BRIEF COMMUNICATION

Poly Cystic Ovarian Syndrome (PCOS): Patient's Perspective and the Need for a Change of Name

Jayashree Nayar Damodaran

Department of Obstetrics & Gynecology, Amrita Institute of Medical Sciences, Kochi, Kerala, India

Published online on 29th June 2016

ABSTRACT

What name should we give to PCOS and why?

This has been an onomastic challenge facing the medical community for a very long time. Though first scientifically defined by Stein and Leventhal[1] in 1935 there has been several attempts to change the name bringing in accurate description of aetiopathology and clinical effects of the syndrome. From the patient's perspective also PCOS is a misnomer. Here, an attempt is made to answer the question why not change the PCOS nomenclature to the Stein Leventhal Syndrome and the reasons for the same.

Key Words: Misnomer, PCOS, Patient's perspective, Public health interest, Onomastic challenge

Cite this article as: Jayashree ND. Poly Cystic Ovarian Syndrome (PCOS): Patient's Perspective and the Need for a Change of Name. Journal of Health Systems. 2016 Jun 29;2(1):24–7.

Overview

Though first scientifically defined by Stein and Leventhal[1] in 1935, the Polycystic ovarian syndrome as it is called today is a heterogeneous disorder encompassing metabolic, cardio vascular, dermatological and psychological conditions. The classical cluster of signs and symptoms include hyperandrogenism, ovulatory dysfunction and evidence of polycystic ovaries. Prevalence is around 4 to 18 percent[2] making it the most common endocrine syndrome affecting women of reproductive age.

The Metabolic Syndrome[3]occurs later on in about 50 percent of women. This common disorder having such a wide spectrum of presentation, however, is till today bereft of a suitable name. PCOS remains a misnomer as the ovaries do not contain epithelial cysts as the name suggests.

Tracing the history of this disease from the days of Ambroise Pare[4] to Stein and Leventhal and now to the 21st century, PCOS continues to be an enigma both for the sufferer as well as the treating physician. While heads are being pounded and hands thrown up in despair trying to find a suitable name for PCOS, the simple question remains-- why not SteIn Leventhal Syndrome once again?

PCOS is an ancient disorder , which has persisted down the course of human evolution. Susceptibility to this disorder seems to be genetic as proved by the global prevalence of PCOS. As defined by the NIH 1990 criteria,[5] there is a 6 to 9% prevalence of PCOS world wide. A cross sectional study in 2014[6] showed that PCOS is an emerging disorder during adolescence reporting 22.5% by the Rotterdam criteria[7] and 10.7% by the Androgen Excess Society criteria. Mild PCOS (USG findings and oligomenorrhoea) was the most common phenotype being up to 52.6%. The extent of the problem being so great, a lot of research has been done for more than 80 years on the genetic, hormonal, clinical and metabolic effects of PCOS.

Radiological findings (PCO appearance on ultrasound) have been in the forefront ever since the naming -fathers changed Stein- Leventhal Syndrome into PCOS in the 1990s.

Aetiopathogenesis

A quick review of the current understanding of the patho-physiology of PCOS and the controversies surrounding its diagnosis and nomenclature will show us why the name is a misnomer in every sense.

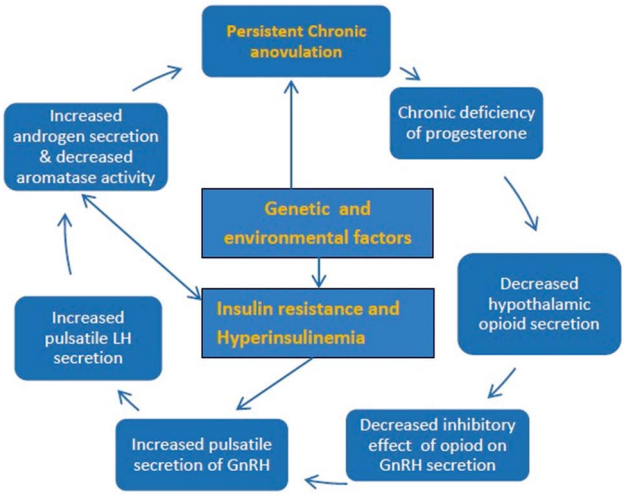
From being a syndrome, associated with the presence of ovarian cysts and anovulation as described by the American gynecologists Irving F. Stein, Sr and Michael L. Leventhal, the scope of PCOS has widened to an endocrine metabolic disorder. Implications on the several

