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Article

A Global Survey of Ethnic Indian Women Living with Polycystic Ovary Syndrome: Concerns, Diagnosis Experiences, Quality of Life, and Use of Treatment Methods

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Abstract: Background: Polycystic ovary syndrome (PCOS) is a common endocrinopathy that is highly prevalent in women of Indian ethnicity. Clinical practice guidelines do not adequately consider ethnic-cultural differences in the care of women with PCOS. This study aimed to explore ethnic Indian women's experiences with PCOS diagnosis and management, their concerns and it's impact on their quality of life (QoL). Methods: Global online survey of ethnic Indian women of reproductive age living with PCOS. Results: Respondents (n=4409) had a mean age of 26.8 (SD 5.5) years and the majority were diagnosed with one or more co-morbidities (anxiety/depression being the most common). Women waited one year on average before seeking treatment following symptom onset. Irregular periods, cysts on the ovaries and excess unwanted facial hair growth were their three major concerns. Weight and emotional concerns had the greatest impact on QoL. One-third did not receive information on long-term complications, appropriate behavioral advice to improve diet or exercise, or emotional support following diagnosis. Among those who received information at diagnosis, the majority were dissatisfied. Conclusions: Ethnic Indian women wait for a considerable time before seeking medical help for PCOS, have poor QoL relating to weight and mental health and are dissatisfied with the information and support provided at diagnosis. These gaps in care should be addressed in clinical practice and future research.

Keywords: Polycystic Ovary Syndrome; PCOS; key concerns; diagnosis; Indian women; survey

1. Introduction

Polycystic ovary syndrome (PCOS) is a highly prevalent disorder characterized by oligo-ovulation and/or anovulation, hyperandrogenism and polycystic ovarian morphology (PCOM) [1, 2]. Women with PCOS experience lifelong metabolic (i.e., insulin resistance (IR), type 2 diabetes (T2D), adverse cardiovascular risk profiles) [3, 4], reproductive (i.e., infertility, pregnancy complications) [5] and psychological consequences (i.e., anxiety, depression, poor quality of life (QoL), eating disorders) [6-8].

Experiences related to symptoms, diagnosis and management of PCOS and its impact on QoL can differ markedly between women of various cultural backgrounds and ethnicities. Emerging evidence has demonstrated that ethnicity has an effect of on the

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phenotypic expression of PCOS [9-11]. For example, ethnic Indian women with PCOS present with earlier onset of PCOS symptoms and have more severe hirsutism, increased PCOM, metabolic risk (i.e., central obesity and insulin resistance) and reproductive symptoms (i.e., infertility, lower birth rates following in vitro fertilization) compared to Caucasian women [12-15].

Ethnic Indian women present with altered genetic susceptibility leading to early onset and increased severity of symptoms in most complex diseases including PCOS [16]. Studies suggest that metabolic complications associated with PCOS, including central obesity, IR, T2D and cardiovascular diseases are increasing rapidly among ethnic Indians irrespective of their geographic location globally [17]. For instance, according to a 20-year longitudinal follow-up study, Indian Asian migrants residing in the United Kingdom reported an incidence of T2D almost three times higher compared with the Caucasians controls [18]. With people of Indian ethnicity representing the world's largest diaspora [19], it is important that we consider PCOS phenotypes and comorbidities in ethnic Indian women living worldwide. Understanding the unique clinical manifestations of PCOS in ethnic Indians will help to better tailor diagnostic and management strategies to improve the patient experiences.

PCOS is a complex condition and women have reported seeking help from multiple health professionals and having poor diagnosis experiences [20]. Diagnosis experiences associated with delay in diagnosis and inadequate information provision are known to influence treatment outcomes and cause impaired QoL and increased risk of long-term consequences [21, 22]. Dissatisfaction with diagnosis experience and a lack of awareness and open dialogue about PCOS might be more intense in women with ethnically diverse backgrounds such as ethnic Indian women, considering the high prevalence of stigma associated with some of the PCOS manifestations such as menstruation, infertility and obesity [6, 23-25]. Suboptimal treatment experiences may also be heightened in ethnic Indian women, who receive the same standards of care used for Caucasian women, which likely neglects the ethnic influence and cultural associations of PCOS [22, 24]. Despite being a growing issue in ethnic Indian women [26-28], who present with worsened metabolic and reproductive phenotypes, we did not find any large study that explored concerns, PCOS symptomology, information needs, diagnosis experiences and quality of life in ethnic Indian women living with PCOS anywhere in the world.

We conducted a global survey of ethnic Indian women with the aim of: (i) investigating their key concerns about PCOS, comorbidities, and quality of life; and ii) explore diagnosis experiences and information provided.

2. Material and Methods

2.1. Ethical Approval and Consent

The research protocol was approved by the University of Western Sydney, Human Research Ethics Committee in February 2021 (reference H14103). A copy of the participant information sheet was provided electronically to participants before commencing the survey, which highlighted that the survey was anonymous, voluntary, confidential and that participants could leave the survey at any time. Informed consent was implied upon commencement of the survey.

2.2. Study design and Research Instrument

The research team, consisting of content experts and researchers from various healthcare backgrounds (i.e., general practitioners, dietitians, women's health researchers, public health practitioner, exercise physiologists and yoga therapists), developed an online anonymous survey using Qualtrics software (Qualtrics Ltd.). Upon development, the survey was piloted with ten adult ethnic Indian women- five residing in Australia and five residing in India. Their feedback was considered and the final survey amended accordingly.

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The 72-item survey questionnaire included questions on the demographics, co-morbidities, family history of PCOS and T2D, diagnosis experiences (adapted from a previously published study) [20], important concerns of PCOS, health-related quality of life (HRQoL), health professionals consulted for PCOS, and treatment strategies used to manage the symptoms of PCOS, including Traditional, Complementary and Integrative Medicine (TCIM)) dietary and exercise interventions. A mixture of closed, multiple-choice, and open-ended questions were used.

The Modified Polycystic Ovary Syndrome Questionnaire (MPCOSQ) [29, 30] was used to assess HRQoL. The MPCOSQ includes 30 questions from six HRQoL domains: emotional disturbance (8 items), weight concerns (5 items), infertility (4 items), acne (4 items), menstrual symptoms and predictability (4 items), and hirsutism (5 items). Each item was rated on a 7-point Likert scale where higher scores represent a better function. The domain scores are the sums of the scores for the items within each domain.

A copy of the survey instrument can be found in Supplementary File 1. The survey took approximately 20-30 min to complete. Features were enabled within Qualtrics that prevented multiple completions from either a single IP address or the same computer.

