Silent Epidemic or Silenced Epidemic: Positioning Polycystic Ovary Syndrome in Sustainable Development Goals

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Abstract

Polycystic Ovary Syndrome (PCOS) is a neglected, non-communicable endocrine disorder affecting women worldwide. It is a recognised multisystem disorder associated with Type 2 Diabetes, cardiovascular disease, endometrial cancer, increased risk of depression, anxiety, bipolar disorder, eating disorder and obsessive-compulsive disorder. While the mean prevalence of PCOS in India is 21.27 per cent of the female reproductive population, there is currently no reliable data on the diagnosis rates. The Sustainable Development Goal (SDG) 3 Good Health and Well-Being: Ensure healthy lives and promote well-being for all at all ages includes target 3.4 to reduce mortality from non-communicable diseases and promote mental health; target 3.8 to achieve universal health coverage; target 3.9 to reduce illness and death from hazardous chemicals and population and target 3.D to improve early warning systems for global health risk. Progress on these targets requires a pertinent focus on diagnosing, preventing, and managing PCOS. Additionally, reducing non-communicable diseases like PCOS is an essential target in determining the success of at least nine SDGs. This paper positions PCOS in SDGs using conceptual mapping to identify and establish the interlinkage between PCOS prevention and management and SDGs. These findings highlight the need for gender-sensitive policies and emphasise the importance of tailored screening and prevention programs to guide the development of Universal Health Coverage in an androcentric healthcare system.

Keywords: Polycystic Ovary Syndrome; Sustainable Development Goals; Non -Communicable Diseases; Mental Health.

Introduction

The 2030 Agenda for Sustainable Development, declared in September 2015, presented 17 Sustainable Development Goals (SDGs) and 169 associated targets, marking a pivotal point in global developmental strategies. Building upon the Millennium Development Goals (MDGs), this new vision was unanimously adopted by 193 member countries in January 2016. The focus pivoted towards key tenets—People, Planet, Prosperity, Peace, and Partnership. The SDGs are ambitious, as they attempt to transform the world; Perhaps the most overambitious goal is Goal 3: "Ensure Healthy lives and promote well-being for all at all ages" Under this overarching aim, Target 3.4 commits to "reduce by one-third premature mortality from non-communicable diseases (NCDs) through prevention and

treatment and promote mental well-being" by 2030 (United Nations, 2015). Notably, this target emerges in the SDGs as a corrective measure, addressing the oversight of Non-Communicable Diseases (NCDs) in the MDG era.

NCDs, often synonymous with chronic diseases, tend to have a disease progression of long duration and emerge from a confluence of genetic, physiological, environmental, and behavioural elements (World Health Organisation, 2018). Disturbingly, NCDs have a disproportionate impact on populations in low and middle-income nations like India, accounting for a staggering 85 percent of all premature deaths. The Indian Council for Medical Research underscores that deaths attributable to NCDs increased from 37.9 percent in 1990 to 61.8 percent in 2016. on par with the global increase in the burden of NCDs.

Polycystic Ovary Syndrome (PCOS), an endocrine disorder with an unknown aetiology, remains a relatively neglected non-communicable disease affecting women globally. With a mean prevalence rate of 21.27 percent among the female reproductive population, (Deswal et al., 2020) PCOS was dubbed a silent epidemic in India, killing women prematurely with the associated long-term comorbidities like Cardiovascular diseases, Diabetes and Endometrial, Ovarian and Breast Cancers. Additionally, recent studies highlight a concerning link between PCOS and heightened risks for mental health disorders, like depression, anxiety, bipolar disorder, eating disorders, and obsessive-compulsive disorder Barry (2019). Data from ICMR, PHFI, and IHME (2017) further emphasizes the gravity by revealing an uptick in Disability-Adjusted Life Years (DALYs) for women with cardiovascular diseases from 2.9 percent in 1990 to 6.6 percent in 2016. Concurrently, DALY rates for diabetes and breast cancer in women witnessed increments, from 0.7 percent to 2.2 percent and from 0.7 percent to 0.9 percent, respectively.