Corresponding author:

Dr Jayashree Nayar Damodaran, Professor, Department of Obstetrics & Gynecology, Amrita Institute of Medical Sciences, Kochi, Kerala, India.
E-mail: jshr2008@mail.com

Access this Article Online

Scan this QR Code



Source: Fritz M. A. Speroff L. Clinical Gynecologic Endocrinology and Infertility 8th edition, Wolters Kluwer Health Lippincot Williams and Wilkins,. 2010: 83-103

Figure 1. Vicious Cycle of Persistent Anovulation

consequences to female health include infertility, hyperandrogenism, insulin resistance (IR) and hyper insulinaemia.

Cosmetic problems like hirsuitism, co morbidities like obesity, dyslipidemia, hypertension, type 2 Diabetes mellitus (DM2) etc. are higher in PCOS women. Of late, endothelial dysfunction, chronic low grade inflammatory state have been added on to the pathophysiology throwing light on the association of PCOS with greater risk of cardiovascular disease and mortality.[8]

Chronic or persistent anovulation in the reproductive age over a period of time leads to a state of PCOS, Stress, anxiety, thyroid or pituitary disorder or crash diet can be causes of anovulation. Here the essential three components of normal ovulation are at fault. If not corrected, a vicious cycle sets in **(Figure 1).** Intact central Hypothalamo-Pituitary- ovarian axis, synchronised feed back signals and normal local response within the ovary are essential for normal ovulation.

Abnormal feedback signals in the form of altered Oestrodiol, autocrine/ paracrine activity causing altered local ovarian conditions all lead to prevention of dominant follicle selection, IR, [insulin resistance], Hyperinsulinaemia and hyperandrogenemia are essential components of the vicious cycle. Obesity also plays a vital role in initiating the process.

Diagnosis

So the currently accepted diagnostic criteria are:

1. Hyper androgenism
2. Ovulatory dysfunction

Of late, a third diagnostic criterion has been added on by AES (Androgen Excess Society)[9] (2006) i.e. exclusion of other androgen excess or related disorders.

Apart from core diagnostic criteria of hyperandrogenism and ovulatory dysfunction, a host of clinical, pathological and biochemical abnormalities co- exist with the syndrome, and add to its severity. Associated conditions include obesity, insulin resistance, impaired glucose tolerance (35%), Type 2 Diabetes mellitus [7-10%], Arterial Hypertension, Metabolic syndrome, Mood disorders like depression and anxiety.[10]

The apparent similarities shared with other disorders makes PCOS a disease of exclusion as well. Several other pathological conditions have to be differentiated including 21 – hydroxylase -deficient non- classic adrenal hyperplasia, androgen secreting tumors, androgen/ anabolic drug usage, Cushing's syndrome, HAIR-AN syndrome (Hyperandrogenaemic-Insulin Resistance-Acanthosis Nigricans Syndrome), thyroid dysfunction, hyperprolactinaemia. After so much reflection and discussion on the genetic, hormonal, clinical and metabolic effects of PCOS let us go into the controversies surrounding its nomenclature.

Why is PCOS not a good name for this disorder?

For a quarter of a century (1990 onwards) arguments, panel discussion and creation of task forces have all sought to address this problem. The radiological findings (typical of PCO appearance at ultrasonography) have been in the forefront ever since the naming fathers changed Stein- Leventhal Syndrome into PCOS. The barrage of onomastic acrobatics that followed never seems to stop.

The names suggested were based on the clinical manifestations and/or the aetiopathogenesis of the disorder. The tangible finding of polycystic ovaries on ultrasonography continued to dominate the picture. Thus the name PCOS stuck in spite of being a misnomer. Ovaries do not contain cysts, they are antral follicles less than 8 mm. Obviously the name PCOS neither reflects the hyperandrogenism, which is essential for diagnosis nor the metabolic derangements associated.

What were the alternatives suggested?

