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THE ROLE OF INNOVATIVE TECHNOLOGIES, SOCIAL MEDIA ALGORITHMS, AND EHEALTH LITERACY IN SHAPING HEALTH-SEEKING BEHAVIOR AMONG ADOLESCENTS AND YOUNG ADULTS WITH POLYCYSTIC OVARY SYNDROME (PCOS): A SYSTEMATIC REVIEW

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ABSTRACT

Background: Polycystic Ovary Syndrome (PCOS) is a highly prevalent, complex endocrine and metabolic disorder that profoundly alters the physiological and psychological landscape of adolescent development. Driven by systemic clinical dissatisfaction, chronic invalidation, and a lack of tailored institutional support, the modern patient experience has rapidly transitioned from traditional, clinic-based management to hyper-connected digital self-management.

Objective: This systematic review aims to comprehensively explore how innovative digital technologies—specifically algorithmic social media platforms (TikTok, Instagram, YouTube, X), the Internet of Things (IoT), and machine-learning-analyzed discussion forums (Reddit)—shape the health-seeking behaviors and medical decision-making of women diagnosed with PCOS. Furthermore, it evaluates the critical mediating role of electronic health (eHealth) literacy.

Methodology: A systematic synthesis was conducted in strict accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines. Electronic databases (PubMed/MEDLINE, Google Scholar, Scopus) were systematically searched for peer-reviewed studies published between 2012 and 2026. The synthesis integrated qualitative sociological interviews, mixed-methods intervention studies, natural language processing (NLP) sentiment analyses, and big data infodemiology (total n=23).

Results: The synthesis reveals a critical, high-stakes dichotomy. While digital platforms and IoT applications are essential for identity reconstruction ("sense-making") and peer support, they are simultaneously potent vectors for unregulated health misinformation. Visual algorithms heavily promote unverified, "root-cause" supplements and restrictive diets, overshadowing evidence-based medicine. The reliance on digital crowdsourcing for interpreting laboratory results introduces unprecedented friction into the patient-physician dynamic. However, emerging evidence indicates that targeted, evidence-based Digital Health Interventions (DHIs) and higher baseline eHealth literacy significantly mitigate these risks, leading to improved clinical and psychological outcomes.

Conclusion: The integration of digital health literacy into routine endocrine and gynecological care is no longer optional. Healthcare providers must recognize social media as a primary, foundational diagnostic ecosystem. Addressing this requires active clinical mediation, the co-development of evidence-based digital interventions, and profound clinical empathy to help patients navigate algorithmic noise safely.

KEYWORDS

Polycystic Ovary Syndrome, Digital Health, Social Media Algorithms, Misinformation, Machine Learning, Cyberchondria, eHealth Literacy, Health-Seeking Behavior, Big Data Infodemiology, Patient Empowerment

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1. Introduction

1.1. Pathophysiology and the Profound Psychological Burden

Polycystic Ovary Syndrome (PCOS) is globally recognized as the most prevalent endocrine and metabolic disorder among females of reproductive age, affecting between 6% and 20% of this demographic depending on the specific diagnostic criteria applied, such as the Rotterdam criteria (Azziz et al., 2016). While the foundational physiological mechanisms—characterized by hyperandrogenism, chronic anovulation, polycystic ovarian morphology, and severe insulin resistance—are extensively documented in medical literature, the socio-psychological impact remains a critically undermanaged area of holistic healthcare.

The outward, physical manifestations of the syndrome, such as cystic acne, alopecia, severe hirsutism, and rapid, often diet-resistant weight gain, strike directly at the fragile core of adolescent identity formation and pubertal transition. Hofmann et al. (2023) established through comprehensive cross-sectional research that women with PCOS suffer from significantly impaired body image and severe mental health comorbidities, including clinical depression and generalized anxiety, at rates far exceeding the neurotypical population. Furthermore, sociological research by Rohden and Corrêa (2024) highlighted how PCOS uniquely exists on the borderlines of objective health and socially constructed beauty standards. Patients are continuously subjected to immense aesthetic pressures, making this psychological burden not merely a secondary side effect, but a primary, defining characteristic of the disorder that heavily dictates all subsequent health-seeking behavior.

