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An Ecosocial Perspective on Barriers to the Management of Polycystic Ovary Syndrome Among Women in Urban India

Abstract:
Polycystic ovary syndrome (PCOS) is a hormonal disorder associated with increased risks of type II diabetes and cardiovascular disease. It is also the leading cause of female infertility worldwide. Both lifestyle and genetic factors have been tied to the condition, and in the last couple of decades, it has been affecting a growing number of urban Indian middle-class women; whereas global prevalence is in the 4–11 per cent range, studies in India suggest a prevalence of around one in four urban middle-class women. In this article, I focus on the lived experiences of women with the condition. Drawing from ethnographic fieldwork in Mumbai, India, I use an ecosocial approach to examine barriers to the management of PCOS commonly experienced by women. Such an examination reveals potential bases for intervention to improve management outcomes, particularly as they relate to strengthening the patient–practitioner relationship and improving the clinical encounter.

Keywords:
barriers to management, clinical encounter, ecosocial, healthcare, India, patient–practitioner relationship, PCOS
Polycystic ovary syndrome (PCOS) is an endocrine disorder associated with menstrual irregularities, overweight and obesity, acne, hair fall, and hirsutism (male-pattern hair growth) (Balen, Homburg & Franks, 2009; Ehrmann, 2005). The syndrome has been largely ignored by the social scientific, let alone anthropological, literature (Kitzinger and Willmott, 2002 being an exception), despite being one of the most commonly reported endocrine disorders and the leading cause of female infertility across the globe (Boomsma, Fauser & Macklon, 2008). It is also tied to increased risks of type II diabetes and cardiovascular disease (Dumesic et al., 2015). Although the exact aetiology of the syndrome has not been established, both genetics and lifestyle factors are thought to play a role (Balen, Homburg & Franks, 2009; Ehrmann, 2005; Franks, 1995). The syndrome has also been tied to middle-class lifestyles across the globe (Inhorn, 2015), and in India, it affects a growing number of middle-class women (Pathak & Nichter, 2015). As a result, the condition, individually and together with the other outcomes linked to it, exacts significant economic and psychological costs from affected individuals and households. Although large-scale epidemiological studies on PCOS in India are lacking, preliminary studies suggest a prevalence of higher than one in four urban middle-class women (Joshi et al., 2014)—which is much higher than the global prevalence of around 4–11 percent (Wijeyaratne, Udayangani & Balen, 2013)—and a rising number of cases in the decades following the liberalisation of the Indian economy in 1991 (Pathak & Nichter, 2015). PCOS is thus an emerging public health problem for India, and it requires timely intervention and appropriate management.

PCOS gets its name from the cyst-like ovarian follicles that are often seen upon a gynaecological sonography of women with the condition. In a normal menstrual cycle, a single dominant follicle releases an egg; in PCOS, several follicles develop but none becomes dominant (Soulez et al., 1996). This often leads to a lack of ovulation, and the menstrual cycle may be delayed or absent. However, not all women with PCOS show the appearance of ovarian cysts (known as polycystic ovaries), and the appearance of such cysts alone does not constitute a definitive diagnosis of PCOS (Balen,
Homburg & Franks, 2009). Obesity and overweight are not just symptoms; they can also contribute to worsening other symptoms (Balen, Dresner, Scott & O Drife, 2006; Ehrmann, 2005). Nevertheless, even lean women can have PCOS, and not all women with the syndrome are obese or overweight (Franks, 1995). Studies suggest that PCOS results from insulin resistance (Franks, 1995)—a condition, considered to be a pre-cursor to diabetes, by which the cells of the body become less sensitive to insulin. Thus, although the name and its association with reproduction and the menstrual cycle might imply that PCOS is a gynaecological issue, it is in fact an endocrine issue with a range of symptoms (although not all women manifest all symptoms), and it forms part of a cluster of metabolic disorders. Given the range of symptoms associated with PCOS, various medical and paramedical practitioners can be involved in its diagnosis and management, and in India, this includes alternative practitioners, usually homeopaths and ayurvedic practitioners (or vaidyas).