PCOS has rapidly emerged as a significant public health concern in India. Noting its growing prevalence, on 26 July 2019, the Minister of Family Health and Welfare, Shri Janardan Singh Sigriwal, addressed the issue in the Lok Sabha, responding to the unstarred question number 5502 about PCOS cases in the nation. This highlighted the growing apprehensions surrounding this intricate and heterogeneous condition. In 2013, India took a pioneering step by becoming the first nation to join the global monitoring framework dedicated to major Non-Communicable Diseases (NCDs). Regrettably, this framework overlooked the inclusion of PCOS, a crucial NCD (Sivanantham et al., 2021). While PCOS prevention and management (P&M) have been recognized at both the national and international levels, the global development community-with its expansive agenda from gender equality to climate change and health—has yet to adequately emphasize the role PCOS prevention and management plays in advancing the Sustainable Development Goals (SDGs).

This paper presents a comprehensive exploration of the existing and potential linkages between PCOS and the SDGs. It also identifies the priority targets related to PCOS for health sector to monitor. By underscoring the potential implications of PCOS P&M in realizing the SDGs, and highlighting how it can be monitored within these goals, this paper aims to accentuate the fundamental role of PCOS P&M in reducing poverty and inequalities, improving health and well-being, ensuring gender equality, and propelling economic growth.

Positioning Polycystic Ovary Syndrome in Sustainable Development Goals: A Framework

In addressing global health priorities, the importance of PCOS Prevention and Management aligns with the SDGs in these particular ways: (See Figure 1)

- 1. PCOS P&M directly supports specific SDGs, but its role often goes unnoticed or isn't thoroughly studied;
- 2. Progress towards certain SDGs can shape PCOS P&M, highlighting its significance in gender-centric health initiatives.
- 3. PCOS P&M and certain SDGs share a bidirectional relationship, influencing each other. This underscores the importance of prioritizing it in health dialogues.

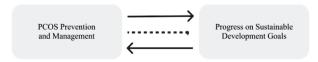


Figure 1 Relationship between PCOS P&M and Sustainable Development Goals (SDGs)

Linkages between the SDGs and PCOS can be made evident by questioning how the overall achievement of a given SDG may be altered if PCOS is not addressed. For example, in examining SDG3, which focuses on health, is it possible to achieve health and wellbeing for all if there is no access to preventative healthcare for PCOS? If not, the global community must consider the policy levers available to address this gap. Or, in examining SDG5, is it possible to end all forms of discrimination against women and girls everywhere if the androcentric healthcare system doesn't account for better policies to diagnose, treat and prevent PCOS? If not, governments must consider resource investments to address this need.

The linkages between the SDGs and PCOS becomes evident when assessing the potential implications of neglecting PCOS P&M on the successful realization of SDGs. For instance, the SDG3, which champions universal health and well-being, one must question the feasibility of achieving this objective without ensuring comprehensive preventive healthcare for PCOS. Similarly, Considering SDG5's commitment to ending discrimination against women and girls, it's critical to evaluate the existing health system, which many view as androcentric-centric. If this system falls short in addressing PCOS—from diagnosis to treatment and prevention—it signals a clear need for governments to shift resources and reshape policies, keeping women's health front and center.

Over the last decade, there has been significant growth in attention to PCOS and its related co-morbidities. However, despite this significant growth, PCOS remains underacknowledged, underfunded, dismissed and risks continued marginalization unless its relevance across development goals is explicitly highlighted. Moreover, there lacks a consistent and universally accepted method for monitoring PCOS, which hinders the assessment of PCOS related outcomes over time. The SDGs framework provides an opportunity to demonstrate how interconnected PCOS P&M is with other globally recognized priorities and it may also facilitate the development of indicators and measures that could be integrated into systems already created for tracking each linked goal. If these ties between PCOS and the SDGs aren't clearly emphasized and monitored, PCOS risks being overlooked or deemed 'irrelevant' to various sectors. Therefore, identifying these explicit linkages is critical to making sure PCOS is appropriately acknowledged and addressed.

The Potential Contribution of PCOS P&M Towards SDGs

This paper primarily examines the ways in which PCOS P&M interacts with and potentially benefits from other SDGs, with a specific focus on Target 3.4. Within this framework, several SDGs have emerged as notably relevant to PCOS P&M.

