Methodology Special Issue

# Nurses' Knowledge and Perceptions of Caring for a Person with Polycystic Ovarian Syndrome

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# Abstract:

Polycystic ovarian syndrome (PCOS) is a condition which affects 4-20% of reproductive-aged women worldwide, yet the education, understanding and support for both healthcare staff and patients is relatively limited in comparison. This study aimed to explore nurses' knowledge and perceptions of caring for a person living with PCOS across healthcare settings.

An integrative review guided by Whittemore and Knafl (2005) was conducted. Six electronic databases were searched: CINAHL, MEDLINE, Ovid, Scopus, PubMed and ProQuest. Included studies were critically appraised using the Joanna Briggs Institute critical appraisal tools. The findings from all studies were iteratively analysed through inductive thematic analysis (Boyatzis, 1998).

Eleven studies involving approximately 1002 nurses were included. Three themes, eight categories and 172 codes were generated from 287 findings: (1) clinical manifestations (menstruation, reproduction, and fertility; physical presentation; and risks of PCOS), (2) management (functional lifestyle intervention; managing PCOS; diagnosis), (3) health literacy (PCOS knowledge; and sources of knowledge).

Deficits in the knowledge and perceptions of nurses were identified and congruent with those of other healthcare practitioners, with educational interventions proving to be beneficial to improve knowledge and understanding of PCOS. This necessitates further educational support for nurses and further development and distribution of care protocols to improve the lives of people living with PCOS.

# **Key Words**

Knowledge, Polycystic Ovarian Syndrome, Nursing

# **Research Background And Objectives**

Polycystic ovarian syndrome (PCOS) is one of the most common endocrine disorders experienced by females and is commonly characterised by amenorrhea or oligomenorrhea, elevated androgen levels and the appearance of cystic follicles on the ovaries, however no clear aetiology has yet been determined (Trikudanathan, 2015). PCOS affects approximately 4-20% of reproductive-aged women worldwide, yet the education, understanding and support for both healthcare staff and patients is relatively limited in comparison (Deswal et al., 2020).

Not only does PCOS have a varied range of symptoms including acne, it also includes difficulty also ovulating and conceiving, hirsutism, hair loss and weight gain (El Hayek et al., 2016), when left unmanaged, there is an increased risk of several comorbidities, including hypercholesterolaemia, type 2 diabetes mellitus, gestational diabetes, cardiovascular disease, sleep apnoea, psychological disorders, thyroid imbalances and endometrial cancer (Joshi. 2024).

This is further compounded in people of different ethnicities where women of Hispanic and Mexican ethnicity are at higher risk of developing insulin resistance (Engmann et al., 2017; VanHise, et al., 2023). In addition, Black American women are at increased risk of hypertension and South Asian and Indian, woman are at higher risk of metabolic syndrome, compared to white women (Engmann et al., 2017; VanHise, et al., 2023).

Being a syndrome adds complexities to understanding and diagnosing PCOS as an individual can present with a different constellation of symptoms (Sanchez-Garrido & Tena-Sempere, 2020). This, in conjunction with limited research and education on PCOS, puts clinicians such as nurses in a difficult position when it comes to supporting patients living with PCOS, because it prevents the delivery of clear evidence-based information (Hallam et al., 2022). There is some emerging evidence to show positive outcomes of the utilisation of lifestyle modifications for those living with PCOS (Cowan et al., 2023). Pharmacological interventions, targeted lifestyle changes are also a fundamental tool in management and are presented in the International Evidence Based Guidelines for PCOS (2018) as the gold-standard first-line treatment (Teede et al., 2018). Lifestyle interventions are noted as the most effective first-line treatment and management tool for PCOS, however further work still needs to be undertaken to translate this information into practice (Norman & Teede, 2018). Although current research on lifestyle modification interventions is insufficient to implement into practice, pharmacological interventions, such as the oral contraceptive pill, anti-diabetic drugs, and spironolactone (to help with excess androgen levels) are usually the first line of treatment used (Cowan et al., 2023). In addition, laboratory tests provide an understanding of the severity of symptoms a patient is experiencing, aiding in diagnosis, and thus determining the correct pharmacological approach (Ni et al., 2020).

