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Full length article

Insights from the EGOI-PCOS patient survey: Diagnosis, treatment, and quality of life according to Italian PCOS patients

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ABSTRACT

Background: Polycystic ovary syndrome (PCOS) is an endocrine-metabolic disorder; however, the current guidelines do not adequately address the metabolic aspect. By gathering patients' perspectives, this survey investigates potential issues with the current diagnostic process to identify key points that need addressing in the future.

Method: A survey comprising of 49 multiple-choice question was distributed to members of the Italian PCOS community *NoiPCOS*, including topics such as demographics, PCOS diagnosis experience, symptom management, quality of life, and access to information about PCOS.

Results: 769 women aged 18–40 responded to the survey. 72.2% of responders were employed and perceived their socio-economic status as "good". PCOS diagnosis was primarily obtained in adolescence (35.1%) or late adolescence (33.6 %), with the most common symptoms being polycystic ovaries (85.8%), irregular menses (80.4%), and hirsutism (64.1%). Moreover, PCOS symptoms were seen to severely impact the mental health for 64.7% of responders. Treatments prescribed for PCOS were diet (49.5%), exercise (46.9%), metformin (27.6%), hormonal contraception (26.4%), and myo-inositol and D-chiro-inositol (25.2%). When accessing information about PCOS, women often relied on unofficial sources (i.e. internet sources) rather guidance from their physician.

Conclusion: Findings of this survey highlight that a thorough update of PCOS diagnostic criteria is required, which should consider the endocrine and metabolic aspects of the syndrome. Such revision should enable a more accurate, precise diagnosis that translates to effective therapy. Finally, any reconsideration of the PCOS guidelines should increase the perceived reliability by patients of medical care, reducing the communication gap between specialists and patients.

Introduction

Polycystic ovary syndrome (PCOS) is a chronic and multi-factorial condition, which manifests in women of reproductive age. Symptoms of PCOS include oligo-anovulation, clinical and/or biochemical hyperandrogenism, and polycystic ovarian morphology (PCOM) [1]. Since 2003, patients have primarily been diagnosed according to the Rotterdam criteria, which described PCOS as a condition featuring at least two out of three of the aforementioned symptoms [2]. The combination of the individual symptoms considered by the Rotterdam criteria results in four phenotypes, three of which represented by hyperandrogenic phenotypes (A, B, C) and one normoandrogenic phenotype (D). To date, the Rotterdam criteria are the most widely applied diagnostic tool for patients and clinical studies [3].

The Rotterdam consensus was drawn up in 2003 at a conference cosponsored by the European Society of Human Reproduction (ESHRE) and American Society for Reproductive Medicine (ASRM) [2]. These criteria have been revised over time; however, questions remain

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regarding the need for additional updates. The desire to revise the current guidelines stems from the wish to properly consider the etiopathogenesis of PCOS and its clinical definition [4]. Moreover, it is argued that further revisions should consider the known link between PCOS and metabolic alterations, which are not covered by the current diagnostic guidelines [5]. Recently several authors have discussed associations between insulin resistance (IR) and PCOS, suggesting that metabolic alterations manifest and subsequently lead to the endocrinological disorder [6]. In detail, ovarian cells remain sensitive to insulin even in case of peripheral IR resulting in compensatory hyperinsulinemia, which overstimulates androgen production in theca cells [7,8].

In this context, the term "PCOS" may be misleading, or inappropriate, as it fails to consider PCOS as an endocrine-metabolic syndrome (EMS), which includes the metabolic aspect of the syndrome. Furthermore, the "cysts" observed through ultrasound analysis are actually arrested follicles occurring due to hormonal impairment [9]. Moreover, as PCOM is not detected in all patients, the inclusion of the word "polycystic" in the name is not an accurate representation of the condition. Consequently, Myers and colleagues have advocated for a comprehensive revision of the PCOS nomenclature in order to highlight its multifaceted endocrine-metabolic features [4].

