking a variety of items ranging from menstrual cycle and flow to diet, exercise, mood, and medications, they often offer limited customization features (e.g., Clue gives the option to track only 4 types of exercises: running, yoga, biking, swimming). A person could easily give up on tracking when the tracking tool, however comprehensive it might be, does not support one or two key items that are particularly crucial and relevant to the individual [27]. These subtle cues of exclusion become important to address. Thus, it is important to support customizable features in self-tracking tools used for a highly individualized health context such that users can flexibly add, edit, or remove tracking items in configuring their own tracking regimen. We also highlight

the potential of integrated tracking systems for supporting holistic tracking for PCOS, incorporating co-existing conditions and lifestyle information along with menstruation-specific parameters. However, we find that such systems cannot be designed using a one-size-fits-all approach as that can lead to exclusion of diverse needs of different PCOS-having individuals. Flexible self-tracking platforms, such as OmniTrack [64] can be used to create a customized tracker to meet individual needs. However, providing new users with extensive customization opportunities can be overwhelming and confusing, while providing them with a “default” setting to begin with can also be challenging to create given the diversity in symptoms, treatments, and co-existing conditions associated with enigmatic conditions such as PCOS. Future work can investigate this tension for designing custom tracker(s) for tending to PCOS-related variables. An alternate consideration can be to augment existing tracking techniques, instead of creating whole new applications, and allowing for cross-application data sharing (e.g., tracking exercises and steps using Apple Health and syncing that with the period tracking application) as a means to simplify the creation of an integrated tracking system. While these design considerations are drawn from the needs of people affected by PCOS, we believe that supporting personalized and holistic tracking experience may also be applicable to those having enigmatic conditions of similar characteristics with PCOS (i.e., diversity in symptoms and treatments, and associated stigma).

5.1.3 Support Contextual Tracking and Sense-Making. As indicated by our participants, contextual tracking of a wide range of parameters associated with lifestyle, periods, co-existing conditions, and medications could support their sense-making and self experimentation process. For example, P5 expressed the need for contextually tracking her diet, exercise, and periods. However, tracking many data does not necessarily guarantee gaining insights. Even for expert self-trackers, not having a control condition while tracking potential triggers and symptoms was seen as one of the common pitfalls [27], making it difficult to identify triggers and effective treatment options. While existing PCOS trackers (e.g., My PCOS Team [82], PCOS Guide [30], PCOS Tracker [113]) cater more to the symptoms of people with PCOS, they lack the ability to track factors “*in context of each other*.” To overcome the pitfall of tracking too many things without necessarily gaining useful insights, we suggest that PCOS tracking tools provide capabilities to *systematically* track contextual factors (potential triggers, treatments) along with symptoms, and explore relationships among these factors. In particular, *temporal comparison*—visually and statistically comparing data from multiple time segments (e.g., before or after starting a particular treatment regimen)—can help people draw interesting personal insights and generate hypothesis [26]. While such exploration has been supported in a desktop & web environment (e.g., Visualized Self [26]), it has not been well-supported in mobile devices. Because many personal data are being collected on mobile devices, we believe that supporting data exploration on mobile devices is a promising future direction.

5.1.4 Cater for Long-Term Tracking. Throughout this paper, we characterized PCOS as a lifelong journey, providing detailed accounts of people’s experience from discovering, diagnosing, and living with PCOS. Most of our participants indicated using either

paper-based or digital methods for tracking their PCOS and some (P6, P10) even shifted between different methods depending on their evolving needs and understanding of the condition. We also note how individuals have varying experiences with PCOS at different stages of their lives (e.g., adolescence, college, pregnancy). For example, P8’s experiences of diagnosing and managing PCOS were quite different as compared to other participants given her age and the time and situation (trying to get pregnant) in which she got diagnosed. Given the chronic and changing nature of PCOS symptoms over time [4, 127], it becomes important to design tools that provide a sustainable way to support long-term care. Meyer and colleagues define long-term tracking as “*monitoring parameters of one’s own life in timescales of years*” [79]. Accordingly, tracking for PCOS falls under the realm of long-term tracking. While designing for long-term tracking is an open research question, supporting interoperability is critical in achieving this aim: people can easily migrate their data between different tracking platforms (e.g., Android and iOS) as well as between physical and digital tracking tools (e.g., auto-filling a digital application from a picture taken of the previously used paper-based tracking tool, exporting data from one app and importing it into another in a consistent format). Another area for future exploration is to understand and design for supporting diverse tracking needs at different life stages of individuals—separately and in tandem.