The Rotterdam criteria are the most commonly used criteria used to diagnose PCOS. The diagnosis requires the presence of at least two of the following: 1) irregular ovulation or lack of ovulation, 2) excess androgenic activity, as per either laboratory tests or clinical assessment of symptoms such as cystic acne and hirsutism, and 3) polycystic ovaries (Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 2004). PCOS has no cure, but lifestyle changes, typically targeted at weight reduction (especially in the case of overweight or obese women, but also for lean women with abdominal obesity or high levels of visceral fat), are often recommended in its management (Balen & Rutherford, 2007). Management of symptoms also involves medication, such as oral contraceptives (to regulate the menstrual cycle), ovulation inducers and reproductive technologies (to increase fertility), and insulin sensitizers (to combat insulin resistance and weight gain) (Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012; Balen & Rutherford, 2007).
A long history of work in medical anthropology and medical sociology has demonstrated that social structures are embodied as biological realities. The body reflects the social and material world it inhabits, and bodies and their biological conditions can only be truly understood when situated within their social and ecological contexts. This is particularly true for chronic and lifestyle conditions such as PCOS. While such social production of health approaches highlight structural barriers to health, the epidemiologist Nancy Krieger (1994, 2001) has criticised them for not addressing the pathways through which structural factors affect biological dimensions. She argues that such approaches render biology opaque and points out that they rarely go beyond calling for wider socioeconomic justice to suggest concrete interventions. As a corrective, she recommends an ecosocial perspective, which combines a focus on biological, social, historical, and ecological factors. Such a focus pays particular attention to biological pathways of embodiment and the cumulative interactions between exposure, susceptibility, and resilience. As mentioned, there have been very few social studies of PCOS and women’s experiences of the condition, whether in India or abroad. Therefore, in this article, using qualitative data from ethnographic fieldwork in Mumbai, India, I take an ecosocial approach to shed light not just on sociocultural factors affecting PCOS management among urban middle-class Indian women but also on their interactions with biological dimensions. These interactions function as barriers to management and reveal potential bases for intervention, particularly in terms of strengthening patient–practitioner partnerships in the clinical encounter.

**Methods**

The findings described in this article are from ethnographic fieldwork conducted in Mumbai, India, from 2012–2017. Given the high prevalence of the condition among the urban middle-class (Pathak & Nichter, 2015), this class was the focus of investigation. Although middle classness in India
is more a performative socioeconomic grouping than an economic bracket (e.g. Deshpande, 2003; Donner & de Neve, 2011; Fernandes, 2006; Mazzarella, 2005), Fernandes and Heller (2006) have outlined three major segments of the middle class: a segment with professional educational credentials; a petit bourgeoisie of merchants and shopkeepers; and an educated segment in non-professional jobs. My focus was on the professional middle class and the petit bourgeoisie, as reflected in lifestyles that involved formal housing, comfort with English, engagement with and economic access to new practices of consumption and global popular culture, and an undergraduate English-language education at minimum.

The fieldwork included observation and in-depth semi-structured interviews and involved a total of 160 participants. In-depth interviews and participant–observation were conducted among a base of eighty-one participants to understand the health practices, popular health culture, and patterns of living of Mumbai’s middle class. Semi-structured interviews were conducted with endocrinologists (n=5), gynaecologists (n=5), dermatologists (n=5), dietitians/nutritionists (both terms are often used interchangeably in India; n=5), and vaidyas (n=5). Practitioners were selected through referrals by key informants. Thirty middle-class women diagnosed with PCOS and aged 21 and above (10 never married, 10 ever married without children, 10 ever married with children) formed a core sample for the research. Interlocutors were identified through referrals within social networks and from within social circles; this allowed for triangulation of data from interviews with those from observation. In-depth interviews, follow-up phone interviews, and informal conversations were conducted with this sample of interlocutors. Furthermore, they were visited on several occasions across time points and observed during their day-to-day interactions. Interviews were primarily in English, but there was also significant code switching between English, Hindi, and Marathi. The Institutional Review Board of the [blinded for peer review] approved the research. Informed consent was obtained from all participants, and all names provided are pseudonyms.
Findings

Fieldwork revealed several barriers to the early and effective management of PCOS. These barriers begin at a young age, around the time of menarche (first menstrual period), and continue throughout the life course. Seven major themes emerged from the data, as presented below.