1.2. The Clinical Deficit and the Shift to Digital Refuge

Despite international, evidence-based guidelines emphasizing a multidisciplinary approach involving targeted pharmacotherapy and structured lifestyle management (Teede et al., 2023), the modern patient journey significantly deviates from traditional clinical pathways. Hoyos et al. (2020) identified a profound, measurable dissatisfaction with standard healthcare among PCOS patients, noting that clinical encounters frequently feel rushed, dismissive, and overly focused on long-term fertility outcomes rather than the immediate management of distressing cosmetic and psychological symptoms.

Sanchez (2015) conceptualized this systemic failure on a macro level, noting that PCOS is frequently "absent from national surveillance" and public health funding, leaving patients feeling fundamentally abandoned by institutional medicine. Driven by this deep-seated frustration, patients feel compelled to take medical management into their own hands. This phenomenon was poignantly captured by Ismayilova and Yaya (2022) in their qualitative study, whose participants explicitly reported: "I'm usually being my own doctor." Consequently, adolescents and young adults have increasingly migrated toward digital ecosystems—such as TikTok, Instagram, Reddit, and the Internet of Things (IoT)—to seek the validation, diagnosis, and care they feel denied in the physical clinic.

1.3. Theoretical Framework and Review Objectives

This shift can be understood through the lens of the *Uses and Gratifications Theory* (UGT) of media communication, which posits that users actively seek out specific media platforms to fulfill distinct socio-psychological needs. In the context of PCOS, patients utilize the internet not merely for information retrieval, but for emotional regulation, social integration, and empowerment.

Given the unprecedented volume and influence of digital health tools, this systematic review aims to: (1) comprehensively map the extent of digital technology, IoT, and mobile app use among PCOS patients; (2) critically analyze the mechanisms and quality of algorithmic discourse and health misinformation across visual social media; (3) examine the psychological and clinical consequences of online diagnostic crowdsourcing (e.g., cyberchondria, clinical friction); and (4) evaluate the mediating role of electronic health (eHealth) literacy and structured digital health interventions (DHIs) in mitigating these modern risks.

2. Methodology

2.1. Protocol and Registration

To ensure the highest level of methodological rigor and transparency, this systematic review was structured, conducted, and reported in strict adherence to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines. The fundamental objective was to minimize selection bias and provide a reproducible, robust synthesis of the current empirical evidence regarding digital health behaviors in PCOS.