Such a substantial revision is further supported by other authors in the scientific community, which have indicated that the current guidelines do not give practical instruction for adequate patient care [10]. Furthermore, due to unclear guidelines, women experiencing PCOS symptoms and in pursuit of a diagnosis may face several costly consultations or clinical tests. This may ultimately lead to a loss of trust in medical professionals, creating a communication gap that could further extend prolong the diagnostic and treatment process [11]. Since the modern concept of precise medicine tailors its approach to the individual patient, communication between specialists and affected women is vital. Previous attempts to gauge the global satisfaction of PCOS women towards health care professionals managing their disease, described a fragmented health service which prolongs the diagnostic process [12]. Besides an integrated and multidisciplinary approach, other improvements of the current clinical protocols may simplify and accelerate the diagnostic process and may improve the quality of life of women with PCOS. Consequently, patients may offer a different point of view and source of additional information to achieve a more comprehensive revision of clinical practice.

The present report summarizes the results of a survey concerning the clinical experience of women with PCOS in Italy. In this study we outline differences in demographic characteristics, medical history, achieving a PCOS diagnosis, and the steps required to identify an effective therapeutic approach.

Materials and methods

To investigate the demographical and clinical background of patients with PCOS, we shared a Google Form survey via the social-media channels of the Italian web-based community NoiPCOS. The survey was conducted between the 1st and the 30th of October 2024 and included women with PCOS that spoke Italian as their first language, who agreed to the General Data Protection Regulation (UE 2016/679). Participation was on a voluntary basis and was anonymous. The survey comprised of 49 multiple-choice questions, which were responded to by more than 700 women; however, every question was not responded to by every participant.

The questionnaire covered four main topics: 1) demographic characteristics (age, sociological context, highest level of education, etc.); 2) PCOS diagnosis personal experience (clinicians consulted, independent research, time taken from initial manifestation of PCOS symptoms to receiving a diagnosis, age, symptoms at onset, comorbidities, effectiveness of treatments etc.); 3) impact of PCOS on quality of life (QoL) and mental health; 4) source of medical information.

Results

Demographic characteristics of the investigated cohort

Overall, 769 women participated in the survey, with ages ranging from 18 to 40 years old. Many of them had a university education, with the rest of participants having graduated from high or middle school (Fig. 1, panel A). Among the respondents, 72.2 % were employed and socio-economic status was self-reported as "good" by the majority of participants (Fig. 1, panels B and C).

PCOS diagnosis personal experience

On average, the age reported at diagnosis of PCOS was equally distributed between adolescence (11–18 years), late adolescence (19–23 years), and adulthood (24+years) (Fig. 2, panel A). The symptoms reported by the participating cohort are reported in Fig. 2, panel B and included: menstrual or gynecological disorders (i.e. polycystic ovary, irregular menses, amenorrhea, anovulation,); dermatological issues (i.e. hirsutism, acne); endocrinological impairment (i.e. hyperandrogenism); metabolic impairments (i.e. obesity).

According to their experience, the survey participants were seen by a variety of clinicians, depending on their specific needs. Most women required the opinion of more than one specialist before receiving a final diagnosis, with gynecologists and endocrinologists representing the first point of contact for most patients (Fig. 3, panel A).

Among the clinical parameters and assessments, pelvic ultrasound (US) and dermatological evaluation are commonly recommended, but glycemia and levels of insulin were also often measured (Fig. 3, panel B).

Pharmacological treatment with metformin or hormonal contraceptives, often combined with life-style adjustments, appeared to be the therapy of choice (Fig. 3 C). Interestingly, inositol-based supplementation was almost equivalent to drug-based approaches.

Impact of PCOS symptoms on QoL

The survey revealed that PCOS profoundly impacts the mental health of the majority of patients as reported in Fig. 4 panel A. More than half of them have feelings of depression connected to their condition (Fig. 4, panel B), with common worries including weight issues, followed by irregular menses, and infertility (Fig. 4 panels C, D and E).

Sources of medical information

In the submitted questionnaire, 706 patients responded to questions regarding the most commonly used sources of information about PCOS, and how they rated the reliability of this information.

The internet was the primary source of information (scientific articles, medical websites, blogs), followed by social media (Instagram, YouTube, Facebook, etc.), Fig. 5, panel A.

