

ABHIYAAN PCOS, A Consortium for Multidisciplinary Strategy for Management

Gulrez Tyebkhan¹, Beena Joshi², Rama Vaidya³

Summary

Polycystic Ovary Syndrome (PCOS), a common reproductive-endocrine-metabolic disorder of women with its galloping prevalence is reaching epidemic proportions today in India and abroad. Women suffering from PCOS have a wide spectrum of clinical manifestations like irregular menstrual cycles, infertility, hirsutism, acne and vulnerability for obesity. Besides these women are at a risk for concurrently manifesting obesity and prediabetes or subsequent development of type 2 diabetes mellitus and consequent cardiovascular diseases. Some of the manifestations have caused stigmatization and social isolation of women with PCOS contributing to its adverse psycho-social impact. This multiplicity of diverse manifestations makes it difficult for the patients to choose a specialist. As a consequence, there is often a fragmented attention to PCOS from diverse specialties like dermatology, gynecology, diabetology and psychiatrist. Additionally, the less known and poorly understood etiology of PCOS have also posed a challenge for medical science for committed research, education and organized services. This is more so due to the compartmentalization and divergence into super specialization in modern medical and biomedical sciences. Recognizing PCOS as a condition of great public health issue in India, a group of committed clinical and basic scientists from four major institutes of Mumbai formed, ABHIYAAN PCOS, a consortium for a co-operative endeavor in addressing the multiple aspects that concern women with PCOS. In the present article, we have covered the ground reality of the PCOS in India, the need to develop India-specific guidelines in-view of the pluralistic healthcare and the current efforts in the domain of PCOS by both private and public health-sectors.

Non-Communicable Diseases (NCDs) today are a major cause of a global increase in morbidity and mortality; more so in the low and middle-income countries like India.^[1] Between the years 1990 and 2016, the disease burden in India due to NCDs increased from 48% to 75%.^[2] In 2013, India became the first country to be a part of the global monitoring framework for major NCDs,^[3] which did not include one such NCD viz. Polycystic ovary syndrome (PCOS).

PCOS is a common reproductive endocrine disorder affecting women from womb to tomb; predominantly manifesting and troublesome during adolescence and reproductive age with metabolic consequences even prior to menopause. This condition which was a “hidden epidemic” just a few decades ago has emerged as a major public health challenge to the world. However, for India, in view of the paucity of data on national incidence and prevalence, a quantitative assessment of

¹Hon Consultant Dermatologist, Medical Research Centre- Kasturba Health Society, Mumbai, India. Hon Dermatologist, Saifee Hospital, Mumbai, India

²Scientist F, Department of Operational Research, ICMR-National Institute for Research in Reproductive Health, Mumbai, India

³Director, Division of Endocrine and Metabolic Disorders, Medical Research Centre- Kasturba Health Society, Mumbai, India

Corresponding Author: Dr. Rama Vaidya, Director, Division of Endocrine and Metabolic Disorders, Medical Research Centre- Kasturba Health Society, Mumbai, India. Email: vaidya.rama@gmail.com

the degree of the challenge becomes difficult. It is difficult to draw a clear conclusion from the Indian studies on the prevalence of PCOS due to geographic limitations, smaller sample sizes and different diagnostic criteria used. However, from the limited data available, it can be said that the prevalence of PCOS in India ranges from 3.7 to 22.5 per cent.^[4,5]

This term “Polycystic Ovarian Syndrome” is truly a misnomer since multiple ovarian follicles are only a small/no part of the full jigsaw that is PCOS. The syndrome is enigmatic with unclear etiology and it manifests as a spectrum of symptoms rather than any specific one. The adolescents usually are bothered by the signs of clinical hyperandrogenism viz. hirsutism, acne and alopecia which make them present to a dermatologist or a cosmetologist. The irregular menses, anovulation, and infertility direct them to seek help from gynaecologists. As a consequence, dermatologists/cosmetologists and/ gynaecologists are often the first points of physician contact for patients of PCOS. Subsequently, treatment-resistant symptoms and metabolic complications may induce patients to consult other specialists like diabetologists, endocrinologists, bariatricians. This clinical reality on the ground compels us to evolve a multidisciplinary and multispecialty strategy for PCOS. The average time that elapses from the onset of symptoms of PCOS to diagnosis is more than two years. Early detection and identification are key to improve health-related quality of life in such patients. In addition to early detection; a collaborative effort for comprehensive and effective management of all aspects of its wide spectrum of manifestations is called for. Even emotional problems in PCOS often present a major challenge.