2.3. Setting and Recruitment

The survey was open to any women of ethnic Indian origin living in any country. Recruitment strategies included leveraging personal and professional connections of the research team, paid social media advertisements, and posting to various PCOS social media advocacy and support groups, Indian women's groups, and global Indian migrant groups (including on Facebook, Twitter, and Instagram). Data collection occurred from mid-February to June 2021.

2.4. Eligibility

Eligibility criteria included women of self-reported Indian ancestry (ethnic Indian women either born in India or having at least one parent or grandparent who was born in India), aged 18-55 years, with a self-reported diagnosis of PCOS by a medical doctor and who were able to read and understand English.

3. Data analysis

Descriptive analysis was performed for normally distributed data (means and standard deviation), non-normally distributed data (median and interquartile ranges) and categorical variables (number and percentage). Body mass index (BMI) was calculated as (weight)kg/m^2 (height). We categorized participants according to BMI as per guidelines for obesity and metabolic syndrome for Asian Indians, as lean (BMI <23kg/m2) and overweight/obese (BMI ≥23kg/m2) [31]. Missing values were only replaced for height and weight data. Patterns of missing values were examined and median height (n=411) and weight (n=381) data related to the age groups was imputed [32]. The range of weight and height were considered from 37 - 157 kg and 110 – 188 cm respectively. For the MPCOSQ analysis, participants were included who completed the whole questionnaire and a mean score of each domain was calculated. Analysis was performed in SPSS (version 28.0.1.0, 2021) [33].

4. Results:

A total of 5546 women responded to our survey invitation. Of these, 733 were empty responses and were deleted, and 404 were not eligible to complete the survey (368 indicated that they had not been diagnosed with PCOS by a physician, while 36 indicated they were not of ethnic Indian ancestry). A total of 4409 responses were included in the final analysis.

4.1. Sample characteristics

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Demographics of the participants are presented in Table 1. The mean age was 26.8 (SD 5.5) years, with more than two-thirds aged 18-29 years (3189/4409, 72%). Body weight was 68.9 kg (SD 15.0), with a mean BMI in the overweight range (26.8 kg/m^2, SD 5.6). Over 90% were born in India with the remainder born in 33 different countries. Around three quarters (2046/2780, 74%) of the participants were residing in India, while the top five countries of residence outside of India were Australia, the United States of America (USA), United Arab Emirates (UAE), Canada, and the United Kingdom (UK).

Almost all women (93%) were university educated, with 44% (1213/2780) having completed a postgraduate degree. The majority were in the workforce (1521/2806, 54%). Approximately 40% of the participants (1113/2780) were single, while 39% (1071/2780) were married and/or living with a partner. More than two-thirds were nulliparous (2185/2780, 79%). Of the participants who reported a history of pregnancy, almost half (282/589, 48%) reported seeking medical help to conceive.

Table 1. Demographics of the participants.

Demographics	Responses, n, (%)
Age (years)	**4409**
18-22	979 (22)
23-29	2216 (50)
30-34	803 (18)
35 and above	411(9)
BMI (kg/m^2)	**4409**
<18.5	149 (3)
18.5-24.9	1565 (36)
25.0-29.9	1627 (37)
>=30.00	1068 (24)
Country of birth	**2780**
India	2577 (93)
United Arab Emirates (UAE)	42 (2)
United Kingdom (UK)	32 (1)
Other countries	120 (4)
Missing	1629 (37)
Country of current residence	**2780**
India	2046 (74)
Australia	195 (7)
The United States of America (USA)	119 (4)
UAE	114 (4)
Canada	61 (2)
UK	49 (2)
Other countries	196 (7)
Missing	1629 (37)
Length of stay in current country of residence	**2774**
> 10 years	2166 (78)
6-10 years	150 (5)
1-5 years	335 (12)
<1 year	123 (4)
Missing	1635 (37)
Education	**2780**
Postgraduate degree	1213 (44)
Undergraduate degree	1375 (49)
Below undergraduate degree	192 (7)
Missing	1629 (37)
Occupation	**2806**
Full time	1041 (37)
Studying	860 (31)

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Home duties	330 (12)
Self-employed	313 (11)
Unemployed and looking for work	289 (10)
Part time	167 (6)
Unemployed and not looking for work	76 (3)
Volunteer	42 (1)
Unable to work because of Polycystic Ovary Syndrome (PCOS)	38 (1)
Other	29 (1)
Retired	1 (0.001)
Missing	1603 (36)
Relationship status	**2780**
Single	1113 (40)
Married and living with a partner	1071 (39)
In a relationship	552 (20)
Divorced	26 (0.9)
Separated	15 (0.5)
Widowed	3 (0.01)
Missing	1629 (37)
History of pregnancy	**2780**
No	2185 (79)
Yes	595 (21)
Missing	1629 (37)
Ever needed treatment to fall pregnant	**589**
No	307 (52)
Yes	282 (48)
Missing	6 (0.01)
Number of biological children	**526**
One	228 (43)
Currently pregnant	160 (30)
Two and more	73 (14)
None	70 (13)
Missing	69 (12)
Family history of PCOS	**3993**
No	3274 (82)
Yes	719 (18)
• Sister	513 (66)
• Mother	250 (32)
• Daughter	14 (2)
Missing	416 (9)
Family history of type 2 diabetes	**3969**
No	2251 (57)
Yes	1712 (43)
• Father	1290 (75)
• Mother	828 (48)
• Sister	40 (2)
• Brother	35 (2)
• Daughter	4 (0.1)
• Son	1 (0.1)
Missing	446 (10)

4.2. Family history of PCOS and Type 2 diabetes

As per Table 1, 18% of women (719/3993) reported having a family history of PCOS. Among these, sisters (513/719, 66%) and mothers (250/719, 32%) were the most reported family members diagnosed with PCOS. Over one-third of women (1712/3963, 43%) had a

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family history of T2D. Of these, fathers (1290/3969, 59%) and mothers (828/3969, 38%) were the most reported family members with T2D.

4.3. Co-morbidities associated with PCOS

Most women (2555/4012, 64%) had been diagnosed with one or more co-morbidities, with psychological co-morbidities (61% or 1548/2555 diagnosed with anxiety, 36% or 912/2555 with depression) and sleep disorders (694/2555, 28%) being the most common (Figure 1). Multiple co-morbidities were common, with women diagnosed with anxiety also being diagnosed with depression, chronic fatigue, thyroid disorders, sleep disorders, and eating disorders.