Physical Activity Among Adolescents

India has a hyper-competitive educational environment where middle-class students in particular face intense pressure to do well in school. As more people enter the middle class (thanks to economic growth) and with the increasing acceptance of women having careers, these pressures have only gotten more intense. This intense focus on academic performance means that children decrease their engagement in physical activity as they enter secondary school (see also Swaminathan, Selvam, Thomas, Kurpad, & Vaz, 2011); heavy homework loads, exhaustive examination preparation, and numerous academic coaching classes (e.g., Ghosh, 2009; Panigrahi, 2012) result in increasingly sedentary lives with little time for play or sports. Furthermore, observations in Mumbai and comments from key informants suggested that the time around puberty also results in more gender-segregated play, such that physical activity for girls drops even more than it does for boys. Meanwhile, this is a highly stressful time for students, and interactions in the city revealed that eating is one of the only socioculturally sanctioned outlets; in fact, parents often use calorie-dense treats to both reward and motivate gruelling study sessions.

All of this coincides with the period around puberty. Various reports suggest that the average age of menarche across India lies in the 9–15 age range (Acharya et al., 2006; Bagga & Kulkarni,
The time around menarche is typically a period of decreased insulin sensitivity, although sensitivity returns to pre-pubertal levels a couple of years later (Goran & Gower, 2001). However, drastically reduced movement at this stage, combined with a diet rich in sugar and calories, leads to weight gain. Weight gain adversely affects insulin sensitivity, which increases the chances of developing PCOS, which, in turn, leads to weight gain and further decreased insulin sensitivity, in a negative feedback loop. As one endocrinologist stated, ‘Fat is an endocrine organ’. She explained that she meant that fat, once stored in the body, has larger endocrine effects that are more difficult to reverse than they are to prevent. Thus, the particularly vulnerable age around menarche is also the time when young girls face multiple stressors linked to the development of PCOS.

**Conflation of Early Symptoms with Normal Signs of Adolescence**

As mentioned, for middle-class girls, the years around menarche in India also involve high degrees of stress. Through its effects on the hypothalamic–pituitary–ovarian axis, stress is associated with irregular menstruation, a key indicator of PCOS. Moreover, symptoms of the syndrome, such as menstrual irregularities and acne, are also common features of adolescence. Interlocutors reported that when they spoke to their mothers or older female relatives about experiencing symptoms of PCOS such as infrequent menstruation (oligomenorrhea), they were told it was not a matter to be concerned about. ‘People kept telling me, “it’s okay, it’s just started, 14/15 ke baad [after 14/15] it will normalise”’, an interlocutor who had experienced irregular menstruation right from the age of 12 recounted. At the same time, the secular trend in puberty—by which better nutritional status seems to result in an earlier onset of puberty—has meant that girls, especially from the middle and higher socioeconomic strata, start menstruating earlier than their mothers did (Bagga & Kulkarni, 2000; Khadilkar et al., 2006; Khanna & Kapoor, 2004; Rokade & Mane, 2008). As a result, although
menstrual irregularities usually settle within a couple of years of menarche, older female relatives, who form the first line of advice regarding menstruation, perceive these irregularities to be normal even into late teenage, irrespective of age of the first menstrual period. Thus, an interlocutor, who had achieved menarche at age nine but complained of menstrual irregularities at age 13 was still told to give her body ‘time to settle’.

Lack of Consensus Among Medical Practitioners

Gynaecologists and endocrinologists were the practitioners most consulted for the management of PCOS, but there were significant differences in how they approached the diagnosis and management of the condition. Endocrinologists saw PCOS as a more wide-ranging disorder of the endocrine system. As one endocrinologist told me, a PCOS diagnosis was a ‘diagnosis of exclusion’. All the endocrinologists I spoke to mentioned that they required laboratory tests to rule out a host of other conditions, including, for example, thyroid dysfunction or hyperprolactinemia (high levels of the hormone prolactin). Besides such hormonal assays, endocrinologists recommended laboratory tests to check for insulin resistance, and insulin sensitizers were only prescribed after testing.

On the other hand, gynaecologists in the study focused on the menstrual and reproductive aspects of PCOS. In most cases, they told me that they would deliver the diagnosis of PCOS based on a sonography and clinical symptoms, without requiring hormonal assays. Of these clinical symptoms, overweight or obesity was the symptom most relied upon. As two of the lean women with PCOS whom I spoke to attested, this often resulted in delays in the diagnosis for lean women with PCOS. Gynaecologists in the study stated that they rarely recommended testing for insulin resistance, and four even prescribed insulin sensitizers based solely on menstrual irregularities combined with the
presence of overweight or obesity. Women with PCOS told me that they did not learn of the links between PCOS and diabetes and metabolic syndrome risks from gynaecologists. The focus on reproductive health also meant that women with PCOS reported that many gynaecologists either told them not to be concerned about PCOS unless they wished to conceive or advised them to start planning pregnancies early on in their marriages to avoid fertility issues.