Of note, 80.7 % of participants considered internet sources "quite reliable" (Fig. 5, panel B); meanwhile, half of the population indicated that information provided by physicians and specialists was "not very clear", stating that characterization of PCOS phenotype was lacking in 65.1 % of diagnoses (Fig. 5, panel D). In addition, general awareness was low, with participants indicating that information on PCOS was available before diagnosis only in 0.7 % of cases (Fig. 5, panel E).

On average, patients waited at least one year to receive a diagnosis of PCOS, with most respondents reporting a quite or very difficult experience. Such results relate to the primary barriers encountered during the research of an appropriate PCOS treatment which complained as long times in 20.1 % of cases. 71.4 % and 53.9 % respectively felt a lack of competent specialists or information; 51.8 % complained high costs as reported in Fig. 6 B. After receiving a PCOS diagnosis, women perceived difficulties in receiving proper care (Fig. 6, panel C).

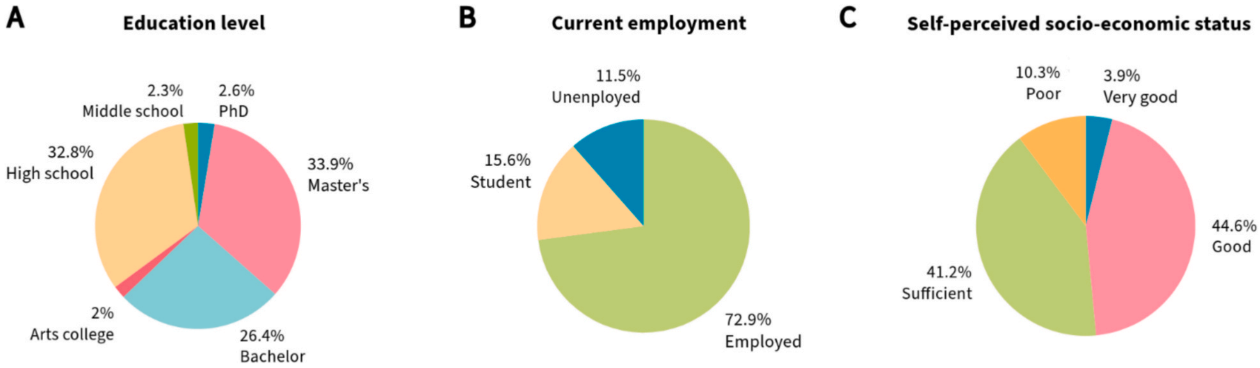

Fig. 1. Demographics of the interviewed cohort: a) educational level; b) current employment; and c) self-perceived socio-economic status of the interviewed cohort.

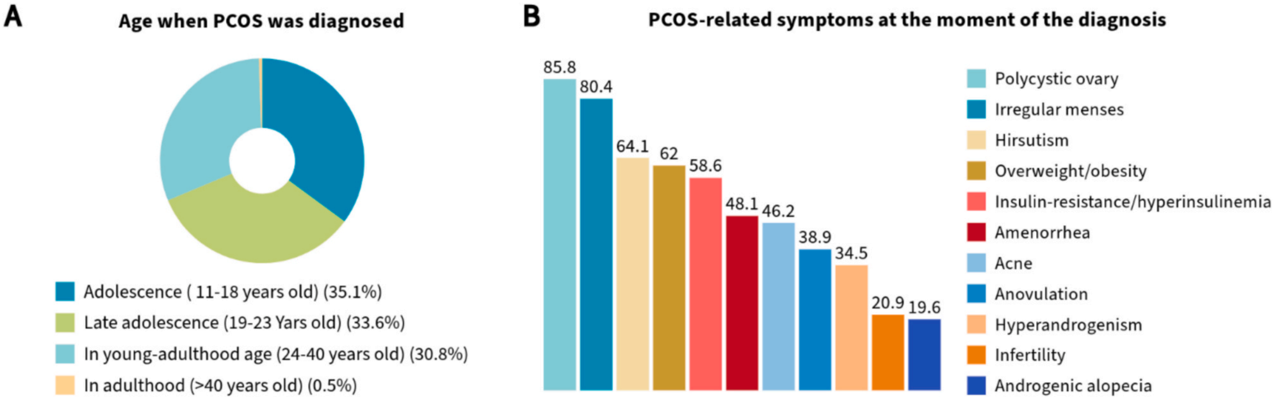

Fig. 2. Diagnostic characteristics of patients: A) age when PCOS was diagnosed; B) PCOS-related symptoms at the moment of the diagnosis.