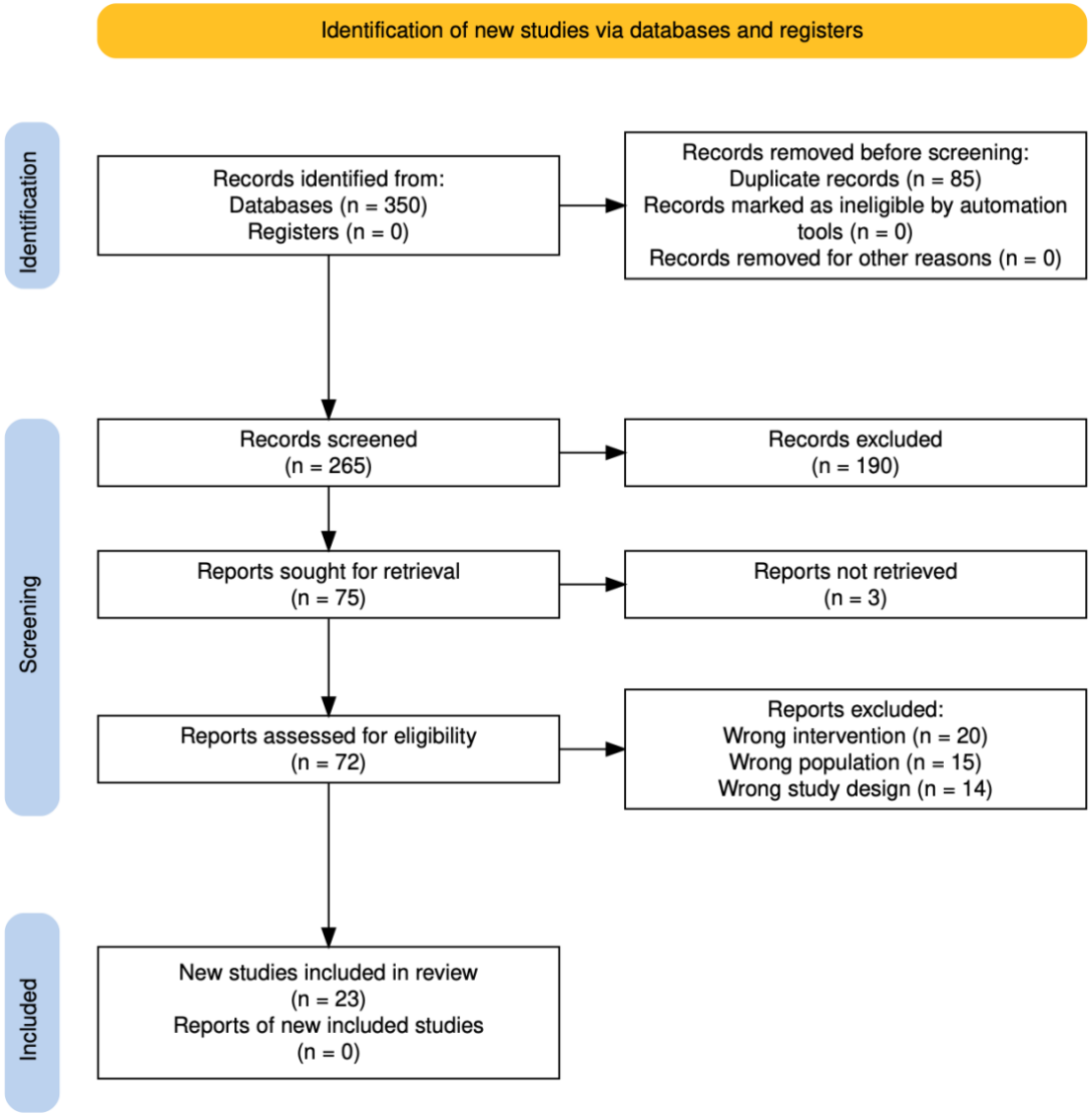

Fig. 1. *PRISMA 2020 flow diagram detailing the database search and study selection process.*

Haddaway, N. R., Page, M. J., Pritchard, C. C., & McGuinness, L. A. (2022). PRISMA2020: An R package and Shiny app for producing PRISMA 2020-compliant flow diagrams, with interactivity for optimised digital transparency and Open Synthesis Campbell Systematic Reviews, 18, e1230. https://doi.org/10.1002/cl2.1230

2.2. Eligibility Criteria (PICOS Framework)

Strict inclusion and exclusion criteria were established utilizing the PICOS framework:

- Population**:** Adolescents and women of reproductive age formally diagnosed with or actively self-diagnosing Polycystic Ovary Syndrome (PCOS).
- Intervention/Exposure**:** Active engagement with digital health technologies. This encompasses algorithmic social media platforms (TikTok, YouTube, Instagram, X), peer-to-peer online discussion forums (Reddit), the Internet of Things (mobile tracking apps, wearables), or specific web-based eHealth interventions.
- Comparison**:** Standard, traditional clinical care, varying levels of baseline eHealth literacy, or not applicable (in the context of descriptive infodemiology studies).
- Outcomes**:** Primary outcomes included psychological impacts (cyberchondria, altered body image), the quantifiable prevalence of online medical misinformation, changes in patient-physician trust dynamics, health-seeking behaviors and overall health-related quality of life.
- Study Design**:** Peer-reviewed primary research (quantitative, qualitative, and mixed-methods), big data infodemiology, natural language processing (machine learning) analyses, and scoping/systematic reviews. Studies published prior to 2015, non-English publications, and purely pharmacological or surgical trials lacking a digital, psychological, or sociological component were strictly excluded to maintain the focus on health informatics.