In one study, emotional problems in the form of feeling moody, irritable, and depressed were present in 63% of cases with PCOS and 7% of cases without PCOS.^[6] The psychosocial, socio-cultural and psychosexual aspects are not explored enough. Amongst the profusion of physical symptoms and signs, emotional and psychosocial problems often get scant attention in the current unidisciplinary mode of management of PCOS.

At a point, the diagnostic criteria were way too many with confusion about which one to follow. The lack of awareness at all levels of the hierarchy of the health system, including the general practitioners, physicians and even super-specialists among specific specialties as well as the community at large, only added to the challenge. Rising to these challenges, the pioneers and visionaries across the world as in India stirred in-

to action to draw attention to this issue. In 2008, the Jean Hailes Foundation for Women’s Health facilitated a national meeting on PCOS with 25 leaders attending from the research, clinical and community sector. The outcome of this meeting was the formulation of the PCOS Australian Alliance and the mapping of an ambitious plan to improve health outcomes in women with PCOS.^[7] Today these pioneering efforts from Australia have gone beyond its geographical boundaries and widened the scope of its utilization as recommendations from the international evidence-based guidelines for the assessment and management of PCOS.^[8]

Historical Steps and Strategy for India

As early as in the 70s, the increasing prevalence of PCOS was noticed by various specialists. However, the concerted basic and clinical research was sporadic and infrequent. Hardly any epidemiological data existed. In 2012 Dr. Rama Vaidya (KHS-MRC), in her 42nd NIRRH-ICMR foundation day oration, emphasized the public health importance of PCOS and the need to evolve a national strategy for the management of PCOS. In addition, she presented a blueprint for the Indian National PCOS Programme (INPP). Dr. V M Katoch, the then DG ICMR, was present at the oration. The DG took the subsequent steps for INPP implementation. Later a major flagship program “PCOS in India a thrust area of research” was initiated by ICMR with Dr. M Ashraf Ganie as chief coordinator, including other institutes like NIRRH-ICMR.

Since 2015, individual or small group efforts have picked up momentum. Dr. Sonia Malik, the then President of the Indian Fertility Society, had taken a lead by publishing the first practice guidelines on the management of PCOS in India.^[9] In the same year, another group of Mumbai-based multi-disciplinary specialists, working on PCOS, brainstormed and shared their experiences.^[10] The proceeding of the debate was published in a comprehensive book titled, “Multidisciplinary Opinion on Challenges in Medical Management of PCOS- An Indian Perspective.”, edited by Dr. Rama Vaidya and Dr. Gulrez Tyebkhan. There it was further stressed that the magnitude of PCOS was of immense public health concern. Besides the need for community participation, the medical fraternity must be complemented by lifestyle therapists, social scientists, health activists and support groups. This would be of vital importance for management and long-lasting optimal response in PCOS patients. Dr. Sanjay Chauhan, (Scientist-G) from NIRRH-ICMR, in the foreword for the book, wrote, “Contributors to this book

had a wide range of expertise and ground-level experience either in laboratory, clinic, and community or health system-related issues pertaining to this disorder." Referring to the multidimensional holistic vision of PCOS by Dr. Rama Vaidya (KHS-MRC), he wrote about the forthcoming organization of a multidisciplinary clinic at ICMR-NIRRH under Dr. Anushree Patil (Scientist-E) and Dr. Beena Joshi (Scientist-F). This book could be requested by sending an email to Roda Dalal, Knowledge Cell-KHS-MRC. (mrckhs@gmail.com / rodadalal@hotmail.com)