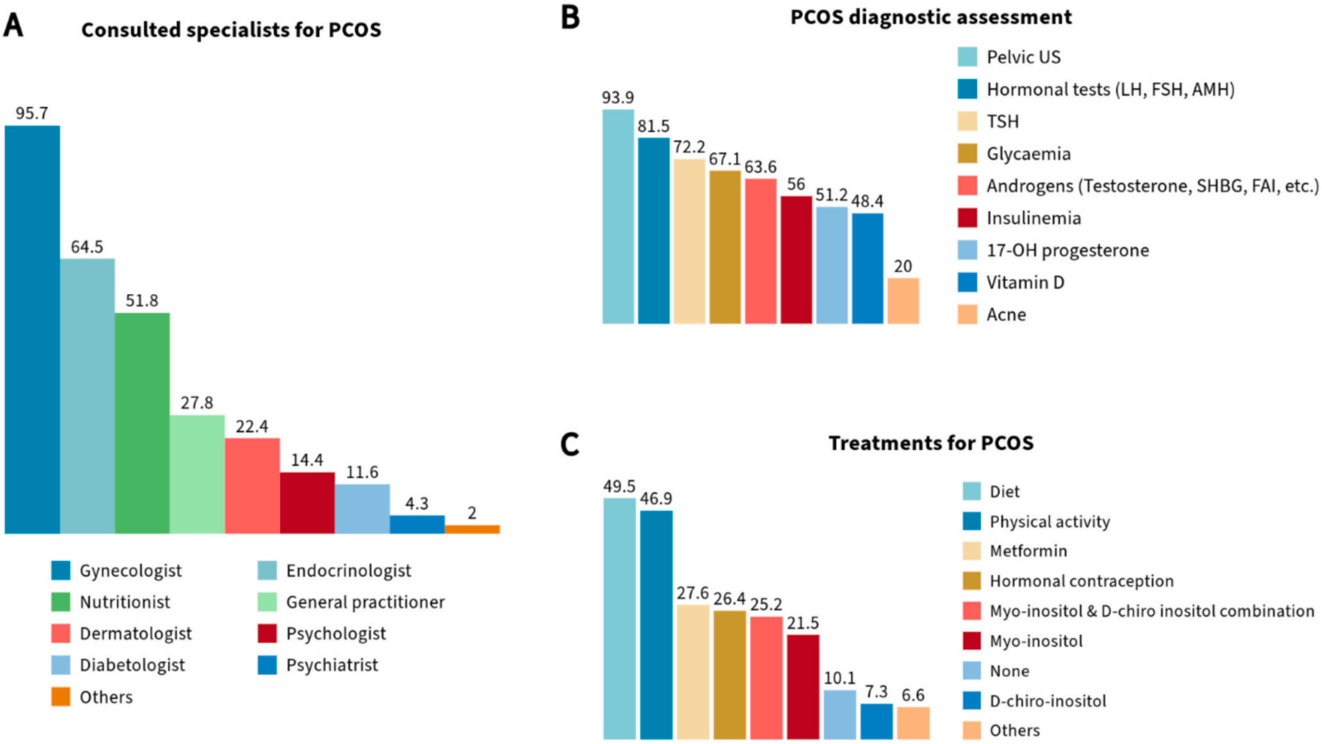

Fig. 3. A) Consulted specialists; B) performed diagnostic tests for a PCOS diagnosis; C) prescribed treatments.

Fig. 4. A) Impact of PCOS on psychological wellness; B) frequency of feelings of depression due to PCOS. The impact of the commonly observed PCOS symptoms of QoL: C) Question: In the last six months, how problematic has having irregular menses been for you? D) Question: for the last two weeks, how long have you felt worried about being overweight? E) Question: for the last two weeks, how long have you felt worried about infertility issues?

Discussion

Demographic characteristics of the surveyed PCOS cohort

In this study, we assessed the social conditions of respondents to evaluate any possible influence on the awareness of their condition and on the likelihood of receiving a diagnosis of PCOS in Italy.