The Sustainable Development Goals (SDGs) demonstrate key connections with NCD target 3.4, particularly in relation to nine SDGs, as deduced through a network analysis approach developed by the UN Department of Economic and Social Affairs (Le Blanc., 2015). These crucial SDGs include: SDG 1 - Reduction of poverty (Jamison et al., 2013), SDG 2 - Eradication of hunger (Hu, 2002), SDG 3 - Ensuring health and wellbeing (Sikiru et al., 2023), SDG 4 - Promoting quality education (Cutler & Lleras-Muney, 2006), SDG 5 Achieving gender equality (Sen, Östlin, & George, 2007), SDG 8 - Encouraging decent work and economic growth (Bloom & Canning, 2000), SDG 10 - Reduced inequalities (Marmot, 2005), SDG 11 - Fostering sustainable cities and communities (Rydin et al., 2012), and SDG 12 -Advocating for sustainable production and consumption(Jozkowiak et al., 2022).

The theoretical linkages highlight how PCOS P&M relate to SDGs, specifically focusing on the connections established by the associated targets and indicators. These hypothesized linkages can be characterized as: (1) PCOS P&M directly contributes to the SDG, (2) PCOS P&M have an indirect relationship. or (3) SDG directly contributes to PCOS P&M.

A systematic presentation of these of these theoretical linkages is presented in the table 1: Relevance of PCOS to the Sustainable Development Goals and the type of linkages.

Table 1 Relevance of PCOS to the Sustainable Development Goals and the type of linkages.

Sustainable Development Goal.	Hypothesized linkage to PCOS	Type of link
SDG 1 - Reducing poverty	Out-of-pocket expenses related to PCOS diagnosis, treatment, and the management of its long-term comorbidities can push families into financial distress or poverty. Conversely, poverty may limit the accessibility and affordability of proper diagnosis, treatment, and management of PCOS.	1,3
SDG 2 - Zero hunger	PCOS can induce malnutrition through mechanisms like hidden hunger and iron-deficient anemia. At the same time, undernourishment and a lack of access to nutritious and safe food can increase the risk of PCOS.	1,3
SDG 3 - Health and well-being	PCOS plays a significant role in increasing the mortality rate due to cardiovascular diseases, cancers, diabetes, or chronic respiratory diseases. Furthermore, PCOS also increases the risk of mental health issues like depression, anxiety, eating disorders, and emotional distress. There is also a prevailing lack of accessibility and affordability concerning essential healthcare services for PCOS diagnosis and management.	1,3

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SDG 4 - Education	Comprehensive and quality education may bolster knowledge and awareness about PCOS, potentially leading	2
	to earlier diagnosis, better management, and broader societal understanding.	
SDG 5 - Gender equality	The absence of robust policies on PCOS at various levels can lead to gender-specific biases in medical care, emphasizing the need for gender-equitable health policies and legislation to ensure fair outcomes for women with PCOS.	3, 2
SDG 8 - Decent work and economic growth	The loss of Quality-Adjusted Life Years (QALY) due to chronic illnesses such as PCOS can negatively influence the work productivity and wages.	3
SDG 10 - Reduced inequalities	The absence of effective prevention and management for PCOS can exacerbate existing inequalities, especially among populations facing substantial barriers such as individuals with disabilities and transgender people. Furthermore, economic disparities can heighten the unmet health needs of those with PCOS.	1,3
SDG 11 - Sustainable cities and communities	Access to safe, affordable, accessible transport systems can improve the accessibility of health care.	3

SDG 12 - Sustainable	The absence of	3
production and	environmentally	
consumption	sound management of	
	chemicals in air, water,	
	and soil can increase	
	the exposure to	
	endocrine disruptors,	
	subsequently	
	heightening the risk of	
	PCOS.	

Some key linkages have been highlighted below to prevent the reiteration of the content in the table. PCOS can directly worsen poverty due to the out-of-pocket expenses associated with its diagnosis, treatment, and management of its long-term co-morbidities. At the same time, poverty can impede access to PCOS diagnosis, treatment, and management. Economic disparities might amplify the unaddressed health needs of those with PCOS, and without specific screening, prevention, and management initiatives for PCOS, economic inequalities could grow through various pathways.

Drawing on the Social Determinants of Health (SDOH) framework, the relationship between PCOS prevention and management (PCOS P&M) and the Sustainable Development Goals (SDGs) is illustrative of the profound interconnectedness between health and the socioeconomic fabric of our societies. PCOS, as examined here, is deeply intertwined with not just the biological factors, but also with the social, economic, and environmental determinants that individuals encounter throughout their lives.