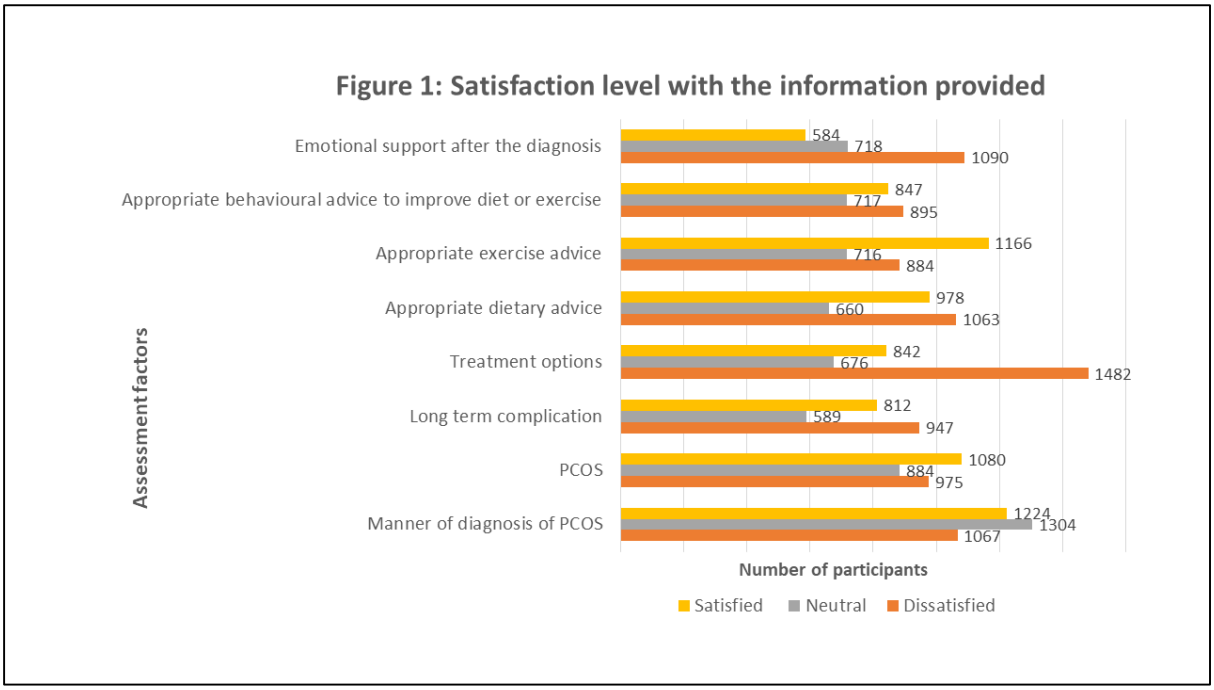

Figure 1. Satisfaction level with the information provided.

4.4. Key concerns of PCOS

Three signs/symptoms of PCOS that matter most to women were irregular menstrual cycles/periods (2220/3550, 63%), difficulty losing weight (2021/3550, 57%) and excess unwanted hair growth over the face (1625/3550, 46%) (Figure 2). Other concerns included cysts on the ovaries (1437/3550, 40%), increased tendency for weight gain (1376/3550, 39%), excess hair loss (1359/3550, 38%), and acne/pimples (1119/3550, 32%).

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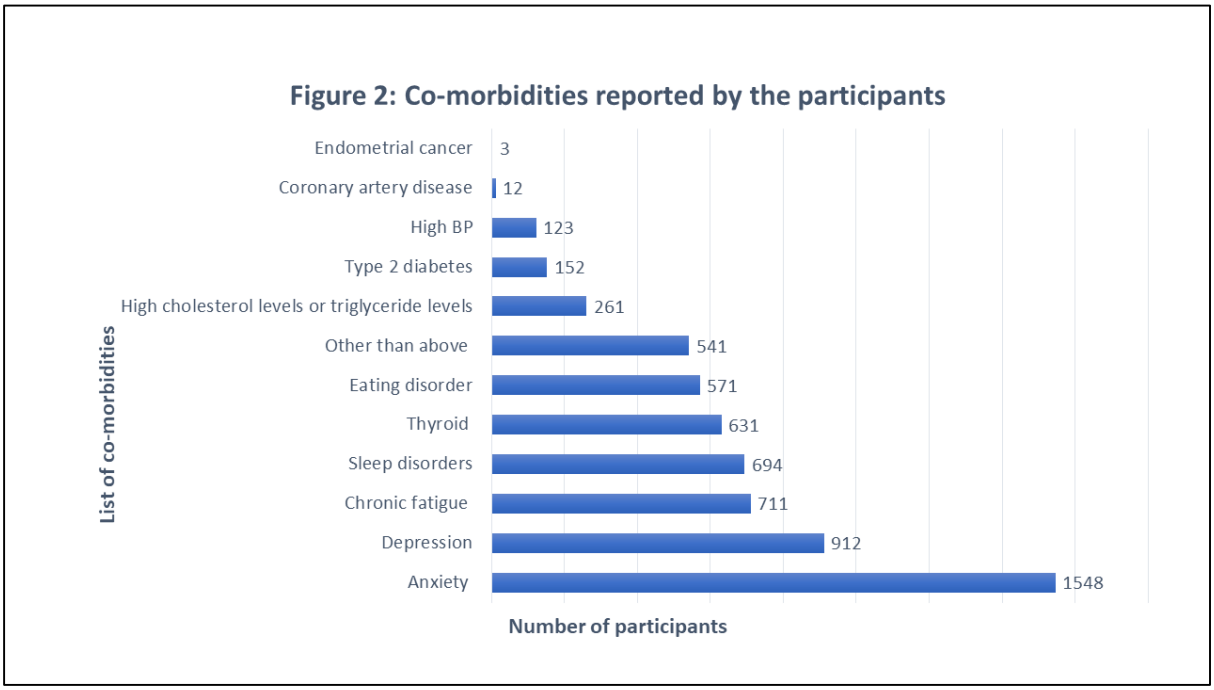

Figure 2. Co-morbidities reported by the participants.

4.5. Treatment methods including TCIM, diet and exercise used to manage PCOS

Table 2 describes the different treatment approaches used by the participants to manage symptoms of PCOS. More than half of women were using the combined oral contraceptive pill (1613/2547, 63%), followed by metformin (1048/2547, 41%) and anti-androgen drugs (637/2547, 25%). The majority practiced yoga (1775/3027, 59%) followed a specific diet (1978/2921, 68%) and were actively engaged in some kind of physical activity (2241/2921, 77%) to manage their symptoms. A large proportion of participants (1986/3201, 62%) reported using TCIM to manage PCOS, Ayurveda (traditional Indian medicine) being the most used (1159/1974, 59%).

Table 2. First sign/symptoms experienced by the participants.