In the majority of cases, respondents had a higher degree of education and rated their socio-economic status to be sufficient to good. These findings may be interpreted in two ways. On the one hand, as the diagnosis of PCOS is generally achieved after a long and costly process, often requiring consultations from multiple specialists, patients with higher education levels and who are middle to upper-middle class may have the required economic freedom to properly manage their health. Moreover, they may be more inclined to participate with social media communities for PCOS and share their own experiences, with the aim of improving their QoL. Through this lens, the responses to the present survey uncover a degree of social inequity. Therefore, the medical community must find a way to access these underserved PCOS patients. A fundamental requirement to achieve this goal is that clinicians understand the multifaceted aspects of the syndrome, collaborating across diverse medical fields via an integrated diagnostic approach. The overall

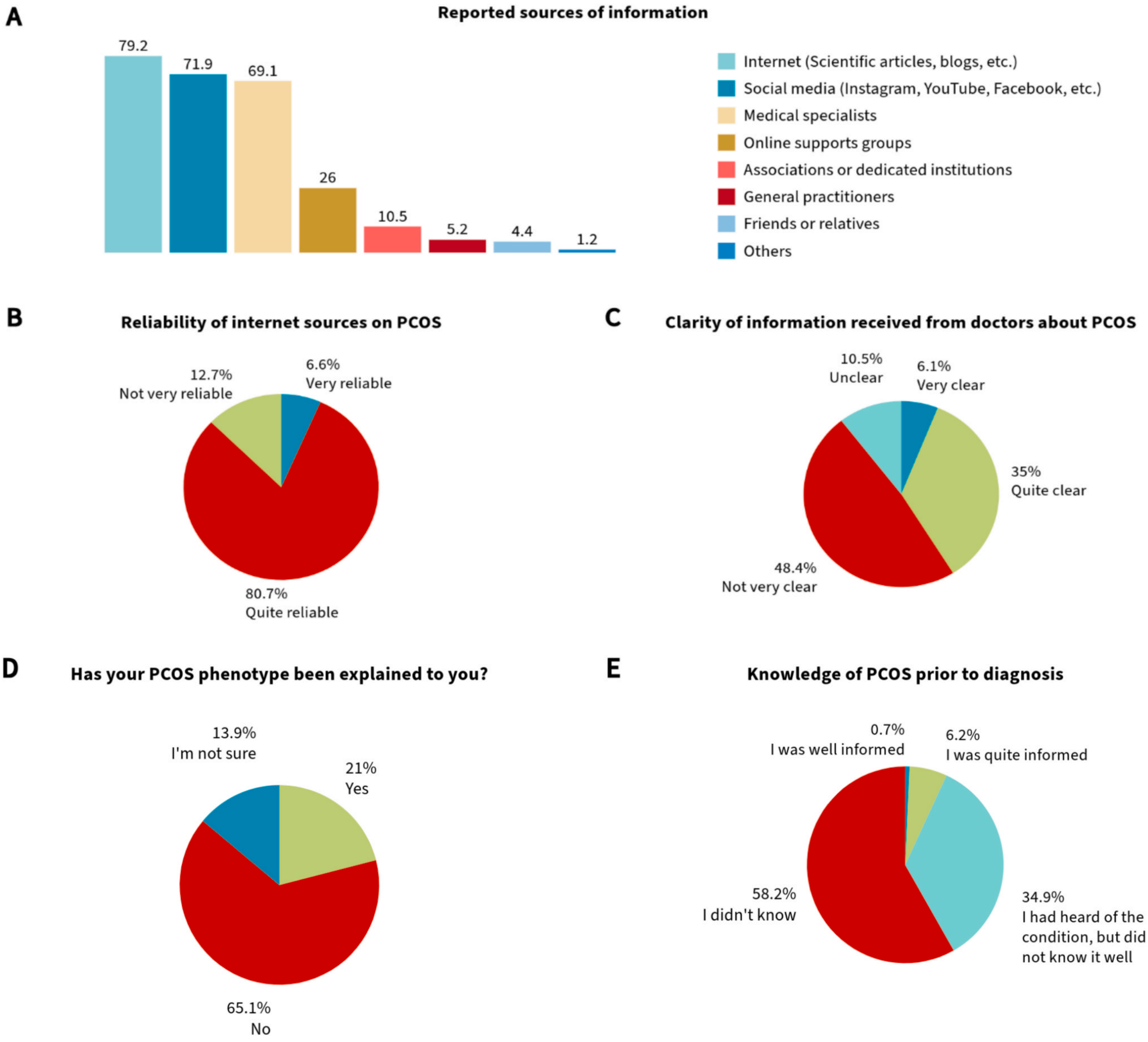

Fig. 5. A) Reported sources of information about PCOS; B) relative reliability perceived by PCOS patients C) clarity of information received by doctors about PCOS; D) responses to the question “Has your PCOS phenotype been explained to you?; E) reported knowledge about PCOS prior to diagnosis.

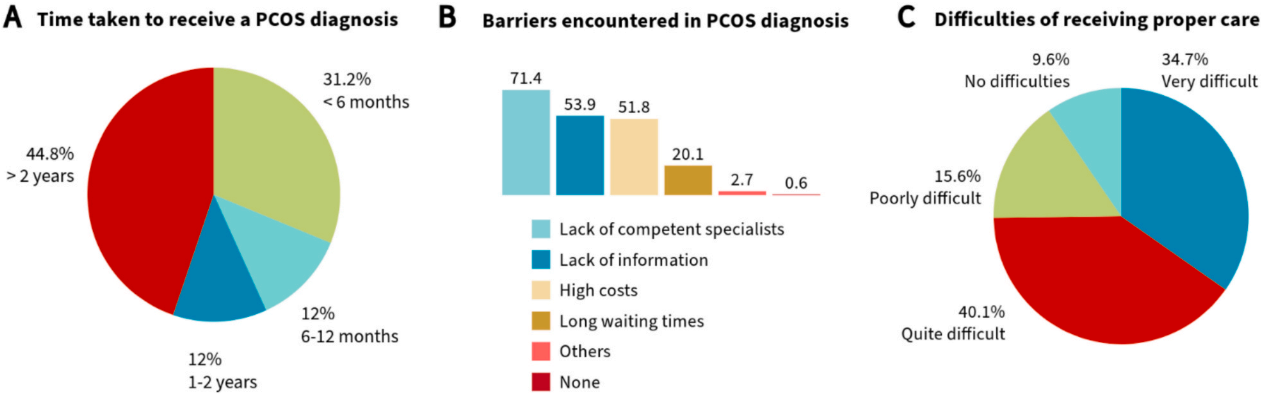

Fig. 6. A) Time waited by surveyed women before receiving a PCOS diagnosis; B) Main barriers encountered during the PCOS diagnosis; C) Responses to the question “How hard was it for you to receive proper care for PCOS?”.

aim is to achieve a quicker and more accurate diagnosis, paired with tailored treatments based on the specific characteristics of the patients.

A second interpretation may consider that women with PCOS who come from less privileged socio-economic background may be less inclined to share their experience or to take part in social media communities for PCOS. Although a more in-depth analysis is required to correctly assess their motives, this subset may not be in a financial position to allocate the appropriate time for selfcare, and likewise the pursuit of medical attention may be largely postponed. In both cases, those women from disadvantaged demographic backgrounds may be less prone to consult clinicians or thus be prescribed appropriate treatments [13]. Considering the above, greater efforts must be made to increase the accessibility of PCOS consultation and treatments.

Diagnostic journey through a complex endocrine-metabolic disorder.

The survey revealed that the diagnostic journey of women with PCOS often starts at the onset of clinical hyperandrogenism and ovulatory dysfunction [14,15], explaining why gynecologists and endocrinologists are the first point of contact in most cases. However, a general trend of consulting several specialists emerges from our investigation. This outcome offers two insights. On the one hand, it suggests a segmented clinical approach where each specialist possibly recommends an additional consultation, considering themself not entirely able to resolve the specific situation. Alternatively, patients may progressively encounter different symptoms during their diagnostic experience, requiring the consultation of different doctors.