These biochemical markers can include but aren't limited to lipid profiles, fasting glucose, fasting insulin, sex hormone binding globulin, dehydroepiandrosterone-sulphate as well as total and free testosterone (de Medeiros et al., 2020).

PCOS is typically diagnosed by way of excluding other conditions such as hypothyroidism, noncongenital adrenal hyperplasia, hyperprolactinaemia, and hypothalamic amenorrhea (Kyritsi et al., 2016). The varying nature of the condition can, in some cases, lead to incorrect diagnosis, missed diagnosis, and long delays between the onset of symptoms to diagnosis (Gibson-Helm et al., 2016).

Nurses are positioned favourably to provide high quality, evidence-based care for people living with PCOS to help improve quality of life and improve clinical indicators (Garad et al., 2019). Nurses can build genuine rapport with patients living with PCOS and provide real-time opportunities for the delivery of accurate information, support and resources, adherence to medications/treatment, satisfaction in care and self-management practices for better health outcomes (Hoyos et al., 2020). A nurse's role in caring for people with PCOS involves educating them about the condition's pathophysiology and the long-term consequences of poor management, sharing unbiased, evidence-based information on lifestyle choices, and explaining pharmacological and surgical treatment options. Additionally, nurses dispel misinformation and collaborate with patients to create tailored care plans that suit their unique needs, situations, and lifestyles (Bergh et al., 2016).

There are several reported factors that impede the delivery of high-quality care for people living with PCOS (Blackshaw et al., 2019). Systemic and organisational issues within nursing and healthcare generally are a major component that limit the care nurses can provide (Manzano García & Ayala Calvo, 2020; Zhang et al., 2018). This includes poor staffing levels, inadequate resources, limited experiential knowledge, a lack of confidence and competency, dissatisfaction, and burn out, which inherently make it difficult for nurses to provide the gold standard level of care they would like, as well as the necessary consultation time needed to understand each individuals lived experience (Dall'Ora et al., 2020; Lau et al., 2022; Nantsupawat et al., 2016). Limited education and potentially outdated or unclear information on PCOS within nursing/medical education further impairs nurses and other clinicians' role to provide high quality PCOS-specific care to their patients. They are not only restricted in providing up-to-date, sound information to their patients, but dispelling misinformation in a timely manner is more challenging (Lau et al., 2022).

The key skills that aid nurses in providing high quality care for people living with PCOS are not dissimilar to those needed to provide care for the wider population, albeit with the added layer of an in-depth understanding of PCOS (Bergh et al., 2016). These include skills such as cultural safety, providing equitable care, increasing patient engagement by genuinely listening to patients concerns and providing person-centred car.

It is also imperative that nurses have an understanding in sufficient detail the various clinical presentations of PCOS, long-term risks, consequences and application of first-line treatments (Curtis et al., 2019; Kourkouta & Papathanasiou, 2014).

By providing holistic, person-centred care, people living with PCOS can share their unique needs, experiences, and desires with nurses, which provides nurses the unique opportunity to build a trusting relationship, rapport and ultimately provide people living with PCOS the level of support and care they need (Crete & Adamshick, 2011).

Exploring nurses' knowledge and perception in caring for people living with PCOS, across various healthcare settings, will provide a platform of knowledge to direct future nursing practice, policy, and research. In undertaking a critical review of the literature, analysing, and assessing the perceptions and knowledge nurses' have in caring for a person with PCOS, this research will aid to develop further practice, update educational initiatives and guidelines for nurses as well as assist in informing future research on the therapeutic relationship between nurses and patients with PCOS.