First sign/symptoms (Total responses, N=3824/4409,87%)	Responses, n (%)
Irregular menstrual cycles/periods	3156 (83)
Cysts on the ovaries (in an ultrasound)	2263 (59)
Excess unwanted hair growth over face	1836 (48)
Increased tendency for weight gain	1820 (48)
Difficulty losing weight	1763 (46)
Acne/Pimples	1637 (43)
Excess hair loss	1443 (38)
Anxiety	757 (20)
Problems with ovulation	662 (17)
Depression	578 (15)
High blood levels of androgens/male hormones (eg. testosterone)	511 (13)
Not able to fall pregnant (Infertility)	375 (10)
Other than above	189 (5)
Increased metabolic risk (eg. fear of developing type 2 diabetes)	23 (1)
I do not remember	19 (0.1)
Missing	585 (13)

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4.6. Onset and diagnosis experiences of PCOS

On average, women experienced the first signs/symptoms of PCOS at age 18.9 (SD 5.0), first consulted a medical professional about their symptoms at age 20.0 years (SD 5.0) and were diagnosed at the age of 20.8 years (SD 4.8). Women waited for an average of 1.05 years (SD 2.3) between the first onset of symptoms before they attended their first medical consultation about PCOS, and there was a gap of 0.71 years (SD 2.3) between the first medical consultation and receiving a diagnosis. The majority of participants were living in India (3208/3800, 84%) at the time of diagnosis and were diagnosed by a gynecologist/obstetrician (3149/3839, 82%) (Table 3).

Table 3. List of medical professionals who made the diagnosis of PCOS.

Medical professionals (Total responses, N=3839/4409, 87%)	Responses, n (%)
Gynecologists/obstetrician	3149 (82)
General practitioner/family physician/family doctor	376 (9.8)
Endocrinologist	150 (3.9)
Dermatologist	82 (2.1)
Infertility specialist	77 (2.0)
Cardiologist	3 (0.001)
Psychiatrist	2 (0.001)
Missing	577 (13)

Irregular menstrual cycles/periods (3156/3824, 83%) were the most frequently reported first symptom, followed by cysts on the ovaries (in an ultrasound) (2263/3824, 59%), excess unwanted hair growth over the face (1836/3824, 48%), increased tendency for weight gain (1820/3824, 48%) and difficulty losing weight (1763/3824, 46%) (Table 4). Most women consulted more than two health professionals for their PCOS-related issues. Gynecologists/obstetricians were the most frequently visited (2809/3117, 90%) followed by general practitioners/family physicians (825/3117, 26%) and allied health professionals (621/3117, 20%) (Table 5).

Table 4. List of health professionals consulted for PCOS.

Health Professionals (total responses, N=3117/4409, 71%)	Responses (n)
Only one professional	1444 (46)
Two or more professionals	1673 (54)
Missing	1292 (29)
Gynecologists/obstetrician	2809 (90)
General practitioner/family physician/family doctor	825 (26)
Allied health professionals (eg. dietician, exercise physiologist)	621 (20)
Endocrinologist	518 (17)
Dermatologist	505 (16)
Infertility specialist	350 (11)
Psychiatrist	122 (4)
Cardiologist	14 (0.1)
Other than above	225 (7)
Never seen a medical doctor or allied health practitioner for PCOS treatment	58 (2)
Missing	1292 (29)

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Table 5. Use of treatments methods to manage PCOS.

Conventional treatments, total responses (N=2547/4409,58%)	**Responses, n (%)**
Combined oral contraceptive pills (estrogen + progestin)	1613 (63)
Metformin (insulin-sensitizing medicines)	1048 (41)
Anti-androgen drugs (to correct male-hormone levels)	637 (25)
Ovulation induction to fall pregnant (eg. Letrozole, Clomid, gonadotropins)	359 (14)
Anti-obesity drugs	174 (7)
Intrauterine insemination (IUI)	131 (5)
Laparoscopic surgery (ovarian drilling)	123 (5)
In-vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI)	99 (4)
Intrauterine device (IUD) (eg. Mirena or Depo Provera)	39 (2)
Bariatric surgery	15 (1)
Other than above	463 (18)
Missing	1862 (42)
Diets used to manage PCOS in the past five years, total responses (N=2921/4409,66%)	
Yes	1978 (68)
No	943 (32)
Missing	1448 (33)
Use of exercise, total responses (N=2921/4409,66%)	
Yes	2241 (77)
None of the given forms	680 (23)
Missing	1488 (34)
Use of TCIM, total responses (N=3201/4409,73%)	
Yes	1986 (62)
• Ayurveda	1116 (56)
• Homeopathy	980 (49)
• Other TCIM	740 (36)
No	1215 (38)
Missing	1208 (27)
Use of yoga, total responses (N=3027/4409,69%)	
Yes	1775 (59)
No	1252 (41)
Missing	1382 (31)

4.7. Satisfaction with information provided at the time of diagnosis

More than one-third of women (1400/3595, 39%) did not receive information on emotional support, long-term complications (1323/3595, 37%), and behavioral advice to improve diet or exercise (1157/3595, 32%). For women who did receive information from their healthcare providers regarding treatment and management options, half of the women reported dissatisfaction with the information provided on emotional support (1090/3595, 50%), and treatment options (1482/3595, 49%) (Figure 3).

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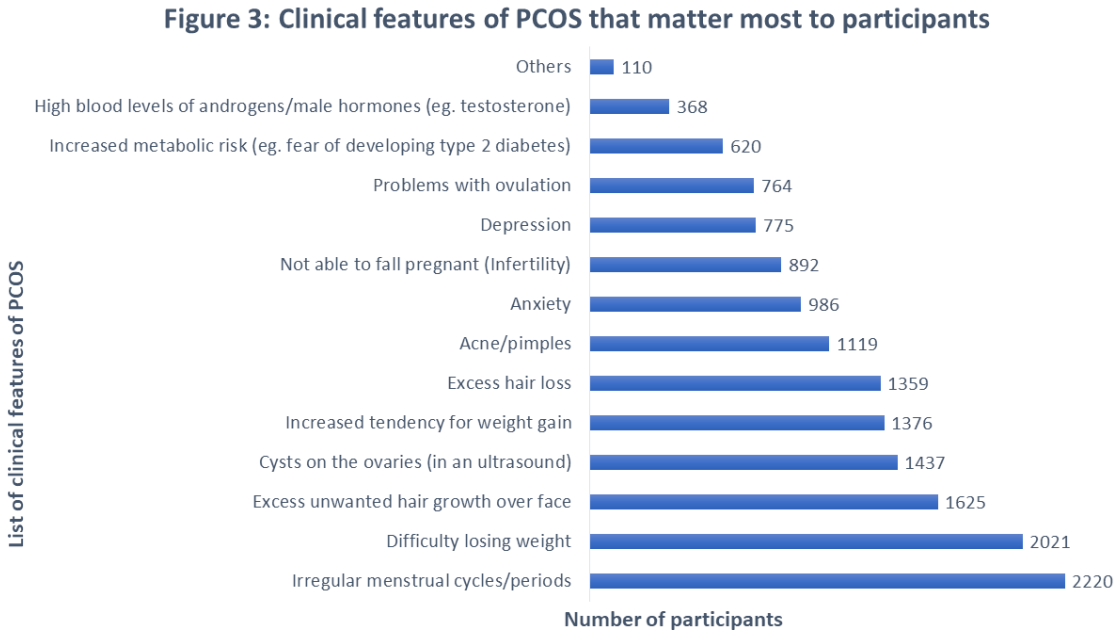

Figure 3. Clinical features of PCOS that matter most to participants.