The Rotterdam criteria are still widely used in clinical practice to diagnose PCOS. For adults of reproductive age, the revised 2023 International Evidence-Based Guidelines for PCOS state the required for at least two of the following characteristics to be present: PCOM (i.e. at least 20 follicles with diameters ranging from 2 to 9 mm and/or an ovarian volume exceeding 10 mL in at least one ovary) or elevated anti Müllerian hormone levels (AMH); clinical and/or biochemical hyperandrogenism, and oligo-anovulation [1]. Responses to our survey are in line with the application of these criteria and the most investigated clinical outcomes are reported to be pelvic ultrasound and hormonal serum quantification (Fig. 3, panel B). However, the determination of circulating levels of insulin or glucose deserves particular attention, as it highlights the increasing notion from clinicians to consider metabolic alterations associated with PCOS [8]. Despite the current diagnostic criteria not including insulin resistance, several authors have voiced their support for its contributing role in the pathogenesis of the syndrome [16,6,10]. This discordance between theoretical guidelines, and the potential realities of the conditions, calls for urgent reassessment of PCOS and its management [17].

In the present survey the reported ages for a PCOS diagnosis are equally distributed among adolescence, late adolescence, and adulthood. Despite data from the World Health Organization (W.H.O) indicating that PCOS is mainly diagnosed in adult age, our results are in line with a novel trend that focuses on PCOS in adolescents, as also reported by Yu and co-workers in 2023 which highlight an increasing sensibility to a tempestive diagnosing and treatment of the disease [18].

Adolescence is a transitional phase typically characterized by hormonal fluctuations and may vary greatly among individuals. Therefore, a defined classification of hormone physiological range and of menstrual irregularities is not appropriate, depending instead on individual parameters such as the age of menarche [19]. These factors may complicate clinical evaluations; hence physicians tend to postpone the diagnosis of PCOS until eight years after menarche [20]. However, recent data suggest that an early diagnosis in the puberal or post-puberal ages may prevent further worsening of endocrine-metabolic disorders [20]. Crucially, physicians lack diagnostic guidelines tailored towards younger patients, although the 2023 International Evidence-Based Guidelines started to devote attention in this regard. Specifically, sonographic appearance of the ovaries and AMH serum levels are considered less reliable for teenagers, while specific details were included to define menstrual irregularities. The understanding of PCOS features in adolescence is still in its infancy, and further discussions are required to define more precise diagnostic assessments for PCOS in younger patients.

This aspect has strong social and clinical implications, as the role of parents and pediatricians is pivotal. Therefore, both must be adequately educated and engaged to correctly read the signs that may indicate endocrine and/or metabolic alterations typical of PCOS.

Prescribed treatments

Although current guidelines for PCOS primarily advocate lifestyle modifications as a first-line approach, the survey indicates that pharmacological treatment is also often recommended. Participants report that metformin and oral contraceptives (OCs) are the most prescribed, a notable difference with earlier practice, where OCs were almost the only option for treating PCOS [21]. This observation may reflect the growing concerns about OC side effects [22], particularly regarding increased cardio-vascular risk, combined with the idea that OCs treat the phenotypic manifestations of PCOS rather than the underlying causes [23].

In addition, a high rate of prescriptions of Metformin likely indicates an increasing opinion that counteracting metabolic alterations is essential in the management of PCOS. Correspondingly, the use of nutraceuticals that improve insulin sensitivity, such as inositol, has been gaining traction. In detail, several *meta*-analyses have shown myo-inositol to be equivalent to metformin in treating metabolic and hormonal dysfunction in patients with PCOS. A *meta*-analysis conducted by Fatima and colleagues reported no significant difference between metformin and myo-inositol especially in terms of fasting insulin (SMD: 0.00, 95 % CI: -0.26 to 0.27, $p = 0.97$), fasting blood sugar (SMD: 0.11, 95 % CI: $-0.31$to 0.53, $p = 0.60$), HOMA index (SMD: 0.09, 95 % CI: -0.20 to 0.39, $p = 0.50$), and LH/FSH (SMD: 0.20, 95 % CI: -0.24 to 0.64, $p = 0.37$) [24]. Furthermore, Zhang and coworkers compared myo-inositol with metformin stating a non-significative difference in the ability to lower testosterone and increase sex-hormone binding globulin levels [25].