## **Research objectives**

To explore nurses' perceptions, and knowledge in caring for a person with PCOS: An integrative review. The Sample, Phenomenon of Interest, Design, Evaluation and Research (SPIDER) type tool was utilised in this review as represented in Table 1 (Polit & Beck, 2021).

Sampla	Nurses within any healthcare setting and at any level of experience
Campic	(student nurse through to nurse practitioner).
Phenomenon of Interest	Knowledge and perceptions in caring for a person living with PCOS
Design	Integrative review
Evaluation	Nurses self-reported knowledge and perceptions
Research type	Empirical published peer-reviewed manuscripts, dissertations,
	and/or theses

#### Table 1. SPIDER

# **Research Design**

An integrative review. Whittemore and Knafl (2005)'s methodological strategies framework was used to undertake this research. The framework includes: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis and (5) presentation.

## Database Search

Six databases (CINAHL, MEDLINE, Ovid, Scopus, Pubmed and ProQuest) were searched for empirical peer-reviewed studies published between 2014 and 2024. A senior university librarian was consulted to verify the validity of the key search terms, to gain an extensive understanding of the functionality of each of the databases and to reduce the risk of database search bias.

Using the text all text function across each database, the sets of search results were combined using either the Boolean operation 'AND' or 'OR' as represented in Table 2. The screening process is presented in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow chart (Moher et al., 2009) (Figure 1).

Table 2. Search	Term	Categories
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Subject line one	"PCOS" OR "PCOS" OR "polycystic ovaries" OR "polycystic ovary					
	syndrome"					
AND	<u> </u>					
Subject line two	"nurse" OR "nurses" OR "nursing" OR "registered nurse" OR "RN" OR					
	"student nurse" OR "nurse specialist" OR "specialist nurse" OR "nurse					
	educator" OR "nurse practitioner" OR "enrolled nurse" OR "clinical					
	nurse specialist"					
AND						
Subject line three	"knowledge" OR "understanding" OR "education"					
AND						
Subject line four	"care" OR "delivering care" OR "providing care" OR "caring"					
AND	<u>.</u>					
Subject line five	"perceptions" OR "attitudes" OR "experience" OR "views" OR					
	"feelings" OR "opinions"					
AND						

Subject line six	"people"	OR	"person"	OR	"patient"	OR	"women"	OR	"female"	OR
	"woman.'	,								

### Inclusion and Exclusion Criteria

Inclusion criteria included empirical peer-reviewed studies (manuscripts, dissertations, and/or theses) published between 2014 and 2024 on nurses' perceptions, and knowledge in caring for a person with PCOS. Studies were required to have evidence of Human Research Ethics Committee approval (Table 3) and were excluded if they did not meet the inclusion criteria



Figure 1. PRISMA Flow Chart

Inclusion Criteria	Exclusion Criteria				
Literature (Empirical published peer-					
reviewed manuscripts, dissertations, and/or					
theses) published between 2014 and 2024					
Literature published in English					
Literature that focused on experiences or	Articles that did not				
knowledge	meet all of the				
Literature with a nursing focus	inclusion criteria				
Literature with a focus on PCOS					
Human Research Ethics Committee					
approval					

#### Table 3. Inclusion and Exclusion Criteria

## Definitions

Definitions were used to classify each search term area, thus ensuring the inclusion criteria were properly adhered to (Table 4).

# Table 4. Definitions of Terms

	A condition discovered by Stein and Leventhal in 1935		
	PCOS is diagnosed when a patient presents with a		
	minimum of 2 out of 3 of the following symptoms:		
PCOS	polycystic ovaries, high serum androgen levels/signs of		
PC03	high androgen levels and irregular/missing periods		
	(Louwers & Laven, 2020). This is called the Rotterdam		
	Criteria, which is used to determine if someone has		
	PCOS (Louwers & Laven, 2020).		
Perceptions and Knowledge	Perceptions and knowledge refers to the level of		
	understanding a nurse holds (in this case, in relation to		
	PCOS).		
Nurse	A nurse refers to any person who is a nurse, ranging		
	from nursing student, enrolled nurse up to nurse		
	practitioner.		
Person	A person refers to someone who has female		
	reproductive organs.		