4.8. Health-related quality of life- MPCOSQ

HRQoL was lowest in the domain of weight (2.7, SD 1.6) followed by emotions (3.0, SD 1.3) and menstrual cycle (3.1, SD 1.2). Figure 4 presents a summary of the mean scores of the six domains of the MPCOSQ for the respondents (2020/4409, 45.8%). The lower the score, the greater the negative impact on HRQoL. The total mean score of all the six domains was 3.2 (SD 1.0). Acne (4.3, SD 1.7) and infertility (3.8, SD 2.0) were highest-scoring HRQOL domains.

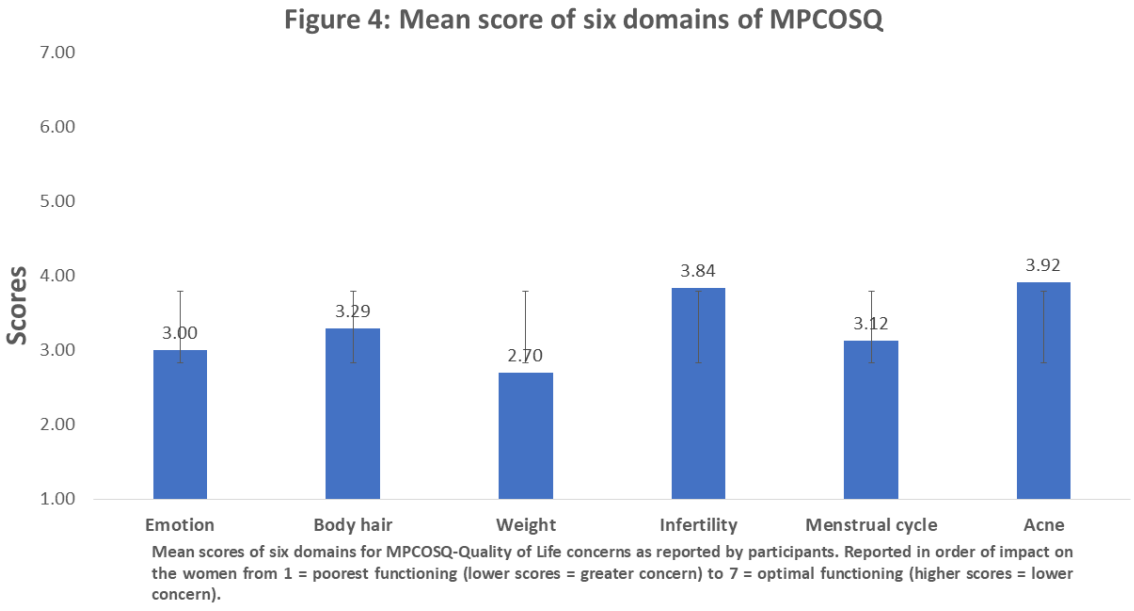

Figure 4. Mean score of six domains of MPCOSQ.

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5. Discussion:

While previous research in Caucasian women has reported dissatisfaction with delayed diagnosis and inadequate information [20, 34, 35], we report here novel findings from this large, international study of ethnic Indian women with PCOS relating to reluctance in healthcare seeking and the use of inappropriate educational resources. Although the majority of participants were young, university educated and working for wages, yet they reported delays in seeking treatment after the onset of symptoms. Most women had multiple co-morbidities, received inadequate information and reported dissatisfaction with the information provided at the time of diagnosis. Women's most important concerns were irregular menstrual cycles/periods, difficulty losing weight, and excess unwanted hair growth over the face. Women visited several health professionals and used different treatment modalities.

Irregular menstrual cycles were the one of first symptoms experienced and a key concern reported by most women. Most women experienced signs and symptoms of PCOS between the ages of 13-20 years and received a PCOS diagnosis between the ages of 17-24 years. These findings are consistent with previous research which indicate that South Asian women are experiencing symptom including irregular cycle onset at an early age and hence diagnosed at a younger age (between 16-25 years) than Caucasians (between 20-30 years) [22, 36-38]. When PCOS symptoms present early in life (preadolescence and adolescence) women may be at a higher risk of developing complications [39] and experience a lower HRQoL [40], emphasizing an increased need for timely and appropriate diagnosis and adequate information provision and support following diagnosis. For example, alteration in the menstrual cycle more than two years post menarche during adolescence could be an important mean for identifying adolescents at higher risk of developing PCOS and metabolic syndrome [41].

Delayed treatment seeking following symptom onset also suggests socio-cultural factors need to be better explored. PCOS is a women's health issue that relates directly to menstruation/fertility, and it is possible that young women maybe hesitant to discuss these issues, as they may believe that the symptoms will subside on its own in a due course of time [22]. While time to diagnosis in our study (0.7 year, SD 2.3) was consistent with research in Caucasian women (which shows a wide variation of 43% ≤ six months and 34% ≥ two years) [21], we observed a considerable delay (1 year (SD 2) in seeking treatment following initial symptom onset. This is longer than the three-month delay in seeking treatment reported by previous research in ethnic Indian women (n=275) where it was suggested that a key barrier to timely diagnosis was their propensity to endure symptoms silently until the severity was no longer tolerable [22]. Another survey of women from India (n=100) aged 25-55 years found that approximately half of women were not comfortable talking about one or more women's health issues due to the societal taboo associated with them, and 84% of women experienced discrimination and judgment related to their menstruation [42]. Further research exploring reasons for delaying seeking treatment following symptom onset in ethnic Indian women with PCOS is required to ensure timely diagnosis.