As in the case of diagnostic criteria, our survey suggests differences in PCOS treatments exist between guidelines, clinical practice, and patient preference.

Impact of PCOS on psychological wellness

According to the W.H.O, mental health disorders have a global prevalence of 12.5 %; however, this is greatly increased in women with PCOS, who have a 40 % prevalence of such disorders including anxiety, mood swings, and social fears [26]. Although pathological mechanisms are still not understood, multiple factors likely contribute and merit further study [27,28]. The results of our survey may help to shed light on the state of mental health within the Italian PCOS community.

Patients often experience difficult receiving adequate diagnosis and treatment for their condition, which may lead to confusion and feeling of helplessness (Fig. 6). Furthermore, multiple medical consultations may incur significant financial and time costs, which may be unacceptable for some patients. In addition, the physical manifestations of PCOS and its association with reduced fertility may influence patients' mood; furthermore, signs of hyperandrogenism and weight gain may undermine a patient's self-esteem.

The psychological impact of PCOS is rarely discussed or accounted for, but it brings about additional burden and costs for patients and national health systems, which may be greatly reduced by a more efficient and effective diagnosis and therapeutic approach.

Additional psychological stress is possibly caused by the lack of clarity in the directions that physicians provide (Fig. 6, panel B). This uncovers a worrisome communication gap that may result in women turning to less reliable channels as primary source of information (Fig. 5, panel B).

Conclusion

Our comprehensive survey of greater than 700 PCOS patients yields significant insights into contemporary diagnostic methodologies, therapeutic strategies, and obstacles in the delivery of healthcare in Italy.

In general, it was observed that a possible socioeconomic discrepancy may possibly hinder the access of PCOS patients to appropriate medical consultations. Moreover, specialists may be challenged by narrow diagnostic criteria, which do not properly consider the wider complexity characterizing this multifactorial endocrine and metabolic condition. Therefore, patients experience a lengthy and costly process to obtain a correct PCOS assessment, due to a lack of clear interpretable medical information for patients and doctors alike.

As patients with PCOS indicated they tend to suffer from poor mental health, they may face issues attending consultations from physicians and therefore may receive inadequate care. Other contributing factors include socio-economic status and educational level. This lack of clarity opens a communication gap between patient and physician, leading women to look for alternative information sources such as social media platforms or unofficial websites, ultimately increasing their confusion regarding their condition and how to treat it.

Besides raising awareness of the patients' needs in healthcare professionals, viable solutions to this issue include clearer and more standardized clinical pathways. This implies an integrated and multidisciplinary approach, involving collaboration between specialists and official dedicated information channels.

In summary, information may be gleaned from the patients experience which supports the need for easily applied but bespoke clinical advice that accurately considers both the metabolic and endocrinological aspects of PCOS. It is hoped that such changes will improve patient care and restore trust between patients and their physicians.

Limits of the study and future perspectives

The present survey aimed to outline the patients' perception of the clinical management of PCOS, which is a perspective seldom considered. Due to the subjective nature of this investigation, some limitations are intrinsic. In particular, without access to respondents' medical records, it is impossible to derive any precise information regarding exact prescription and therapy efficacy.

Focusing on the patients' experience on diagnosis and treatment, this survey overlooks other clinical aspects that may be correlated with PCOS, such as metabolic, cardiovascular and respiratory alterations. Whether these conditions coexist or derive from PCOS is still subject of debate. Dedicated surveys and analyses are ongoing to deeper investigate these possible connections.

Data availability statement

Data associated with the article is available in supplementary information 1.

Funding information

No funding was received for conducting this work.

CRediT authorship contribution statement

Vito Cosimo Carriero: Writing – review & editing, Writing – original draft, Investigation, Formal analysis. **Gianpiero Forte:** Writing – review & editing, Writing – original draft. **Simona Dinicola:** Writing – review & editing. **Mario Montanino Oliva:** Writing – review & editing. **Gaia Al Mudarris:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Vittorio Unfer:** Writing – review & editing, Supervision, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: VCC, GF, SD, GA, and VU are employees of Lo.Li. Pharma s.r.l. MMO has no conflict of interests.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejogrb.2025.113947.

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