All	healthcare	All healthcare settings refer to the healthcare settings in
settir	ngs	which a nurse works (primary, secondary, tertiary).

### Data Collection

The literature that met the inclusion criteria were independently critically appraised by two authors using the Joanna Briggs Institute (JBI) Critical Appraisal Checklists to systematically assess the validity/rigour of the research (Joanna Briggs Institute, 2022). Critical appraisal scores were discussed between the research team until a consensus was agreed. No literature appraised were excluded based on a low JBI score.

A data extraction table was used to compile relevant information on the characteristics of the included studies to promote transparency and consistency in reporting (Whittemore & Knafl, 2005). This included the title, aim, authors, year of publication, design, population, data collection methods, findings, recommendations, and critical appraisal scores.

### **Data Analysis**

The findings from all studies were iteratively analysed through inductive thematic analysis (Boyatzis, 1998). A thematic analysis approach aligns to analyse the perceptions and knowledge of nurses' caring for people with PCOS as it recognises there is no single objective truth (Dhollande et al., 2021). The concepts of phenomena about nurses' perceptions and knowledge in caring for a person with PCOS were underlined, coded (using NVivo coding) and grouped into categories and then themes based on similarity in meaning and patterns in participants' responses by all authors (Braun & Clarke, 2006).

### **Ethical Considerations**

For an integrative review, being secondary analysis of existing literature, ethical approval was not required.

### Findings

Eleven studies were included in this review that spanned across five countries (United States of America (n=4) (Carron et al., 2018; Huffman et al., 2017; Onwuzurumba, 2020; Williams, 2014)., India (n=4) (Santhi et al. 2021; Sasikala et al. 2021; Sehar, 2020; Sunanda & Nayak, 2016) Egypt (n=1), Saudi Arabia (n=1) (Thabet et al., 2021), and Ghana (n=1) (Adjei, 2019) (Table 5).

The various designs included descriptive quantitative designs (n=8) (Adjei, 2019; Huffman et al., 2017; Santhi et al. 2021; Sasikala et al. 2021; Sehar, 2020; Sunanda & Nayak, 2016; Thabet et al., 2021; Williams, 2014) and quasi-experimental designs (n=3) (Amasha & Heeba 2014; Carron et al., 2018; Onwuzurumba, 2020) (Table 5). The JBI critical appraisal scores ranged from 6-8/8 for the cross-sectional analytical designs and 7-8/9 for the quasi-experimental designs as represented in Table 6 and 7.

From the 11 studies, an inductive thematic analysis generated three themes (clinical manifestations; management; health literacy), 8 categories (menstruation, reproduction, and fertility; physical presentation; risks of PCOS; functional lifestyle intervention; managing PCOS; diagnosis; PCOS knowledge; sources of knowledge), and 172 codes generated from 287 findings (Adjei, 2019; Amasha & Heeba, 2014; Carron et al., 2018; Huffman et al., 2017; Onwuzurumba, 2020; Santhi et al. 2021; Sasikala et al. 2021; Sehar, 2020; Sunanda & Nayak, 2016; Thabet et al., 2021; Williams, 2014) (Table 8).

Table 5. Characteristics of Included Studies<sup>1</sup>

Table 6. Joanna Briggs Appraisal Tool: Quasi-Experimental Studies Checklist

Table 7: Joanna Briggs Appraisal Tool: Cross-Sectional Analytical Studies Checklist

Table 8. Thematic Analyses

#### Theme One: Clinical Manifestations

Seven studies reported on the understanding and knowledge nurses had on the clinical manifestations of PCOS (Adjei, 2019; Carron et al., 2018; Huffman et al., 2017; Onwuzurumba, 2020; Sasikala et al. 2021; Thabet et al., 2021; Williams, 2014). This theme included three categories (menstruation, reproduction, and fertility; physical presentation; risks of PCOS).