Ethnic and socio-cultural differences in the HRQoL in women with PCOS have been described in previous studies with varying results in each domain of MPCOSQ [46, 47]. We found that the weight domain produced the greatest impairment on women's HRQoL. This is not surprising, given most women were obese (mean BMI 26.8 kg/m^2), and 96% were concerned about difficulty losing weight and increased tendency to gain weight. This aligns with previous research conducted among Caucasian women, where the weight domain of the MPCOSQ was found to have the greatest association with poor HRQoL [30, 48]. As ethnic Indian women with PCOS often present with lower BMI than Caucasians [14], health professionals should be careful not to disregard education surrounding weight management including weight prevention, which crucial in healthy weight women with PCOS as it can lead to prevention of weight gain and symptoms worsening.

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In contrast to research in Caucasian women [30, 48], the emotion domain of the MPCOSQ produced the second lowest score (after weight), also showing moderate impairment on HRQoL (mean MPCOSQ score 3.0). This could be explained by the fact that 39% of participants did not receive emotional support during the diagnosis and 50% of participants were dissatisfied with the given emotional support. Significantly lower scores in the emotion domain have been previously reported among Black women compared to White women in a study conducted in the USA [49]. Understanding the impact of PCOS on QoL is key to delivering meaningful outcomes, ensuring that clinicians and women can work in partnership to address women's priorities. Furthermore, anxiety (61%) and depression (36%) were the two most common co-morbidities reported in our study. Findings from a meta-analysis including 24 [43] and 27 [44] cross-sectional studies in primarily Caucasian women with PCOS have shown a prevalence of 36% for depression and 42% for anxiety. This is somewhat consistent with previous research showing that the prevalence of depression and anxiety was 10% higher in women with PCOS living in India (n=414) compared to the UK (n=344) ($P < 0.05$ for both) [45]. Our research shows that in ethnic Indian women weight and emotional wellbeing are key priorities in MPCOSQ domains.

The majority of women were diagnosed by a specialist and most women perceived that they received poor and inadequate information on PCOS at the time of diagnosis. Despite anxiety and depression being the two most common co-morbidities, emotional support was not provided to almost half of the women. Likewise, although weight concerns had the greatest impact on HRQoL, and most women reported difficulty losing weight as their key concern, the provision of lifestyle advice to support weight management was poor, with over a third of women being dissatisfied with the diet, physical activity and behavioral change information received. These findings indicate that current education provided by health professionals to aid management of PCOS is not meeting the needs of ethnic Indian women. High-quality information provided at the time of PCOS diagnosis can increase women's ability to self-manage and prevent disease progression [50]. This is an opportunistic time to initiate engagement with evidence-based management strategies, in particular lifestyle change, which is the first-line treatment for PCOS [51, 52].

Despite women in our study reporting poor provision of lifestyle information by their healthcare provider, over two-thirds were following a specific diet and engaging in physical activity to manage their symptoms. Consistent with previous research, these findings suggest that ethnic Indian women are sourcing information to help them manage their PCOS from alternative avenues [22]. This is concerning because research suggests only a limited number of PCOS websites provide culturally appropriate, accurate and reliable lifestyle management information in accordance with evidence-based guidelines [53, 54]. Ensuring that the content provided to ethnic Indian women adequately addresses their concerns and key priorities, including issues surrounding weight, body image and mental health, will help to improve satisfaction with health professional education and on online. As the majority (68%) of women also reported using TCIM to manage PCOS, therefore, these complementary approaches likely need to be better addressed by the concerning health professional. This should include the provision of evidence-based recommendations surrounding more traditional practices, namely yoga and Ayurveda, which are indigenous medicines used frequently by Indian women [55]. The process for consumers being involved in the prioritization of clinical questions in guideline updates and the need for different countries to ensure specific concerns are addressed in country-specific guideline adaptations should be encouraged in the future.

6. Strengths and Limitations:

This novel study has several strengths. Through several online recruitment channels and paid advertisements on social media, we were able to reach a very large ethnic Indian sample in a community setting living worldwide. To the best of our knowledge, this is the

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largest dataset of ethnic Indian women with PCOS. As the survey was voluntary and anonymous, the results are likely to reflect the authentic views of women with PCOS in the community. We included women who were diagnosed with PCOS by a medical doctor. Findings from this study will inform an international initiative to improve diagnosis and education to better meet the ethnically diverse health needs of women living with PCOS helping to tailor diagnostic assessment and educational resources [56]. This will further help to better characterize their health needs and support culturally informed care globally.

Limitations of this study include the exclusion of women who were younger than 18 years of age and older than 55 years of age. PCOS continues to affect women in their adolescence and post-menopause, however, their experiences were not captured in this survey. This study also might have a risk of reporting bias, recall bias and selection bias. As the cohort was relatively young, recall bias is less likely with diagnosis occurring recently. Selection bias is possible due to all participants being recruited from websites and online groups, eliminating the potential to reach women with PCOS who are not active online. Our sample is also very highly educated with 93% of women receiving a university education, and hence does not adequately capture the experiences of women from lower socioeconomic backgrounds. The survey was only available in English and posted on English websites, and may have excluded non-English speaking women. Additionally, we did not design the study as a case-control study which limits the comparisons with non-Indian women

7. Conclusions

This study suggests that ethnic Indian women are waiting a considerable time before seeking healthcare advice about PCOS symptoms, are not satisfied with their diagnosis experience, and have a poor health-related quality of life relating to weight concerns and psychological co-morbidities. Education at the time of diagnosis and focus on emotional wellbeing, as well as information on managing clinical manifestations that can affect body image, namely weight gain and hirsutism. While screening for and treatment of mood disorders is paramount in PCOS management of ethnic Indian women, health professionals should ask about the concerns which matter most to the individual woman. High levels of engagement with TCIM also suggest that evidence-based recommendations for culturally relevant practices, including yoga and Ayurveda warrant further investigation. It is also important to consider socio-cultural factors that may delay ethnic Indian women in seeking treatment, including the social stigma surrounding menstruation.

8. Future recommendations

The survey results highlight the importance and need of a shift in clinical healthcare delivery to a multi-disciplinary, person-centered and family focused, and comprehensive approach for this heterogeneous condition. Although international PCOS guidelines provide a great tool to healthcare professionals, a focus on local adaptation may help fill the social and cultural gaps to support culturally appropriate care. Women from ethnic Indian backgrounds experience an earlier onset of symptoms of PCOS, have a high rate of psychological comorbidity and rate weight problems as their biggest concern, and these issues should be taken into consideration by their treating healthcare professionals. More research that can be used to better understand differences in not only PCOS presentations but also health-seeking behaviour in ethnic Indian women should be prioritized, as should research on psychological comorbidities. Incorporating consumer preferences, including engaging consumers in the co-design of educational resource development, will help to ensure management is individualized to suit the unique health goals of different populations. More research on the role of TCIM, particularly yoga and Ayurveda, in the management of PCOS is warranted.