This comprehensive understanding underscores that addressing PCOS goes beyond clinical interventions—it necessitates a broader perspective that encompasses economic policies, educational opportunities, environmental safeguards, and social protections. By situating PCOS within the SDOH paradigm, it becomes evident that multi-sectoral strategies and policies are essential. Fostering healthier societies isn't just about direct healthcare measures but ensuring an environment where each individual, irrespective of their health condition, can thrive and contribute to the collective well-being.

NCD Mortality beyond SDGs

Indicator 3.4.1, under Goal 3, target 3.4, focuses on mortality attributed to four specific non-communicable diseases (NCD4): cardiovascular disease, cancer, diabetes, and chronic respiratory diseases. Notably, this indicator excludes diseases other than the NCD4 and also excludes deaths in individuals younger than 30 years or older than 70 years (Bennett et al., 2020).

Though PCOS isn't directly encompassed in this metric, its implications on NCD4 are profound, as depicted in Figure 2. Studies have shown that women with PCOS are twice as likely to experience a cardiovascular event (Scicchitano et al., 2012), four times more likely to develop type 2 diabetes (Rubin et al., 2017), and at a heightened risk of cancers such as endometrial, ovarian, and breast cancer (Springer, 2014). Furthermore, PCOS's long-term ramifications align with three out of the four diseases listed under NCD4. Research has also suggested that women with PCOS may be more susceptible to severe COVID-19 symptoms, possibly due to vitamin-D deficiencies (Kyrou. I et al., 2020), potentially adding chronic respiratory diseases to the list of concerns linked to PCOS.

Another key indicator under target 3.4 is 3.4.2, which addresses suicide mortality rates. Women diagnosed with PCOS are observed to have an elevated risk of mood disorders, including major depressive and dysthymic disorders, anxiety disorders, eating disorders, and generalized emotional distress (Barry, 2019). However, there's a glaring gap in dedicated research, monitoring, evaluation, and advocacy for PCOS patients. Compounding the concern, the national and state indicator framework, designed to gauge SDG progress in Indian states, have overlooked the significance of monitoring the epidemiological trajectory of PCOS, especially in the context of achieving Goal 3 and, more specifically, Target 3.4.

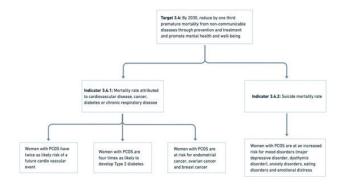


Figure 2 *Measures of PCOS within the existing NCD indicators.*

To achieve substantial progress on Target 3.4, which aims to "reduce by one-third premature mortality from NCDs through prevention and treatment by 2030, and promote mental health and well-being," it's essential to integrate policies for PCOS prevention and treatment. Specifically, we must monitor the incidences of cardiovascular disease, diabetes, and cancers (endometrial, ovarian, and breast) linked to PCOS. Furthermore, the mental well-being of women with PCOS should also be closely observed and addressed.

The complex relationship between PCOS and multiple non-communicable diseases underscores the necessity of comprehensive and inclusive health indicators. While the current framework of Target 3.4 within the SDGs emphasizes a subset of diseases, it inadvertently overlooks the broader health implications of conditions like PCOS. This oversight not only hinders accurate representation and understanding but may also impede effective interventions and policies aimed at overall well-being. By integrating the nuanced health challenges faced by women with PCOS into our global health targets, we can foster a more holistic and informed approach to health policy-making. This will not only serve the immediate population affected by PCOS but will also provide a model for how we address other overlooked conditions in global health metrics. As we advance towards 2030, it is paramount to ensure that our strategies are as comprehensive as the challenges they seek to address.

Linking Health Sector Priority Targets with PCOS

Establishing a clear link between SDG3 targets and PCOS is of utmost importance in public health. PCOS, a common endocrine disorder, affects various aspects of health, including reproductive, metabolic, and mental well-being. By clarifying how PCOS overlaps with SDG3 objectives, we can raise its standing in global health priorities, spark more research, and encourage interdisciplinary teamwork to tackle the diverse challenges it presents.

In the exploration of the relationship between SDG3 targets and PCOS, the methodology of expert elicitation was employed. The choice of this approach was motivated by ne significant factor was the noticeable lack of unified data detailing the ties between SDG3 aims and PCOS. The expertise of specialists, accessible through expert elicitation, acts as a valuable asset to navigate this data void.