#### Menstruation, Reproduction, and Fertility

Four of the seven studies explored nurses' level of understanding of PCOS in relation to menstruation, reproduction, and fertility (Carron et al. 2018; Onwuzurumba, 2020; Sasikala et al., 2021; Thabet et al., 2021). Carron et al. (2018) assessed 48 nurses' knowledge before and after attending an educational presentation on PCOS; 92% were nurse practitioners with an average of 8.2 years of experience.

<sup>&</sup>lt;sup>1</sup> Tables 5 – 8 can be found as separate documents attached to the page of this submission for the reader's interest

The results indicated nurse practitioners had a low level of knowledge on menstrual irregularities such as amenorrhea, oligomenorrhea and dysmenorrhea before the educational session. However, significant changes were observed when nurse practitioners were reassessed on their knowledge of menstrual irregularities after the educational session (p=.000) (Carron et al. 2018). In contrast, Onwuzurumba's (2020) survey on nurse practitioner students on PCOS knowledge found relatively high baseline levels of knowledge on menstrual and fertility-related clinical manifestations. Of all participants in the pre-test, the majority correctly selected polycystic ovaries and oligomenorrhea as common clinical manifestations of the condition (100%, 87.5% respectively).

Similarly, Sasikala et al. (2021) reported nursing students' knowledge on PCOS menstrual and fertility related manifestations as being high, such as '84.09% knew that PCOS can cause infertility'. Thabet et al. (2021) further stated 60.8% of the nursing students knew that 'women suffering from PCOS have small multiple cysts in their ovaries' and in relation to menstruation, the responses were varied such as 15.8% of nurses regarded 'prolonged menstruation, more than 7 days', 13.3% deemed 'complete cessation of the menstrual cycle', 27.8% regarded 'a partial cessation of the menstrual cycle' and 31.6% regarded 'heavy menstruation' as indicators of PCOS.

#### Physical Presentation

Five of the seven studies explored nurses' level of understanding of PCOS in relation to physical presentations/symptoms (Carron et al. 2018; Onwuzurumba, 2020; Sasikala et al., 2021; Thabet et al., 2021; Williams, 2014). Outside of menstrual and fertility related symptoms, there was mixed knowledge across these studies on other clinical presentations of PCOS. Nursing students' knowledge regarding PCOS symptoms included '*hirsutism*' (36.1%), '*acne*' (81.1%) and '*hair loss as common symptom*'s (36.7%) (Thabet et al., 2021).

The PCOS physical presentations/symptom questions answered correctly by nursing students from one nursing school were 'acne' (55.1%), followed by 'unusual amount of hair loss from the scalp' (27.8%), 'uncommon hair growth in different parts of your body' (22.2%), 'discoloration or dark colour patches on skin' (25.3%) and 'continuous abnormal weight gain' (19%) (Thabet et al., 2021). In addition, 'acanthosis nigricans (velvety patches over nape of the neck)' (56.81%) and 'hirsutism' (61.36%) were scored low to moderate knowledge among nursing students in India (Sasikala et al., 2021). With regards to symptoms used in the Rotterdam Criteria, Williams (2014) found relatively high levels of knowledge across their sample of certified nurse practitioners on common PCOS symptoms.

Of significance, comparatively, less than half (43.8%) of the nurse practitioners in the Carron et al. (2018) study identified hyperandrogenism as important physical presentations before undertaking a clinical educators' program on PCOS. However, the nurses' knowledge on hyperandrogenism as an important physical presentation increased significantly after the program to 93% (Carron et al. 2018).