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Data Availability Statement: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Conflicts of Interest: The authors declare no conflict of interest. CE declares that she is the Jacka Foundation Senior Research Fellow, practicing GP and acupuncturist, Chair of the RACGP Integrative Medicine Specific Interest Network (voluntary role), Program Lead of an academic integrative healthcare centre (no financial interest), past GP Advisory Board member for Blackmores Research Institute, has received industry funding from nutraceutical and acupuncture device companies to conduct clinical trials, and has received honoraria and had travel expenses covered for presenting at complementary medicine events. As a medical research institute, NICM Health Research Institute receives research grants and donations from foundations, universities, government agencies, and industry. Sponsors and donors provide untied and tied funding for work to advance the vision and mission of the Institute. (The project that is the subject of this article was not undertaken as part of a contractual relationship with any donor or sponsor).

Appendix: Please see the attached.

References

1. ESHRE, T.R. and A.-S.P.C.W. Group, *Revised 2003 consensus on diagnostic criteria and long-term health risks related to polycystic ovary syndrome.* Fertility and sterility, 2004. 81(1): p. 19-25.
2. Balen, A.H., et al., *Ultrasound assessment of the polycystic ovary: international consensus definitions.* Human reproduction update, 2003. 9(6): p. 505-514.
3. Kakoly, N., et al., *Ethnicity, obesity and the prevalence of impaired glucose tolerance and type 2 diabetes in PCOS: a systematic review and meta-regression.* Human Reproduction Update, 2018. 24(4): p. 455-467.
4. Wekker, V., et al., *Long-term cardiometabolic disease risk in women with PCOS: a systematic review and meta-analysis.* Human reproduction update, 2020. 26(6): p. 942-960.
5. Bahri Khomami, M., et al., *Lifestyle and pregnancy complications in polycystic ovary syndrome: The SCOPE cohort study.* Clinical endocrinology, 2019. 90(6): p. 814-821.
6. Teede, H., A. Deeks, and L. Moran, *Polycystic ovary syndrome: a complex condition with psychological, reproductive and metabolic manifestations that impacts on health across the lifespan.* BMC Med, 2010. 8: p. 41.
7. Barry, J.A., *Exploration of biological causes of psychological problems in polycystic ovary syndrome (PCOS).* 2011, City University London.
8. Pirotta, S., et al., *Disordered eating behaviours and eating disorders in women in Australia with and without polycystic ovary syndrome: a cross-sectional study.* Journal of clinical medicine, 2019. 8(10): p. 1682.
9. Ding, T., et al., *The prevalence of polycystic ovary syndrome in reproductive-aged women of different ethnicity: a systematic review and meta-analysis.* 2017. 8(56): p. 96351.
10. Louwers, Y., O. Lao, and M. Kayser. *Inferred genetic ancestry versus reported ethnicity in polycystic ovary syndrome (PCOS).* in *Human Reproduction*. 2013. OXFORD UNIV PRESS GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND.
11. Azziz, R., et al. *Effect of race on the metabolic dysfunction of Polycystic Ovary Syndrome (PCOS): comparing African-American (AA) and Non-Hispanic White (NHW) patients.* in *Endocrine Reviews*. 2010. ENDOCRINE SOC 2055 L ST NW, SUITE 600, WASHINGTON, DC 20036 USA.
12. Zhao, Y. and J. Qiao, *Ethnic differences in the phenotypic expression of polycystic ovary syndrome.* Steroids, 2013. 78(8): p. 755-760.