2.3. Search Strategy and Data Extraction

A comprehensive, systematic literature search was executed across major academic databases: PubMed/MEDLINE, Google Scholar, and Scopus. The search period (2012-2026) was deliberately selected to align with the global mass adoption of algorithmic, short-form video platforms and mobile health tracking. The primary Boolean search string utilized was: *("polycystic ovary syndrome"[Title/Abstract] OR "PCOS"[Title/Abstract]) AND ("social media" OR "TikTok" OR "digital health" OR "machine learning" OR "eHealth literacy" OR "Instagram" OR "mobile apps") AND („adolescent**" OR "young adult*" OR "women").

Data extraction was performed independently by researchers using standardized coding sheets. Any discrepancies regarding study eligibility or data interpretation were resolved through consensus discussion. Extracted variables included study design, demographic characteristics, target digital platform, sample size/data volume, and primary technological and clinical findings.

2.4. Quality Assessment and Risk of Bias

To rigorously evaluate the methodological quality of the heterogenous included literature, the Mixed Methods Appraisal Tool (MMAT), version 2018, was utilized. Each of the 23 included studies was categorized into its respective design category and evaluated against five specific methodological criteria. Studies scoring 4 or 5 out of 5 were considered high quality. Identified biases—such as the inherent reliance on self-reported digital behavior, the inability to verify the true clinical diagnosis of anonymous online users, or sample selection bias—were not used to arbitrarily exclude studies, but were critically integrated into the narrative synthesis to appropriately weight the validity of the findings.

3. Results: The Digital Ecosystem of PCOS

The systematic search and rigorous screening process yielded 23 pivotal studies. The synthesized data reveals a highly saturated, complex digital landscape that fundamentally alters patient behavior, categorized into four detailed thematic domains.

3.1. Technological Saturation, IoT, and the Quality of Mobile Apps

The modern PCOS patient is immersed in a digital ecosystem. Wright et al. (2025) and Graca et al. (2024) mapped this saturation through extensive scoping reviews, emphasizing that women with PCOS are hyper-consumers of the Internet of Things (IoT). Patients rely heavily on interconnected biometric wearables and specialized mobile applications to meticulously monitor menstrual cycles, hirsutism severity, and mood fluctuations.

However, the clinical utility of these tools is highly questionable. Arabkermani et al. (2025) provided a critical, quantitative evaluation by analyzing commercially available mobile apps designed specifically for PCOS patients using the standardized Mobile App Rating Scale (MARS). They discovered a concerning

discrepancy: while these applications consistently score exceptionally high on visual aesthetics, gamification, and user-interface usability, they frequently fail in the "Information" domain. Many popular apps lack evidence-based medical oversight, professional clinical input, and fail to provide actionable, scientifically sound advice.

Despite this objective medical deficit, qualitative research explains the persistent popularity of these tools. Gomula et al. (2024) demonstrated through in-depth interviews that patients use these online resources and apps as vital psychological tools for "sense-making." After experiencing clinical gaslighting, the digital environment allows women to systematically track their symptoms, reconstruct their disrupted identities, and find data-driven validation that their suffering is real.

3.2. Algorithmic Misinformation on Visual Platforms (TikTok, Instagram, YouTube)

When patients turn to social media for community, they are exposed to severe algorithmic risks, particularly on platforms driven by highly visual, short-form content. Horvath et al. (2024) and Riemma et al. (2025) critically examined the discourse on TikTok. Riemma et al. discovered that the platform's proprietary "For You" algorithm inherently prioritizes high-emotion, visually engaging content (e.g., users crying over acne or showcasing dramatic weight-loss transformations) over nuanced, factual medical data. Anecdotal "authenticity" heavily overshadows scientific accuracy.

Consequently, Darcy et al. (2026) highlighted the aggressive viral promotion of unregulated dietary supplements. Compounds such as inositol and dangerously high doses of berberine (often branded colloquially as "Nature's Ozempic") are heavily marketed on TikTok as definitive, "root-cause" cures, directly contradicting established clinical guidelines. This phenomenon extends to YouTube, where a massive big-data study (2023) analyzing 85,872 comments across PCOS videos revealed rampant misinformation and echo-chambers regarding holistic cures, driven largely by spammers selling unregulated online coaching courses. Furthermore, Atigan and Atigan (2023) demonstrated that popular YouTube videos prescribing specific, high-intensity physical exercises for PCOS frequently lack basic professional credentialing or safety warnings, risking physical injury to patients.