Women usually approached ayurvedic practitioners or homeopaths after receiving their diagnosis, for more long-term approaches to managing the condition. Vaidyas told me that there is no diagnostic category in ayurveda that maps directly on to PCOS; instead, symptoms fall under other diagnostic categories. These categories centre on imbalances in the bodily humours of vata (related to wind), kapha (related to mucus), and pitta (related to bile and digestive fire), with a persistent imbalance in one or more of these humours resulting in ama (built-up toxins). Individual constitutions comprise a combination of the humours, and treatment depends upon a woman’s constitution and her specific humoral imbalance. The vaidyas I spoke to differed in their opinions of PCOS. One defined it as a vata disorder; another felt it was a vata–kapha disorder. Two others differentiated between the lean (a vata–pitta disorder) and overweight (a vata–kapha disorder) phenotypes of the condition. Finally, one vaidya blamed PCOS on ama, with symptoms manifesting according to whether the ama was a result of vata, kapha, or pitta imbalance. Overall, vaidyas treated PCOS as a lifestyle disorder arising from unhealthy food habits (a reliance on junk food), irregular sleep and meal times, lack of activity, stress, and even things such as refrigerated food (seen as nutritionally suspect), or tight clothes (thought to constrict the ovaries and uterus). Therefore, they would advocate changes such as regularity in sleep and meal times, the cutting out or favouring of certain foods (depending upon individual constitution), and yoga. The vaidyas I spoke to did not stress the links between PCOS and diabetes risk, nor did they recommend diets lower in simple carbohydrates.
Homeopaths, on the other hand, used the biomedical diagnostic criteria for PCOS, but, as in ayurveda, treatment differed based on the woman’s individual constitution. Both homeopaths and women with PCOS consulting with homeopaths told me that PCOS could be cured by homeopathy. This was a view not shared by the other medical practitioners, including vaidyas, who saw PCOS as resulting from constitutional tendencies that had to be carefully managed. Nevertheless, homeopaths also saw changes in diet, meal and sleep timings, and physical activity as necessary to effecting a full cure.

Women with PCOS also visited dietitians for advice on weight loss. In India, dietitians can practice even with a post-graduate diploma. Their focus is weight reduction, and few have experience with the dietary management of medical conditions (i.e., clinical nutrition). Only one of the dietitians in the study—a clinical nutritionist—knew of the association between PCOS and insulin resistance, and generally, the focus was on low-fat diets, rather than low-carbohydrate diets with higher protein and fibre. Comments from women with PCOS who visited dietitians suggested a similar pattern. As a result of these contradictory diagnostic processes and management techniques, women with PCOS get widely divergent medical advice on managing their condition.

Patient–Practitioner Communication

Fieldwork pointed to an urgent need for better patient–practitioner communication. Consultations with gynaecologists or endocrinologists, the medical practitioners most commonly associated with PCOS management, in Mumbai were usually only around 7–10 minutes. Interlocutors with PCOS reported that lifestyle advice was typically limited to a sentence about the need for exercise
and a healthier diet, or worse, an admonition to lose weight. One woman recounted how her gynaecologist had only delivered the PCOS diagnosis and written out a prescription without explaining the condition or the need for lifestyle changes in its management. The doctor’s attitude, she felt, also precluded her asking the questions that she had about PCOS. She ended up asking me for those clarifications instead; this was a common occurrence, and more often than not, I found myself answering such queries from interlocutors.

A lack of sensitivity on the part of gynaecologists and endocrinologists when talking about weight loss was another issue. An obese interlocutor told me that she had been told by her endocrinologist to ‘only come back’ to consult him if she lost weight; another described being told by her doctor that she could afford not to eat anything for an entire month given her weight. Such comments, rather than motivating change, made women despair or feel disheartened. Similarly, a lean interlocutor with PCOS was offended when her gynaecologist told her to lose a couple of kilos of weight in order to conceive. Such insensitivity, and feelings of not being listened to, also led to women trying out several medical practitioners without consistently following any of the practitioners’ advice. Interlocutors reported starting and stopping medication without supervision and avoiding follow-ups. The lack of substantive communication also meant that they treated all the medical advice received during the clinical encounter as suspect. Conversely, when women felt comfortable talking to their doctors about their queries and concerns, they were more likely to consult their doctors regularly and to implement lifestyle changes.