## Risks of PCOS

Five of the seven studies explored nurses' level of understanding of PCOS in relation to the inherent risks of PCOS (Adjei, 2019; Carron et al., 2018; Onwuzurumba, 2020; Sasikala et al. 2021; Thabet et al., 2021). Aside from the imminent presenting symptoms, PCOS comes with the risk of poor long-term health outcomes including '*cardiovascular complications*,' '*coronary artery disease'*, '*diabetes mellitus*', '*dyslipidaemia'*, '*metabolic syndrome'*, '*obesity'*, '*hypertension'*, and '*psychological distress*' (Adjei, 2019; Carron et al., 2018; Onwuzurumba, 2020; Sasikala et al. 2021; Thabet et al., 2021). Nursing students in India had a sound knowledge on the risks of PCOS that included '*metabolic syndrome*,' '*dyslipidaemia*,' '*risk for coronary artery disease*,' '*hypertension*,' '*diabetes mellitus*,' and '*endometrial cancer*' (Sasikala et al. 2021). However, third year nursing students had significantly greater knowledge on risk factors and complications compared to first year students (p< 0.001) (Sasikala et al. 2021).

Only three studies touched on mental health and wellbeing (Carron et al. 2018; Adjei, 2019; Sasikala et al. 2021). Less than a fifth of nurse practitioners identified psychosocial mental health implications when surveyed (Carron et al. 2018). Adjei (2019) reported unanimous agreement amongst 142 nurses that '*PCOS is difficult to live*' with and that '*depression*' can be common due to the raft of health complications and presenting symptoms (Adjei, 2019). When synthesising baseline knowledge of nursing students, there was clear emphasis on the mental impact of PCOS, with 84% agreeing PCOS '*can cause psychological upset*' (Sasikala et al. 2021).

### Theme Two: Management

Five studies reported on the level of knowledge nurses had on interventions, treatment, and management of PCOS (Carron et al. 2018; Huffman et al. 2017; Onwuzurumba, 2020; Sasikala et al. 2021; Thabet et al. 2021). This theme included three categories (functional lifestyle interventions, managing PCOS, and diagnosis).

#### Functional Lifestyle Interventions

Four studies reported on nurses' knowledge regarding functional lifestyle interventions for people living with PCOS (Huffman et al. 2017; Carron et al. 2018; Onwuzurumba, 2020; Sasikala et al. 2021). Functional lifestyle interventions included '*diet,*' '*weight loss,*' '*exercise*' *and 'lifestyle modifications*'

(Huffman et al. 2017; Carron et al. 2018; Onwuzurumba, 2020; Sasikala et al. 2021). It was evident in the four studies that functional lifestyle interventions were becoming more recognised by nurses as an effective first-line management tool for those living with PCOS. Nurse practitioners recognised the importance of lifestyle interventions as first-line treatment, finding that 62% 'were more likely to endorse a period of lifestyle modification prior to prescribing medications for ovulation induction' for PCOS-related fertility concerns (Huffman et al. 2017). Onwuzurumba (2020) highlighted the importance of an educational intervention, when assessing the knowledge of using lifestyle modifications as a management tool within a cohort of nurse practitioner students in America. The results prior to the educational intervention showed that only 25% of those surveyed thought lifestyle modifications were used as a first-line treatment for PCOS, whereas after the educational intervention, all participants selected lifestyle modifications as a first-line treatment (Onwuzurumba, 2020). Carron et al. (2018) reported minimal knowledge on the use of lifestyle modifications for PCOS amongst licensed nurse practitioners, nurse practitioner students and clinical nurse specialists in America. Only 20.9% of the nurses reported 'lifestyle modifications' as first-line treatment, whereas 70% of the nursing students in India reported 'poor lifestyle choices' had a negative impact on people living with PCOS (Carron et al. 2018; Sasikala et al. 2021).