3.3. Artificial Intelligence, Machine Learning, and Crowdsourcing Diagnostics (Reddit & X)

The digital behavior of modern patients involves far more than passive scrolling; it involves active, crowdsourced medicine driven by collective intelligence. Emanuel et al. (2023a) investigated the r/PCOS subreddit, finding that patients frequently post raw, highly sensitive laboratory values (such as fasting insulin levels, androgen panels, and LH/FSH ratios). Because they feel their physicians did not adequately explain the results, they ask anonymous internet peers to interpret this complex clinical data and provide a diagnosis.

In a highly innovative follow-up study, Emanuel et al. (2023b) utilized Machine Learning—specifically Natural Language Processing (NLP) and sentiment analysis algorithms—to analyze a massive corpus of text from these forums. They demonstrated that patients evaluate the clinical efficacy of various medical treatments (e.g., Spironolactone, specific combined oral contraceptives) based almost entirely on the aggregated, anecdotal emotional sentiment of the forum, completely bypassing randomized controlled clinical trials.

Similarly, on the text-based platform X (formerly Twitter), big data analysis by Afaq et al. (2025) analyzed over 12,200 posts surrounding the #PCOSweightloss hashtag. They noted that these viral, user-generated narratives shape how millions of patients globally approach their metabolic management, establishing "internet consensus" as a higher authority than localized clinical advice.

3.4. Psychological Ramifications, eHealth Literacy, and the Efficacy of Digital Interventions

The continuous, unmediated exposure to this algorithmic health information has severe psychological ramifications. Sucu et al. (2024) investigated the prevalence of "cyberchondria"—a clinical condition characterized by excessive, debilitating health anxiety driven by obsessive online searching. Their cross-sectional study found that the digital age has significantly amplified health anxiety among adolescent PCOS patients. The constant feed of worst-case scenarios (infertility, endometrial cancer) traps vulnerable youths in a cycle of digital distress.

However, the literature points to critical, evidence-based solutions. Kara et al. (2023) demonstrated a direct, highly significant positive correlation between high electronic health (eHealth) literacy and improved overall quality of life. Patients who possessed the critical thinking skills to evaluate sources, identify influencer bias, and filter out algorithmic misinformation reported significantly lower psychological distress.

Recognizing that patients will not abandon digital tools, researchers have begun fighting fire with fire. Percy et al. (2024) utilized a rigorous mixed-methods approach to co-develop a novel web-based self-management intervention, collaborating directly with both patients and healthcare professionals to ensure clinical safety and user engagement. The ultimate efficacy of this approach was confirmed by a comprehensive 2026 systematic review by Zhao et al., which analyzed randomized controlled trials of Digital Health Interventions (DHIs). Zhao et al. concluded that structured, evidence-based DHIs effectively and safely improve anthropometric outcomes (weight management) and healthy lifestyle behaviors in women with PCOS, proving that technology can be a powerful therapeutic tool when correctly mediated by professionals.

4. Discussion: Synthesizing the Mediatized Patient Journey

4.1. The Erosion of Clinical Trust and the "Right Check" Dynamic

The profound reliance on digital crowdsourcing and social algorithms introduces unprecedented friction into the physical consultation room. Mousiolis et al. (2012) accurately identified this paradigm shift as the "double click and right check" phenomenon. The modern patient utilizes social media to extensively research symptoms and treatments prior to, or immediately after, a medical appointment. They essentially use the internet to "right check" their endocrinologist or gynecologist.

As Ismayilova and Yaya (2022) noted, the historical systemic failure of traditional medicine to provide empathetic care has forced patients into a defensive posture, forcing them to become their "own doctors" and heavily complicating the therapeutic alliance.

4.2. Practical Implications for Healthcare Providers

Dismissing social media as a mere adolescent distraction is now an obsolete and dangerous clinical strategy. The success of evidence-based DHIs (Zhao et al., 2026; Percy et al., 2024) proves that healthcare providers must actively participate in the digital ecosystem.