Simultaneously, the 'The PCOS Society of India', a multidisciplinary association had emerged in 2016 under the leadership of Dr. Duru Shah. In fact, the above book on PCOS was launched at the International PCOS Society's conference held in Mumbai. Drs. Sudha Sharma and Neelam Aggarwal, office bearers of the Indian Menopause Society, have favorably reviewed this book in the *Journal of Midlife Health*, the society's journal.^[11]

Sporadic, individual efforts would not suffice to deal with the magnitude of this multifaceted problem and the humongous challenges it posed. The seed of 'ABHIYAAN PCOS' -a consortium was sown, at a meeting held on 4th of August 2016 at NIRRH-ICMR with Dr. Smita Mahale (Former Director) in chair. Dr. Ashok Vaidya (Former Research Director KHS-MRC) presented the Vision and Mission of such a consortium which he aptly christened as ABHIYAAN PCOS (Figure 1) that transcends the territorial limits and has attempted to push horizons beyond institutional boundaries. The major partners are KHS-MRC, NIRRH-ICMR and the PCOS Society of India. However, not willing to ignore the tremendous psychosocial impact of PCOS, TISS was also invited to join through the good offices of Dr. Sanjay Chauhan. Dr. Shalini Bharat, the Dean of TISS, nominated Dr. Sivakami as their representative. Subsequently, the respective organizations signed the MOU (Figure 1)

The ABHIYAAN was set up with the vision to initiate and encourage an integrative and inclusive endeavor to enable women with PCOS to attain a better quality of life; its mission being research, education and clinical services.

The key objectives were as follows:

1. To ascertain community awareness of PCOS.
2. To determine socioeconomic burden.
3. To generate modules of training in PCOS at multiple levels.



Figure 1: ABHIYAAN PCOS: A Consortium for healthy womanhood

Seated from R to L Dr. Ashok Vaidya, Dr. Smita Mahale, Dr. Duru Shah, Dr. Sivakami. Standing R to L Dr. Anushree Patil, Dr. Beena Joshi, Ms. Roda Dalal, Dr. Gulrez Tyebkhan, Dr. Sanjay Chauhan, Dr. Rama Vaidya, Dr. Srabani Mukherjee

4. To conduct multidisciplinary research in PCOS, with an eye to prevention and management.
5. To develop multispecialty service delivery modules.
6. To develop advocacy, guidelines and policy suggestions for PCOS
7. Any other aim that fulfills the aforesaid objectives

Activities and Accomplishments

The study for the awareness of the health givers and gate keepers was taken up as one of the first research activities by the ABHIYAAN group. This KAP survey was addressed to understand the knowledge about PCOS diagnosis and management by Dermatologists, Gynecologists, Endocrinologists and Family Physicians from Ayurveda and Homeopathy in addition to the practitioners of modern medicine. The preliminary results were presented and highly appreciated at the PCOS Society of India's conference, Gurugram which fetched the first prize in the award paper category.^[12] The findings of this very important study are being published in this very same issue.^[12] The findings from the KAP study of healthcare givers had shown that there was a lack of awareness at the family physician level. This triggered a CME for family physicians which was successfully conducted by the ABHIYAAN group under the leadership of Dr. Beena Joshi and Dr. Anushree Patil. They also conducted a digital awareness program for municipal school students, with interesting data on digital literacy (under publication).