5.2 Improving Support, Co-management, and Communication

Section 4.2 of our findings describes the social implications and impact of PCOS on an individual’s (personal and social) life and self-image. Along with infertility issues, we found symptoms, such as weight gain, acne, hair fall, and hirsutism, which affected the individual’s outer appearance, to be major causes of stigmatization of people with PCOS. In this section, we highlight opportunities for supporting people with PCOS in living with and managing their condition while combating the associated stigma. We differentiate between the types and levels of support provided by different people (and online communities) and further discuss general education and sensitization opportunities. We also contextualize our design suggestions with existing HCI literature in women’s health.

5.2.1 Support Co-Management with Close Circle. We found that people sought social support from those close to them, such as family, friends, and partners. At times, they even depended on them to share the responsibility of managing their PCOS (e.g., P7 and P9 co-managed their conditions with their mothers). Thus, we see potential in supporting collaboration and “co-management” of PCOS, ranging from making the symptomatic experience visible to one’s partner or family, to sharing symptoms and treatment options across generations or among people with PCOS. Period and fertility tracking apps such as Clue and Glow offer users an option to add both male and female partners, allowing sharing of information with them but “*not necessarily all information*” [39]. While we imagine the person with PCOS having complete advocacy over their data, designers may consider allowing people to share varying levels of information with different co-manager(s) depending on the nature of the relationship (e.g. family members, partners,

friends), type of information (e.g., menstrual cycle, ovulation, dietary requirements), and sensitivity of the context in which the information is being shared (e.g., trying to get pregnant vs general PCOS management). However, there is tension between sharing a lot of personal and sensitive information with co-manager(s) and maintaining the privacy and comfort of the individual with PCOS. Future work can tap deeper into understanding these *boundaries of comfort* in co-management and analyze how they may vary depending on the sensitivity and gravity of the situation and context of information sharing. Similar to social networks, tracking applications supporting co-management can allow users to vary their privacy settings, allowing different co-managers to access different types of information. Moreover, users should be able to edit permissions for individual variables, giving users more nuanced control over their data.

5.2.2 Leverage Social Support Platforms and Communities. Next, we highlight the role of social support platforms (e.g., Reddit, PatientsLikeMe) in connecting people with similar health conditions, creating a safe space for them to ask questions, share experiences, learn from one another, and deal with the psychosocial aspects of their condition. Previous literature confirms the usefulness of such platforms, especially ones that allow some level of anonymity, to converse about private and stigmatized topics such as sexuality [18, 25, 50], menopause [69], and mental health [8, 33, 71, 99]. We observed within the context of PCOS, Reddit as a pseudonymous platform facilitated discussions around sensitive topics of fertility, gender identity, and sexuality, not only for those having PCOS but also for family members and partners. By expressing themselves online, posters engaged in self-discourse and self-experimentation, allowing them to reflect on how PCOS shapes their identity and self-image. Similar to [78], we observed that Reddit served as an information resource that increased the aggregated knowledge around PCOS as users turned to it to learn more about the condition from other people's experiences (e.g., self-management techniques). Likewise, Williams et al. [127] found that people with PCOS sought information and support through online groups due to a lack of information from healthcare providers, highlighting the importance of online communities for self-education and support. Engaging deeper with these online communities to understand their conversational dynamics could be a potential next step to improving online and offline social support systems.