Meanwhile, biomedical practitioners often assumed that patients would not adopt lifestyle modifications or take lifestyle advice seriously. Biomedical interlocutors mentioned that anywhere from ‘30–40 percent’ to ‘less than ten per cent’ of women managed to implement the lifestyle changes
that they recommended. Practitioners also mentioned that the implementation of these changes was often periodic and inconsistent; it would reach a peak around the preparation for life events such as marriage or motherhood and went through ‘u-turns’ once these events had occurred.

Information and Trust

Patient–practitioner communication was also closely linked to trust. In the case of PCOS, women were exposed to varied and often divergent advice about the condition from numerous information streams. Thanks to the Internet, my middle-class interlocutors had access to a dizzying array of PCOS-related information from all over the world, and sifting through the material to decide on what was trustworthy, relevant to them, and relevant to the urban Indian context was a confusing, ‘scary’, and complicated endeavour.

Furthermore, as one dermatologist drily remarked, ‘Here in India, there are a lot of doctors nearby. All your neighbours are doctors. And all grannies are also doctors; mothers are also doctors’. This means that people constantly comment on health matters, even dismissing or contradicting advice from health professionals; this, in addition to the lack of consensus among various medical practitioners detailed earlier further complicates efforts to determine what information is relevant and reliable. In general, I found that for women with PCOS, sources who had provided health information that had seemed to yield results in the past were more likely to be trusted. Interlocutors were also more likely to implement advice from sources (including websites or newspapers) they trusted, even when that trust had been generated in non-medical contexts. As described earlier, in the case of medical practitioners, women were more likely to trust those who took the time to communicate with them and explain their rationales. Information that seemed to fit in with patients’ understandings of the
body and explanatory models of illness, or information that was explained to relate to these, was trusted over information that contradicted patients’ established notions. Finally, the higher the degree of distress resulting from the condition and its symptoms, the more the likelihood that women would attempt to put health advice into practice. The comments of one interlocutor in her mid-thirties were typical, especially when it came to cosmetic concerns such as acne: ‘Around that time I was very—I don’t know if I was depressed, but it was certainly how I felt….I was ready to try anything that would help…I was an easy target for anybody selling anything—I would buy’.

Pharmacophobia

Participant–observation, interviews, and interactions with people across Mumbai revealed a general suspicion of and wariness towards biomedicines. Interlocutors were particularly suspicious of hormonal contraception, which was seen as ‘really strong medicines’ that had long-term adverse consequences on women’s fertility and overall health (see also Nichter 1996; Nichter & Nichter, 1996). I found that friends and family also often commented on hormonal contraception as harmful. The distrust was particularly pronounced when medical practitioners did not explain the drugs or their rationales for the prescription to women. For example, two interlocutors with PCOS reported being told by the staff at pharmacies that the insulin sensitizers they had been prescribed was ‘diabetes medicine’. Such a framing alarmed them, as they were unaware of the links between PCOS, insulin resistance, and diabetes risk. Women would therefore disregard prescriptions, avoid medication, stop medication without supervision, or take medication sporadically without consulting their practitioners. When practitioners took the time to communicate with patients about the drugs, interlocutors were more likely to follow prescriptions, but concerns about having to take medication long-term often persisted.
PCOS is tied to parental diabetes and metabolic syndrome (Leibel, Baumann, Kocherginsky & Rosenfield, 2006; Sir-Petermann et al., 2002), and this was a link borne out among my interlocutors. Of the 30 women with PCOS in my study, 15 had one parent who had been diagnosed with diabetes and four had parents who had both been diagnosed with diabetes. At the same time, interlocutors found it extremely difficult to make dietary changes for themselves unless household food patterns were also changed. Women had to consider the preferences of children, spouses, parents-in-law, or parents when making decisions regarding what was cooked within the home. Thus, women were subjected to numerous constraints, as one of my interlocutors noted:

Who is deciding the diet? They [the family] order a chicken biryani—somebody has to finish it. She [the woman] is finishing leftovers, eating the wrong food, and catering to so many people. She can’t cook a healthy meal. If she cooks a salad, the mother-in-law says ‘You are starving my son!’