With so many controversies raging around its diagnosis and nomenclature PCOS has been declared unfit as a name. From Stein –Leventhal syndrome the original name changed to PCOS in the 1990s, Sclerocystic disease,[11] EASY- (Excess Androgen Secretion of the ovary) HAPPY – Hyper Androgen Production-Primarily of the ovarY, -DAISY--Disorder of excess Androgen Inappropriately Secreted from the ovarY, VENUS- OVarian ENdogenous Uncontrolled Secretions of androgen, LYNX -Lesions of ovarY with aNdrogen eXcess, PCO-HA-IR Syndrome and so on.[12]

Misleadingly focusing on the ovarian cysts, which are actually antral follicles, PCOS continues creating confusion in the minds of patients and treating physicians and is certainly a hurdle to conduct research.

Arguments against PCOS as a name having been studied sufficiently from almost all angles let us see this problem of wrong nomenclature from yet another one. From the patient's perspective is this not important too? In the end everyone seems to have forgotten the poor adolescent girl sitting on the other side of the table in the consulting room!

Why not revert to the older name SteIn-Leventhal syndrome?

The very name PCOS creates misconceptions and confusion in the mind of the patient as well as the primary care physician. The picture of multiple cysts or tumors in the ovary is all - dominating for the terrified girl, as well as her family members. Thus starts off a never- ending journey to clinics, consulting rooms and hospitals.

PCOS is certainly a disease to be treated and sorted out with patience and concern. Its long term consequences like gestational Diabetes, type 2 Diabetes, obstructive sleep apnea,. Cardio vascular disease, health related poor quality of life. endometrial cancer, obesity -related risks are well known [RCOG2014][13] Mood disorders have also been described as part of the pattern of disorders associated- Jedel et al, Hollinrake et al.[14]

Teede et al- have even studied the nomenclature of PCOS from the patient's perspective and that of the treating physician in a recent survey conducted in an Australian population of 162 individuals; 57 consumers and 105 physicians.[15] Nearly half [47%] agreed that PCOS is a confusing name-- 51% agreed on changing it. Most (74%) physicians found the name confusing and felt that it should be changed to reflect the broader clinical syndrome (81%).

As practicing gynecologists, many of us have had to face the following situation.

Somewhere, for some reason, a young person undergoes a pelvic scan for abdominal pain or a menstrual disturbance. 'PCO' appearance gets mentioned in the report and gets pride of place! The primary care physician often describes the ovaries as having multiple cysts or growths. What follows is quite distressing for the girl, her family members and for the treating physician in the tertiary care hospital.

The time and the patience needed for sorting out the misconceptions in the mind of the public created by the name PCOS is quite obvious. It is a substantial workload for a busy but truly caring gynecologist. The magnitude of the havoc created is clear, considering also that only 10% are truly PCOS while 25% may just have PCO appearance on ultrasonography[16] The referral to a co- consultant like an endocrinologist or dermatologist may worsen the picture. While awaiting the results of a series of hormone tests, which usually involves a fortnight's time, the poor patient is in agony. Do we need to add deep-seated psychological damage to the patient's woes by merely mentioning the name PCOS? Where- in lies the difficulty of just renaming PCOS? Why not revert to its original name ' Stein-Leventhal syndrome?'

Surely the time is overdue for PCOS to be called Stein Leventhal Syndrome at least now? For scientific correctness and research purpose we could have something like Metabolic Reproductive Syndrome or HA-PODS- (Hyper androgenism Persistent Ovulatory Dysfunction syndrome).[17]

But for the layman and for common usage by the primary care physician the best name would still be Stein –Leventhal syndrome. While acknowledging the scientists who first correctly described the entity in modern medicine, this renaming effectively serves to wipe out all the negative connotations of the term PCOS. Both the patient and the physician breathe easier.

Being a disease of exclusion with its widened scope and varying phenotypic presentation a clear-cut diagnosis is often not clear. Especially in the adolescent, it is preferable to follow the symptoms and repeat the evaluation every 6-to 12 months.

The difficulty of remembering proper names may be quoted as an objection. What about the various acronyms that have cropped up over the past 25 years? Surely, if Koch's disease is synonymous with TB (tuberculosis) and Hanson's with leprosy, we, the medical community can very well remember Stein and Leventhal who first scientifically described the disorder. The social stigma with TB and leprosy continues to haunt society. So does PCOS today. Often self - ostracized in society, the poor patient withdraws into a shell and lives out her life in misery. The name Stein - Leventhal syndrome provides an umbrella for the treating physician to shelter under especially when a clear-cut diagnosis is pending. Yet another reason why PCOS should be renamed S-L syndrome.