13. Kim, J.J. and Y.M. Choi, *Phenotype and genotype of polycystic ovary syndrome in Asia: Ethnic differences.* Journal of Obstetrics and Gynaecology Research, 2019. 45(12): p. 2330-2337.
14. Sendur, S.N. and B.O. Yildiz, *Influence of ethnicity on different aspects of polycystic ovary syndrome: a systematic review.* Reproductive BioMedicine Online, 2021. 42(4): p. 799-818.
15. Chan, J.L., et al., *Racial and ethnic differences in the prevalence of metabolic syndrome and its components of metabolic syndrome in women with polycystic ovary syndrome: a regional cross-sectional study.* American journal of obstetrics and gynecology, 2017. 217(2): p. 189. e1-189. e8.
16. Dadachanji, R., et al., *Replication study of THADA rs13429458 variant with PCOS susceptibility and its related traits in Indian women.* Gynecological Endocrinology, 2021. 37(8): p. 716-720.
17. Allahbadia, G.N. and R. Merchant, *Polycystic ovary syndrome in the Indian Subcontinent.* Semin Reprod Med, 2008. 26(1): p. 22-34.
18. Tillin, T., et al., *Insulin resistance and truncal obesity as important determinants of the greater incidence of diabetes in Indian Asians and African Caribbeans compared with Europeans: the Southall And Brent REvisited (SABRE) cohort.* Diabetes care, 2013. 36(2): p. 383-393.
19. Nations, U., *World Migration Report 2020*. 2019, International Organization for Migration: Switzerland. p. 3.
20. Gibson-Helm, M.E., et al., *Women's experiences of polycystic ovary syndrome diagnosis.* Family practice, 2014. 31(5): p. 545-549.
21. Gibson-Helm, M., et al., *Delayed diagnosis and a lack of information associated with dissatisfaction in women with polycystic ovary syndrome.* 2017. 102(2): p. 604-612.
22. Kaur, I., et al., *Treatment pathways traversed by polycystic ovary syndrome (PCOS) patients: A mixed-method study.* PLOS ONE, 2021. 16(8): p. e0255830.
23. Pathak, G.S., *"Supportive" Masculinities and Polycystic Ovary Syndrome: Changing Gender Relations in Contemporary Urban India*, in *Reconceiving Muslim Men*. 2018, Berghahn.
24. Sharma, S. and A.J. Mishra, *Tabooed disease in alienated bodies: A study of women suffering from Polycystic Ovary Syndrome (PCOS).* Clinical Epidemiology and Global Health, 2018. 6(3): p. 130-136.
25. Widge, A., *Seeking conception: experiences of urban Indian women with in vitro fertilisation.* Patient Education and Counseling, 2005. 59(3): p. 226-233.
26. Gill, H., P. Tiwari, and P. Dabadghao, *Prevalence of polycystic ovary syndrome in young women from North India: A Community-based study.* Indian Journal of Endocrinology and Metabolism, 2012. 16(8): p. 389-392.
27. Joshi, B., et al., *A cross-sectional study of polycystic ovarian syndrome among adolescent and young girls in Mumbai, India.* Indian Journal of Endocrinology and Metabolism, 2014. 18(3): p. 317-324.
28. Choudhary, A., S. Jain, and P. Chaudhari, *Prevalence and symptomatology of polycystic ovarian syndrome in Indian women: is there a rising incidence?* International Journal of Reproduction, Contraception, Obstetrics and Gynecology, 2017. 6(11): p. 4971-4976.
29. Cronin, L., et al., *Development of a health-related quality-of-life questionnaire (PCOSQ) for women with polycystic ovary syndrome (PCOS).* The Journal of Clinical Endocrinology & Metabolism, 1998. 83(6): p. 1976-1987.
30. Barnard, L., et al., *Quality of life and psychological well being in polycystic ovary syndrome.* Human reproduction, 2007. 22(8): p. 2279-2286.
31. Misra, A., et al., *Consensus statement for diagnosis of obesity, abdominal obesity and the metabolic syndrome for Asian Indians and recommendations for physical activity, medical and surgical management.* Japi, 2009. 57(2): p. 163-70.
32. Jadhav, A., D. Pramod, and K. Ramanathan, *Comparison of performance of data imputation methods for numeric dataset.* Applied Artificial Intelligence, 2019. 33(10): p. 913-933.
33. IBM Corp, N., *IBM SPSS statistics for windows*. 2021, IBM Corp.: Armonk, NY.
34. Gibson-Helm, M., et al., *Delayed diagnosis and a lack of information associated with dissatisfaction in women with polycystic ovary syndrome.* The Journal of Clinical Endocrinology & Metabolism, 2017. 102(2): p. 604-612.
35. Ismayilova, M. and S. Yaya, *"I felt like she didn't take me seriously": a multi-methods study examining patient satisfaction and experiences with polycystic ovary syndrome (PCOS) in Canada.* BMC women's health, 2022. 22(1): p. 1-21.
36. Mani, H., et al., *Clinical characteristics of polycystic ovary syndrome: investigating differences in White and South Asian women.* Clinical endocrinology, 2015. 83(4): p. 542-549.
37. Wijeyaratne, C.N., et al., *Clinical manifestations and insulin resistance (IR) in polycystic ovary syndrome (PCOS) among South Asians and Caucasians: is there a difference?* Clinical endocrinology, 2002. 57(3): p. 343-350.
38. Conway, G., et al., *European survey of diagnosis and management of the polycystic ovary syndrome: results of the ESE PCOS Special Interest Group's Questionnaire.* European journal of endocrinology, 2014. 171(4): p. 489-498.
39. Bronstein, J., et al., *Age of onset of polycystic ovarian syndrome in girls may be earlier than previously thought.* Journal of pediatric and adolescent gynecology, 2011. 24(1): p. 15-20.
40. Trent, M.E., et al., *Quality of life in adolescent girls with polycystic ovary syndrome.* Archives of pediatrics & adolescent medicine, 2002. 156(6): p. 556-560.
41. Nair, M., et al., *Menstrual irregularity and poly cystic ovarian syndrome among adolescent girls—a 2 year follow-up study.* The Indian Journal of Pediatrics, 2012. 79(1): p. 69-73.
42. Pharmaceuticals, E. *Indian Women's Health Report 2021*. 2021 [cited 2022 21st July]; Available from: https://unconditionyourself.com/wp-content/uploads/2021/12/UY-Indian-Womens-Health-Report-2021-Final.pdf.
43. Wang, Y., Z. Ni, and K. Li, *The prevalence of anxiety and depression of different severity in women with polycystic ovary syndrome: a meta-analysis.* Gynecological Endocrinology, 2021. 37(12): p. 1072-1078.

44. Cooney, L.G., et al., *High prevalence of moderate and severe depressive and anxiety symptoms in polycystic ovary syndrome: a systematic review and meta-analysis.* Human Reproduction, 2017. 32(5): p. 1075-1091.
45. Hebbar, M., et al. *PCOS SEVa: High prevalence anxiety and body dysmorphia in women with PCOS in the UK and India*. in *Endocrine Abstracts*. 2021. Bioscientifica.
46. Schmid, J., et al., *Infertility caused by PCOS--health-related quality of life among Austrian and Moslem immigrant women in Austria.* Hum Reprod, 2004. 19(10): p. 2251-7.
47. Jones, G.L., et al., *Do South Asian women with PCOS have poorer health-related quality of life than Caucasian women with PCOS? A comparative cross-sectional study.* Health and quality of life outcomes, 2010. 8(1): p. 1-8.
48. McCook, J.G., N.E. Reame, and S.S. Thatcher, *Health-related quality of life issues in women with polycystic ovary syndrome.* Journal of Obstetric, Gynecologic, & Neonatal Nursing, 2005. 34(1): p. 12-20.
49. Alur-Gupta, S., et al., *Racial differences in anxiety, depression, and quality of life in women with polycystic ovary syndrome.* F&S Reports, 2021. 2(2): p. 230-237.
50. Teede, H.J., et al., *Translation and implementation of the Australian-led PCOS guideline: clinical summary and translation resources from the International Evidence-based Guideline for the Assessment and management of polycystic ovary syndrome.* Medical journal of Australia, 2018. 209: p. S3-S8.
51. Ching, H., V. Burke, and B. Stuckey, *Quality of life and psychological morbidity in women with polycystic ovary syndrome: body mass index, age and the provision of patient information are significant modifiers.* Clinical endocrinology, 2007. 66(3): p. 373-379.
52. Colwell, K., et al., *Women's perceptions of polycystic ovary syndrome following participation in a clinical research study: implications for knowledge, feelings, and daily health practices.* Journal of obstetrics and Gynaecology Canada, 2010. 32(5): p. 453-459.
53. Chiu, W.-L., et al. *What can you find about polycystic ovary syndrome (PCOS) online? Assessing online information on PCOS: quality, content, and user-friendliness*. in *Seminars in Reproductive Medicine*. 2018. Thieme Medical Publishers.
54. Htet, T.T., et al., *The accuracy of information for lifestyle management on websites for the management of PCOS.* Clinical Endocrinology, 2017. 86(S1): p. 47-47.
55. Shrivastava, S.R., P.S. Shrivastava, and J. Ramasamy, *Mainstreaming of Ayurveda, Yoga, Naturopathy, Unani, Siddha, and Homeopathy with the health care delivery system in India.* Journal of Traditional and Complementary Medicine, 2015. 5(2): p. 116-118.
56. Teede, H.J., et al., *Recommendations from the international evidence-based guideline for the assessment and management of polycystic ovary syndrome.* 2018. 33(9): p. 1602-1618.