Moreover, family members, friends, and colleagues constantly coaxed individuals to eat. One of my interlocutors with PCOS remarked, ‘My friends will say “You are so thin; why are you not eating?” My parents—you know how Punjabis are—they tell me “eat, eat clarified butter, eat paratha”’. She was lean, but she found it hard to explain to the people around her that she still had to be careful not to put on weight in order to manage her PCOS. Sweets, which are symbols of auspiciousness, were particular objects of such coaxing, and even more so during festivals or periods of celebration; interlocutors found it difficult to refuse sweets without appearing rude or selfish. Given that the festival and wedding season lasts for approximately half the year, from mid-August through December, this can be a socially tricky situation to navigate. The cultural norms governing food and
sociality meant that even as I met healthcare practitioners, who lamented the increased consumption of sugar and refined carbohydrates, I would be offered extremely sweet tea and sweets or cookies. I do not use this observation to put practitioners on the spot or imply that they were hypocrites—rather, they were being gracious and conforming to norms of hospitality—but rather to point to larger attitudes toward food that function as barriers to the effective management of PCOS.

**Discussion: PCOS Management and Ecosocial Barriers to Health**

PCOS incidence and prevalence is higher among urban middle-class women in India than in women from the lower socioeconomic strata and even in women across the world, representing a health disparity caused by urban middle-class Indian women’s location within a unique set of ecosocial factors (Pathak & Nichter, 2015). The barriers to health for women with PCOS mentioned above interact through feedback loops that start early and persist throughout the life course. Indians are thought to be prone to type II diabetes and are considered ‘metabolically obese’—that is, they display several metabolic disturbances even at body mass indices considered conventionally non-obese (Misra & Khurana, 2008; see also Yajnik & Yudkin, 2004). Then, a hyper-competitive educational environment that leads to reduced physical activity, an increase in calorie-rich foods, and high levels of exam stress places multiple cumulative and interactive burdens on the young female body right around the time of menarche, a particularly vulnerable age in terms of insulin resistance and PCOS. Insulin sensitivity—or rather, reduced insulin sensitivity—becomes a pathway to embodiment of the biosocial stresses of the academic system as PCOS. At the same time, even though the indicators of PCOS tend to present as early as menarche (Sheehan, 2004), these early diagnostic markers of PCOS are overlooked as normal features of adolescence well into teenage because of the secular trend in puberty, leading to delayed diagnosis and intervention. A lack of consensus among medical practitioners means that when women with PCOS do seek medical attention, they often
receive contradictory or incomplete management advice. Differences between gynaecologists’ and endocrinologists’ approaches to PCOS have already been reported in Australia (Cussons et al., 2005), but these differences were far more marked in the Indian context. When women get contradictory advice from their doctors it also contributes to a general lack of trust in the clinical encounter. Moreover, the lack of clinical training for most dietitians in India means that the underlying issues related to insulin resistance are not fully addressed in weight loss advice that is focused on fat rather than simple carbohydrates and protein deficit. More consistent clinical guidelines across medical specialisations would therefore go a long way in aiding not just improved management of PCOS, but also in enhancing patient–practitioner trust.

Trust would also be aided by better communication between patients and practitioners. As mentioned, few of my interlocutors with PCOS seemed to know of the link between PCOS and the risks of diabetes. Either medical practitioners were failing to communicate this to patients, or if they had done so, it was in a manner that did not aid recall and retention. Moreover, there was a gap in communication, in that biomedical practitioners often assumed that patients would not adopt lifestyle modifications or take lifestyle advice seriously, whereas women with PCOS felt that practitioners did not translate general lifestyle management advice for their particular lifeworlds. Medical professionals were largely relying on the ‘classic relationship’ model of communication, by which practitioners assume a position of authority and patients are seen as lacking knowledge (Stokken, 2009). For a condition such as PCOS, which does not have a clear aetiology or cure and where the patient’s lifestyle affects illness trajectory, the classic relationship cannot create space for the patient–practitioner collaboration required for successful management. Stefan Ecks (2010), in his study of gastroenterologists in Calcutta, examined how practitioners’ hegemonic claims to sociopolitical power rested on distancing themselves, as the bearers of reason, from their patients, viewed as unreasonable quasi-children. Ecks found this division irrespective of the socioeconomic class of the
patients. This distancing was also in evidence among practitioners helping women to diagnose and manage PCOS in my study, in their reliance on the classic relationship model of communication.