Recently a brainstorming session was held by KHS-MRC and NIRRH-ICMR. The psychosocial impact of PCOS was discussed with the other experts from

the Department of Psychology of SNTD University viz. Dr. Anuradha Sovani (Prof. & Head Dept. of Psychology-SNTD Women's University), Dr. Anita Sanu (Associate Prof. Dept. of Psychology-SNTD Women's University) and their students. In the opening remarks, Dr. Rama Vaidya recalled that often women with PCOS are 'looked at' rather than 'looked after' for their cosmetic discomfort. She said that this invades the individual's sensitivity promoting stress and social isolation. Prof. M. Sivakami, a well-known sociologist, on behalf of the ABHIYAAN group has studied the lived experiences of PCOS women and the psychosocial burden of the condition, made a plea for its focus in the management of women with PCOS. Prof. Sivakami highlighted the four broad areas of social stigma and reservations that PCOS women face, i.e., body image, loss of femininity, infertility and sexuality; she has effectively captured the implications these symptoms have on marital intimacy and the women's position in the marital and parental homes. These findings were summarized at the above brainstorming session where a mention was also made about similar research done by the NIRRH-ICMR group.^[13]

Dr. Shobha Udipi (Research Director KHS-MRC), Dr. Anuradha Sovani and Dr. Anita Sanu while recognizing the deep-rooted social taboo and related stigma, have strongly felt the need for 'health mentorship' and a 'PCOS support group'. This call was strongly appreciated by the research students of the Department of Psychology, SNTD University.

Dr. Gulrez Tyebkhan, Dermatologist of the ABHIYAAN group, has participated as an expert amongst 12 in the O-scar Acne group in 2017. She has been sharing with the nation-wide dermatologists her comprehensive understanding and experience about PCOS beyond the realm of the cosmetic manifestations and treatment. O-scar Acne group (constituted by the Indian Association of Dermatologists, Venerologist and Leprologists (IADVL) had organized 15 CMEs on 'Evolving Issues and New Treatment Approaches in Acne Management' across the country, with the support from an educational grant from the industry.

Steps to Swasthya: The team at KHS-MRC has developed a multidisciplinary and multisystem programme for lifestyle management. The programme is culturally feasible and individually sustainable to women with PCOS who are at a primary risk of obesity and secondary risk of cardio-metabolic disorders. This programme was inspired by our team's earlier experiences of "MAITREYI" for mature women and MMNT

(Monitored Medical Nutrition Therapy) or 'One-Stop Weight Management Programme'.^[14] It is envisioned that holistic aspects of health interventions are balanced with their biomedical reductionist understanding and then translated into a personalized advice. The module, inclusive of Yoga and meditation, has been adapted at both the institutes viz. NIRRH-ICMR and KHS-MRC.^[15]

Recent Events: Product Development Centers (PDC) were established by ICMR at several institutions; KHS-MRC and NIRRH-ICMR are two such PDCs. Amongst their assignments, the development for national guidelines for PCOS management was one identified joint responsibility. Both these institutions have held brainstorming sessions and expert group meetings as foundations for such guidelines. In addition, KHS-MRC also held intersystem dialogue meetings on PCOS, for mutual understanding of differences and commonalities. These dialogues have been very productive.

As a natural corollary, KHS-MRC also took initiative in the creation of a PCOS support group which has held meetings discussing clinical and psychosocial aspects of PCOS. The psychosocial aspects of PCOS also need to be due consideration during the development of national guidelines. (*vide supra*).

Conclusions:

To tackle major health problems of India e.g., PCOS, an inter-institutional collaboration between the government and non-government sectors is an imperative precondition. Intra-national collaboration can be aided by judicious international endeavors in the field. However, any direct extrapolation of one nation's guidelines to another nation without a due diligence of its ground reality is not commendable. ABHIYAAN PCOS is an initiative to evaluate such ground realities for PCOS in India with an eye to the cultural/social impact, economic cost and pluralistic health care of the nation. The early experience of ABHIYAAN PCOS shows that we are on a learning curve. But the declaration of One Nation-One Healthcare by the Niti Aayog offers both a challenge and an opportunity for advanced multidisciplinary, multispecialty and multi-system management of PCOS.

Acknowledgements:

We thank Prof. Ashok Vaidya (Prof. Emeritus- KHS-MRC) for his guidance in the preparation of this manuscript and Ms. Roda Dalal (Knowledge Cell- KHS-MRC) for editorial help.