5.2.3 Augment Patient-Doctor Communication. We further explored the special context of "co-management" and responsibility sharing between doctors and their patients. Previous studies [131] have shown that patients used their personal data as evidence to "self-advocate" when speaking with their doctors. Both our participants and Reddit posters reported various instances where there was a lack of understanding or miscommunication with doctors concerning their PCOS diagnosis or treatment, which aligns with previous research [125, 127] discussing the patient-provider relationship as a source of frustration for people with PCOS. While it became difficult to label instances as the "doctor's fault" purely based on the word of patients, we believe that situation, too, can be improved if doctors provided patients with detailed explanations for their decisions. We imagine that collaborative tools can bridge this communication and information-sharing gap between doctors and

patients, facilitating better interactions. For example, P7's physician requested visualizations of her menstrual cycle details (collected using a self-tracking application), suggesting that such tools might enable direct sharing of data with physicians to assist in treatment. Previous works [57, 75] have also discussed the potential of leveraging visualizations for patient-provider communication around rare diseases, allowing patients to share their medical records as evidence. Thus, visualizations or summary reports can be useful in effectively sharing personal health data without requiring too much time, while simultaneously bypassing the stigma associated with the conversation. Visualization designers can also explore the possibility of letting doctors interact, highlight, and comment on different portions of the visualizations and further share these annotations as feedback directly with their patients.

5.2.4 Educate, Sensitize, and Consider Cultural Differences. We also note the value of sensitizing those who do not or cannot have PCOS. Tuli et al. [114] discussed the opportunity of engaging the non-menstruating sex in Menstrual Health Education (MHE) and encouraged taking an "ecological" approach to design in order to lessen the stigma associated with menstruation. In our case, people who do not or cannot have PCOS not only fit into the ecology [15], but can also potentially support (or even co-manage with) those close to them who have the condition. Designers can explore the potential of fostering embodied experiences in creating technology that enables those who do not or cannot have PCOS, to experience and know what it feels like to have the condition. For example, in the past, designers created a "Menstruation Machine" that sought to generate empathy around menstruation by making those who do not menstruate understand what it feels like to have periods [103]. This technology is in the same vein as Labella—a system augmented into an underwear that supports exploration of intimate body parts by looking at and touching them [3]—and Curious Cycles—a set of objects designed to gather experiences of those who menstruate while "cultivating curiosity" to interact with their bodies [23]—but instead of enabling self-learning about private body parts, the goal is to sensitize others to the condition.

Lastly, we note differences in user needs and resulting technology design that may arise due to people's varying ethnic and cultural backgrounds. For example, previous studies have noted differences in designing for stigmatized health topics, such as menstruation [114] and HIV/AIDS [102], for populations in the global south as compared to the global north. Since all our interview participants were Asian or Asian-American, we observed how their backgrounds shaped their unique practices, experiences, and needs from technologies. For example, interview participants reported using alternate medicines such as Ayurveda, Homeopathy, and Chinese traditional medicines to "treat" or manage their PCOS symptoms; these could be important variables for them to track for self-managing their condition. Future work can further leverage a comparative angle to understand the impact of cross-cultural and socioeconomic dimensions on user practices of self-management and communication in relation to such stigmatized enigmatic health topics.

6 CONCLUSION

In this paper, we presented the results of a qualitative study to understand support-seeking, sense-making, and self-experimentation practices around PCOS and found uncertainty and stigma, including lack of understanding and support from others, to be key in shaping people's experiences and needs. We found that people with the condition, as well as those trying to get diagnosed, self-experimented with diverse variables of their health to deal with the uncertainty that accompanies PCOS. We also noted the effect of stigma on people's perception of their self-image and their social support-seeking practices. We identified opportunities for designing more inclusive women's health technologies that address the diverse needs of people with PCOS while enhancing the general public's awareness of menstrual health and its related health conditions. We provided design recommendations for technologies that can support personalized and contextual tracking, accelerated self-discovery, and co-management of stigmatized conditions such as PCOS. We also described the potential of leveraging Reddit and improving patient-doctor communication to enhance support around PCOS. We further contribute to a growing body of HCI and CSCW research by contextualizing our findings in light of recent works on designing for stigmatized topics in women's health and well-being.

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