There is an urgent need for a change in such attitudes. A more empathetic approach that views the patient–practitioner relationship as collaborative, is more sensitive to patient concerns and a folk view of biomedicines as damaging when used continuously, and is more able to translate management advice to patients’ contexts and lifeworlds would not only lead to better evaluations of practitioner care but would also contribute to better PCOS outcomes. There is also a need for medical training that emphasises these dimensions of care, especially given the steep rise in multifactorial conditions and lifestyle disorders in India, and for training that establishes consistent diagnostic and therapeutic procedures for PCOS across medical specialisations. In an age of multiple information streams with often contradictory advice, there is also a need for further research into how information is prioritised and put into practice. I have pointed to some such factors, but further research would help better understand how these factors interact. Nevertheless, the findings suggest that an enhanced clinical encounter would aid adherence to lifestyle advice and medication and lead to improved PCOS outcomes.

Elizabeth Fee and Nancy Krieger have written about biomedical frameworks centred on the individual that emphasise biological determinants while largely ignoring social determinants. Such models assume that interventions aimed at one or more proximate biological agents or mechanisms will be able to control disease. Furthermore:

The biomedical model is also premised on the ideology of individualism. Adopting the notion of the abstract individual from liberal political and economic theory, it considers individuals “free” to “choose” health behaviors…. There is little place for understanding how behaviors are related to social conditions and constraints or how communities shape individuals’ lives. (Fee & Krieger, 1993, p. 1481)
My biomedical and paramedical interlocutors’ training within such a framework meant that in spite of recognising the role of sociocultural factors in their patients’ PCOS, they could not go beyond individual-centred advice (although one clinician–researcher endocrinologist mentioned the need for public health interventions). Of note, however, was that this sort of individualism was also in evidence among non-biomedical health professionals (homeopaths and vaidyas). Thus, health practitioners helped naturalise PCOS as a condition that is within an individual’s locus of control, obscuring larger sociocultural factors in the production of health.

Medical anthropology has long been stressing the need to move beyond an individualistic ethos to recognise how household and social relations contribute to the production of health. This is especially true for PCOS in India, where the difficulty in making solitary dietary changes is compounded by a gastropolitics that emphasizes food as a culturally sanctioned source of pleasure and as a means of expressing care, prosperity, and auspiciousness (Appadurai, 1981; Wilson, 2010). In such an environment, health-related advice that targets the individual while neglecting the role of the family and other social relations is doomed to fail. Although health practitioners recognise the systemic factors implicated in the rise of PCOS, management advice nevertheless focuses on the individual as the unit of action—women with PCOS are asked to change their diets, increase their levels of physical activity, introduce more structure and regular routines into their lives, or practice forms of stress management such as yoga. This is in spite of the fact that practitioners are aware that women with PCOS are generally not able to manage the condition effectively. Furthermore, given the link between PCOS and familial diabetes, household-level changes in lifestyles, particularly diet patterns, are crucial not just to the health of individual women with PCOS, but also of the entire family.
In this article, I have presented some of the main barriers to effective management experienced by urban middle-class Indian women with PCOS and suggested potential bases for intervention and further research. In doing so, I have adopted an ecosocial approach, highlighting not just sociocultural determinants of health such as a hyper-competitive educational system, increased prosperity, a lack of consensus among medical practitioners, pharmacophobia, and authoritative patient–practitioner relationships, but also some of the biological pathways to their embodiment. At the most immediate level, changing the patient–practitioner relationship from one where the practitioner distances him or herself from patients as the rational expert conveying authoritative advice to one where the knowledge of the patient is collaboratively integrated with that of the practitioner would greatly improve women’s experiences of care, lived experiences of PCOS, and PCOS outcomes. At the population level, there is a need for public health efforts aimed at PCOS prevention and management. Interventions around the time of puberty to increase physical activity could help prevent or mitigate the effects of PCOS. Parents would need to be convinced through awareness initiatives to let their children spend more time playing during these pre-pubertal and post-pubertal years by stressing the link between physical activity and not just health but also mental alertness and academic performance. If such interventions were introduced at the school level, they would need to go beyond the highly limited time set aside for physical activity and to account for the paucity of space in most schools. Simultaneously, emphasising PCOS as part of a related set of metabolic disorders would allow for interventions targeting insulin resistance through changing household—rather than individual—health practices, whether of diet, meal times, physical activity, or sleep. Such interventions would improve not just PCOS outcomes, but also outcomes for diabetes and cardiovascular disease, which have already reached epidemic proportions in India.
Susceptibility need not necessarily be a result of genetic predisposition but could include factors such as epigenetic conditions, intrauterine environments, and birth weights.
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