Clinicians must adopt the practice of "Digital Empathy." Instead of scolding patients for consulting TikTok or Reddit, providers should actively inquire about where patients source their health information, acknowledging the genuine trauma and body image issues (Hofmann et al., 2023) that drive them online.

4.3. Future Research Directions

While this systematic review provides a comprehensive synthesis, the rapid evolution of digital technologies necessitates ongoing research. Future studies must pivot from cross-sectional observations to longitudinal clinical trials to measure the direct, physiological impact of social media-driven behavior—such as the long-term endocrine consequences of following unregulated, TikTok-promoted supplement regimens. Additionally, there is a critical need for interdisciplinary research combining computer science and endocrinology to develop AI-driven fact-checking algorithms that can be integrated directly into social media platforms to flag unverified PCOS treatments in real-time.

Table 1. Comprehensive Characteristics of Synthesized Literature (n=23)

Author(s) & Year	Study Design & Platform	Key Findings & Clinical Implications
Afaq et al. (2025)	Big Data Analysis (X)	#PCOSweightloss narratives heavily influence global management practices.
Arabkermani et al. (2025)	App Content Analysis (MARS)	Discovered mobile apps for PCOS frequently lack evidence-based medical information.
Atigan & Atigan (2023)	Content Evaluation (YouTube)	Demonstrated exercise videos frequently lack professional credentialing.
Azziz et al. (2016)	Disease Primer / Clinical	Established foundational prevalence and metabolic risks.
Darcy et al. (2026)	Infodemiology (TikTok)	Highlighted severe clinical risks of unregulated supplement promotion.

Emanuel et al. (2023a)	Observational (Reddit)	Patients crowdsource complex laboratory result interpretations from peers.
Emanuel et al. (2023b)	Machine Learning (Reddit)	ML sentiment analysis showed reliance on peer emotion for evaluating treatments.
Gomula et al. (2024)	Qualitative Analysis	Patients use online resources for identity reconstruction ("sense-making").
Graca et al. (2024)	Scoping Review (IoT)	Mapped high saturation of the Internet of Things (IoT) in self-management.
Hofmann et al. (2023)	Cross-sectional Study	Confirmed significantly impaired body image and mental health as drivers.
Horvath et al. (2024)	Social Media Analysis (TikTok)	The discourse heavily favors anecdotal evidence over medical facts.
Hoyos et al. (2020)	Retrospective Analysis	Highlighted profound systemic patient dissatisfaction with traditional care.
Ismayilova & Yaya (2022)	Qualitative Interviews	Patients reported feeling forced to act as their "own doctors."
Kara et al. (2023)	Web-based Survey	Demonstrated high eHealth literacy directly correlates with improved quality of life.
Mousiolis et al. (2012)	Observational Review	Identified the "double click and right check" phenomenon altering clinical trust.
Percy et al. (2024)	Mixed Methods (Intervention)	Proved co-developed, web-based interventions provide safe alternatives.
Riemma et al. (2025)	Cross-sectional (TikTok)	Visual algorithms actively prioritize high-emotion, anecdotal authenticity.
Rohden & Corrêa (2024)	Qualitative (Sociological)	Highlighted how PCOS exists on the borderlines of health and beauty standards.
Sanchez (2015)	Policy / Observational	Revealed PCOS is absent from national surveillance, driving patients online.
Sucu et al. (2024)	Cross-sectional Study	Found significant levels of debilitating digital health anxiety ("cyberchondria").
Teede et al. (2023)	Evidence-Based Guidelines	Provided gold-standard management frameworks emphasizing clinical care.
Wrigth et al. (2025)	Scoping Review	Mapped the vast availability and adoption of digital technology among patients.
Zhao et al. (2026)	Systematic Review (DHI)	Confirmed that Digital Health Interventions effectively improve anthropometrics and health behaviors.

(Note: Table 1 features 23 items total, as foundational clinical guidelines by Azziz et al. and Teede et al. were included to establish the clinical baseline against which the 19 digital-focused studies were evaluated).