Conclusion

PCOS is a life - long condition with variable expression across different stages of life. Early recognition is needed and successful management relies on patient involvement, strategies to reduce confusion for health professionals and facilitate diagnosis and treatment. PCO as a term should be restricted only to the morphological feature of the ovaries by ultrasound and is not necessary for diagnosis.

In the interests of public health let us not delay anymore. Let PCOS go back and the 'Stein - Leventhal Syndrome' come in!

My readers, the subject is open for debate. I welcome one and all for this never-ending dialogue on 'what name should we give PCOS and why?'

Acknowledgements: I gratefully remember Dr Behram Anklessaria, a very sincere and active senior member of the profession, for inspiring me to write on this topic. We

met at a conference in Kerala in 2011.Unfortunately he passed away suddenly after a brief illness. I dedicate this article to him.

Conflict of Interest: None declared

References

1. Stein IF, Leventhal ML. Amenorrhea associated with bilateral polycystic ovaries. American Journal of Obstetrics & Gynecology. 1935 Jan 1;29(2):181–91
2. Azziz R, Woods KS, Reyna R, Key TJ, Knochenhauer ES, Yildiz BO. The prevalence and features of the polycystic ovary syndrome in an unselected population. J Clin Endocrinol Metab. 2004 Jun;89(6):2745–9
3. Metabolic syndrome – Wikipedia
4. Pare A. The causes of the supression of the courses or menstrual fluxe Chap. L.1,Lib.24 in: Johnson T , editor. The Workes of that famous Chirurgeon Ambrole Parey :- Translated out of Latine and compared with the French. The Cotes and R.Young; London; 1634. p.947
5. National Institutes of Health- Evidence based methodology work shop on PCOS. Dec 2012, Final statement [pdf] accessed Jan 31, 2013
6. 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):317–24
7. Rotterdam ESHRE/ASRM - Sponsored PCOS consensus on diagnostic criteria and long term health risks related to PCOS. Human Reproduction 2004, 41-47
8. Wild RA. Long-term health consequences of PCOS. Hum Reprod Update. 2002 Jun;8(3):231–41
9. Azziz R, Carmina E, Dewailly D, Diamanti-Kandarakis E, Escobar-Morreale HF, Futterweit W, et al. The Androgen Excess and PCOS Society criteria for the polycystic ovary syndrome: the complete task force report. Fertil Steril. 2009 Feb;91(2):456–88
10. Apridonidze T, Essah PA, Iuorno MJ, Nestler JE. Prevalence and characteristics of the metabolic syndrome in women with polycystic ovary syndrome. J Clin Endocrinol Metab. 2005 Apr;90(4):1929–35
11. Krymskaia ML. [Sclerocystic ovary syndrome: diagnosis and differential diagnosis]. Akush Ginekol (Mosk). 1980 Sep;(9):53–6
12. Kalra S, Baruah MP, Saikia M. Trends in endocrine onomastics: The case of polycystic ovarian syndrome. Indian J Endocrinol Metab. 2013 Jul;17(4):545–7
13. Ledger W L, Sathyapalan T - Long term consequences of PCOS ,Green Top guide line No 33 RCOG Nov. 2014
14. Hollinrake E, Abreu A, Maifeld M, Van Voorhis BJ, Dokras A. Increased risk of depressive disorders in women with polycystic ovary syndrome. Fertil Steril. 2007 Jun;87(6):1369–76
15. Teede H, Gibson-Helm M, Norman RJ, Boyle J. Polycystic ovary syndrome: perceptions and attitudes of women and primary health care physicians on features of PCOS and renaming the syndrome. J Clin Endocrinol Metab. 2014 Jan;99(1):E107–11
16. Lujan ME, Chizen DR, Pierson RA. Diagnostic Criteria for Polycystic Ovary Syndrome: Pitfalls and Controversies. J Obstet Gynaecol Can. 2008 Aug;30(8):671–9
17. Khadilkar SS. Polycystic Ovarian Syndrome: Is It Time to Rename PCOS to HA-PODS? J Obstet Gynaecol India. 2016 Apr;66(2):81–7.