A twelve-member expert committee was tasked with evaluating each health sector target based on a predefined scale: 1- No direct relevance, 2- Indirect or minimal relevance 3- Moderate relevance, 4- Strong relevance, and 5- Direct and significant relevance. To ensure a robust and representative outcome, all the individual ratings were collated and a focus group discussion was led to reach a consensus on the relevance of each target to PCOS.

Table 2 presents the relevance ratings for each healthsector target concerning PCOS as assessed by the expert committee. Based on the evaluations, targets 3.1 Reduce maternal mortality, 3.2, End preventable deaths of children under 5, 3.4 Reduce premature mortality from non-communicable diseases, 3.7 Access to reproductive health-care services, 3.8 Universal health coverage, 3.b Support R&D of vaccines and medicines, and 3.c Increase health financing and workforce training emerged as priority targets warranting focused attention in relation to PCOS.

Table 2 Health-sector Targets and the PCOS Relevance Rating

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Health Sector Targets	PCOS Relevance Rating
3.1 Reduce maternal mortality	4 - PCOS can directly impact pregnancy complications.
3.2 End preventable deaths of children under 5	3 - PCOS complications might affect neonatal health.
3.3 End specific epidemics	2 - General health management for PCOS patients might affect this indirectly.
3.4 Reduce premature mortality from non- communicable diseases	5 - PCOS is directly linked with many non-communicable diseases.
3.5 Strengthen prevention/ treatment of substance abuse	2 - Mental health challenges from PCOS might lead to substance abuse.
3.6 Halve deaths from road accidents	1 - No direct relation with PCOS.
3.7 Access to reproductive health-care services	5 - PCOS is one of the primary reproductive health concerns.
3.8 Universal health coverage	5 - PCOS diagnosis, treatment, and management require comprehensive healthcare access.
3.9 Reduce deaths from pollution	2 - Environmental factors might influence PCOS indirectly.
3.a Implement WHO Framework on Tobacco	2 - Tobacco might exacerbate PCOS-related risks.
3.b Support R&D of vaccines and medicines	4 - Research can lead to better PCOS treatments.
3.c Increase health financing and workforce training	3 - Better health infrastructure can improve PCOS care.
3.d Strengthen global health risk management	2 - Early diagnosis and management of PCOS might be improved.

The Figure 3 showcases a radar chart provides a visual representation of the relevance ratings for each priority health-sector target in relation to PCOS. Each axis of the chart corresponds to a specific health-sector target, with the radial magnitude representing the assessed relevance rating, ranging from 1 (No direct relevance) to 5 (Direct and significant relevance).

Recognizing priority targets provides a clear path for those in policy-making, clinical practice, and research domains. It will not only enrich the discourse around women's health but also foster a more integrative approach, marrying the goals of global health advancement with the specificities of PCOS management.

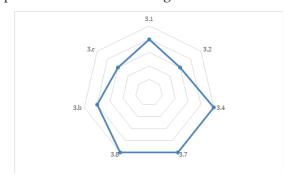


Figure 3 PCOS Relevance Rating for Priority Health Targets

Conclusion

Given the growing prevalence and incidence of PCOS in conjunction with India's designation as the diabetic capital of the world, the country is facing an amplified risk of metabolic non-communicable diseases. These are characterized by specific metabolic risk indicators such as elevated blood pressure, obesity, hyperglycaemia, hyperlipidaemia, and modifiable behavioural risk contributors like sedentary lifestyles, unhealthy diets, hidden hunger, and harmful alcohol consumption.

The ABHIYAAN PCOS initiative seeks to evaluate these prevailing circumstances concerning PCOS in India, considering the nation's unique socio-cultural implications, economic ramifications, and its diverse healthcare system. Initial findings from the ABHIYAAN PCOS study suggest a trajectory of learning. Yet, the "One Nation-One Healthcare" proposition by the NITI Aayog presents both a challenge and an opportunity for advanced multidisciplinary, multispecialty and multisystem management of PCOS.

In the backdrop of PCOS as the silent epidemic, fostering collaborations between governmental and non-governmental sectors is essential. While international initiatives can provide valuable insights, they should complement rather than overshadow national collaborations. Transposing guidelines from one nation

to another without taking into account local nuances is counterproductive.

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