Table 2. Methodological Quality Assessment using MMAT (v.2018)

Author(s) & Year	Study Design Category	MMAT Score	Primary Methodological Limitation / Bias
Afaq et al. (2025)	Quantitative Descriptive	5/5	Lack of longitudinal data on whether online narratives translate to outcomes.
Arabkermani et al. (2025)	Quantitative Descriptive	4/5	MARS assessment is partially subjective despite rater training.
Atigan & Atigan (2023)	Quantitative Descriptive	4/5	Evaluation criteria for video quality can be subjective.
Azziz et al. (2016)	Clinical Review	N/A	Foundational medical primer; MMAT not applicable.
Darcy et al. (2026)	Quantitative Descriptive	5/5	High risk of demographic uncertainty of anonymous online users.
Emanuel et al. (2023a)	Quantitative Non-randomized	4/5	Selection bias: Reddit users represent a highly technologically literate subpopulation.
Emanuel et al. (2023b)	Mixed Methods (ML)	4/5	Sentiment analysis algorithms may misinterpret sarcasm in text.
Gomula et al. (2024)	Qualitative	5/5	Small sample size (n=15), though adequate for qualitative thematic saturation.
Graca et al. (2024)	Scoping Review	N/A	MMAT is not typically applied to scoping reviews.
Hofmann et al. (2023)	Quantitative Descriptive	4/5	Cross-sectional design limits causal inference regarding mental health.
Horvath et al. (2024)	Quantitative Descriptive	4/5	Focuses heavily on top algorithms, missing niche content.
Hoyos et al. (2020)	Quantitative Non-randomized	4/5	Retrospective nature relies on historical medical records and recall bias.
Ismayilova & Yaya (2022)	Qualitative	5/5	Findings specific to the Canadian healthcare context (limited generalizability).
Kara et al. (2023)	Quantitative Descriptive	5/5	Web-based survey inherently excludes PCOS patients without internet access.
Mousiolis et al. (2012)	Observational	4/5	Older dataset limits generalizability to modern algorithmic platforms.
Percy et al. (2024)	Mixed Methods	5/5	Pilot intervention phase; requires large-scale randomized controlled trial.
Riemma et al. (2025)	Quantitative Descriptive	4/5	Analyzed only top videos; algorithms serve different content to individuals.
Rohden & Corrêa (2024)	Qualitative (Sociological)	5/5	Theoretical framing introduces subjective interpretation of beauty standards.
Sanchez (2015)	Qualitative/Observational	4/5	Relies on aggregated national data and historical context.
Sucu et al. (2024)	Quantitative Descriptive	4/5	Cyberchondria scales are vulnerable to social desirability bias.
Teede et al. (2023)	Evidence-Based Guidelines	N/A	Clinical guidelines; MMAT not applicable.
Wright et al. (2025)	Scoping Review	N/A	MMAT is not typically applied to scoping reviews.
Zhao et al. (2026)	Systematic Review	N/A	High-quality systematic review; AMSTAR-2 tool typically preferred over MMAT.

5. Conclusions

The rapid transition of PCOS management from the clinical setting to the digital ecosystem is a profound, irreversible shift driven by systemic healthcare dissatisfaction and the psychological burden of the syndrome. This systematic review highlights a critical dichotomy in modern health-seeking behavior: while digital platforms, IoT applications, and algorithmic social networks provide essential spaces for patient empowerment, peer validation, and identity "sense-making," they simultaneously act as potent vectors for unverified medical misinformation. The widespread promotion of unregulated supplements on visual platforms like TikTok and the reliance on crowdsourced diagnostics on Reddit create significant friction within the traditional patient-physician relationship.

However, the literature consistently demonstrates that these risks are not insurmountable. High baseline eHealth literacy and the implementation of structured, evidence-based Digital Health Interventions (DHIs) significantly mitigate the negative impacts of algorithmic noise, translating into measurable improvements in patients' quality of life. Moving forward, the integration of digital health literacy into routine endocrine and gynecological care is imperative. Healthcare providers must abandon dismissive attitudes toward social media and instead adopt "digital empathy," actively mediating patients' online experiences to foster a collaborative, safe, and scientifically grounded therapeutic alliance.

Author Contributions

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