References

- World Health Organization Regional Office for the Western. Global status report on noncommunicable diseases 2010 [Internet]. Geneva: World Health Organization; 2011 p. 164. Report No.: ISBN 978 92 4 068645 8. Available from: https://www.who.int/nmh/publications/ncd_report_full_en.pdf
- Indian Council of Medical Research, Public Health Foundation of India, Institute for Health Metrics And Evaluation. India: Health of the Nation's States (India State-Level Disease Burden Initiative) [Internet]. [cited 2020 May 9]. Report No.: ISBN 978-0-9976462-1-4. Available from: <https://phfi.org/the-work/research/the-india-state-level-disease-burden-initiative/>
- Sivanantham P, Sahoo J, Lakshminarayanan S, Bobby Z, Kar SS (2021) Profile of risk factors for Non-Communicable Diseases (NCDs) in a highly urbanized district of India: Findings from Puducherry district-wide STEPS Survey, 2019–20. *PLoS ONE* 16(1): e0245254. <https://doi.org/10.1371/journal.pone.0245254>
- Ganie MA, Vasudevan V, Wani IA, Baba MS, Arif T, Rashid A. Epidemiology, pathogenesis, genetics & management of polycystic ovary syndrome in India. *Indian J Med Res.* 2019;150(4):333-344.
- Joshi B, Mukherjee S, Patil A, Purandare A, Chauhan S, Vaidya R. A cross-sectional study of polycystic ovarian syndrome among adolescent and young girls in Mumbai, India. *Indian J Endocrinol Metab.* 2014;18(3):317-324.
- Chatterjee M, Bandyopadhyay SA. Assessment of the prevalence of polycystic ovary syndrome among the college students: A case-control study from Kolkata. *J Mahatma Gandhi Inst Med Sci.* 2020; 25:28-32.
- Teede HJ, Misso ML, Deeks AA, Moran LJ, Bronwyn G A Stuckey BGA et al. Assessment and management of polycystic ovary syndrome: summary of an evidence-based guideline. *Med J Aust* 2011; 195 (6): S65.
- Teede HJ, Misso ML, Costello MF, Dokras A, Laven J et al. International PCOS Network, Recommendations from the international evidence-based guideline for the assessment and management of polycystic ovary syndrome. *Human Reproduction.* 2018;33(9):1602–1618.
- Malik S, Jain K, Talwar P, Prasad S, Dhorepatil B, Devi G et al. Management of Polycystic Ovary Syndrome in India. *Fertility Science and Research* 2014; Vol 1(Issue 1): 23-43.
- Multidisciplinary Opinion on Challenges in Medical Management of PCOS. An Indian Perspective. By Eminent physicians, Clinical and Basic Scientists. March 2016 Edition.
- Sharma S, Aggarwal N. Multidisciplinary opinion on challenges in the medical management of polycystic ovarian syndrome. *J Mid-life Health* 2017; 8:48-9.
- Joshi B, Hasan G, Tyebkhan G, Udipi S, Patil A et al. Knowledge and Management practices about Polycystic Ovarian Syndrome among Health Care Providers in Mumbai, India: a cross-sectional study. *The Indian Practitioner.* 2021; 74:15-22.
- Vaidya R, Pandey S, Vaidya A. Polycystic ovarian syndrome: Is it a Chronic Inflammatory Disease? ECAB Clinical Update: Obstetrics and Gynecology Elsevier Clinical Advisory panel 2008; 1:42-73.
- Vaidya RA. Maitreyi: An Initiative for Comprehensive Health-Care Programme for Menopausal Women. *The Indian Practitioner.* 2019;72(9):42-44.
- Patil A D, Vaidya A, Pathak S D, Chauhan L, Surve S et al. Yoga Therapy: The Fourth Dimension in the Multidisciplinary Management of Women with Polycystic Ovary Syndrome, A Narrative Review. *The Indian Practitioner.* 2018; 71:45-51.

**Subscribe today to
The Indian Practitioner
to keep in touch with all the latest
happenings in the medical world.**