### Managing PCOS

Only two studies reported specifically on the management of PCOS through medication and medical interventions (Carron et al. 2018; Thabet et al. 2021). Common medications reported by nurses included *'metformin'* (to manage metabolic symptoms), *'spironolactone'* (to treat symptoms associated with elevated androgen levels), *'clomiphene citrate'* and the *'oral contraceptive pill'* (for menstrual irregularities), and *'surgery for the removal of ovarian cysts'* (Carron et al. 2018; Thabet et al. 2021). Carron et al. (2018) reported rural nurse specialists' knowledge on the effective management of PCOS prior to an educational intervention were *'oral contraception'* (45.8%), *'metformin'* (75%), *'spironolactone'* (29.2%), *or 'clomiphene citrate'* (4.2%), whereas post-educational intervention were *'oral contraception'* (95.3%), *'metformin'* (62.8%), *'spironolactone'* (67.4%), *or 'clomiphene citrate'* (16.3%), whereas *'insulin-managing drug metformin'* decreased by 12.2%.

Similarly, Thabet et al. (2021) assessed the level of awareness of nursing students regarding PCOS in Saudi Arabia where nursing students reported *'hormone therapy'* (76.6%), *'surgical removal of ovarian cysts'* (73.4%) and *'anti-diabetic medications'* such as *'metformin'* (57%) as what they considered to be effective treatments.

#### Diagnosis

Three studies reported on nurses' knowledge for diagnosing PCOS (Amasha & Heeba 2014; Carron et al. 2018; Williams, 2014). Two studies used the Rotterdam PCOS diagnostic criteria (the current gold-standard) for diagnosing PCOS (Carron et al. 2018; Williams, 2014).

In the Rotterdam criterion, nurses assess areas such as physical manifestations, biochemical signs of elevated androgen levels, oligomenorrhea, anovulation, and ultrasonographic polycystic-ovary morphology (Carron et al. 2018; Williams, 2014). Williams (2014) reported nurse practitioners in America acknowledged there were *'no diagnostic guidelines specific to adolescents'*, which considered symptoms such as *'irregular menses'*, *'acne'*, and *'weight gain'*, as these also commonly present as part of normal physiologic pubertal changes, thus making a definitive PCOS diagnosis difficult. The nurse practitioners used various sections of the Rotterdam criterion for diagnosing patients (Williams, 2014).

Nurse practitioners also reported using other tools to aid PCOS diagnosis such as *'menstrual calendars (62%)*' and *'the NIH diagnostic criteria guide (52%)*', whereas some nurses (11%) used both *'the NIH and Rotterdam criteria*' to aid in diagnosis of PCOS among adolescents (Williams, 2014). Carron et al. (2018) reported nurse practitioner's knowledge prior to an educational intervention was varied such as nurses (56%) identified menstrual irregularity (i.e., amenorrhea, oligomenorrhea, dysmenorrhea, or menstrual irregularities) for the first Rotterdam criterion, nurses (43.8%) identified hyperandrogenism (i.e., acne, hirsutism, androgenic alopecia, elevated testosterone or "androgen levels") for the second Rotterdam criterion and nurses (18.8%) identified polycystic ovaries as an assessment and diagnostic marker for the third Rotterdam criterion. In addition, less than 17% of nurses identified testosterone or dehydroepiandrosterone-sulfate levels as laboratory tests for assessment and diagnosis of PCOS (Carron et al., 2018). However, after the educational intervention the nurses' knowledge of diagnosing PCOS significantly improved (Carron et al., 2018).

More than half (56%) of the nurse practitioners in the Williams (2014) study reported significant barriers that impacted or prevented them making a PCOS diagnosis in the adolescent population.

The main barriers identified include no definitive diagnostic criteria to diagnose adolescents (20%), nurses' lack of knowledge regarding diagnosis and treatment (18%), nurses perception of PCOS manifestations as a part of the normal physiologic pubertal changes that will subside (18%), nurses not recognizing PCOS in adolescents (16%), adolescents not seeking fertility counselling (44%), adolescents infrequent visits to healthcare providers (14%), adolescents limited access to the healthcare system (.01%), and adolescent's reluctance to seek assistance, especially if they were not sexually active (4%).

In addition, nurses' perceived barriers to a PCOS diagnosis was further influenced by parental input and beliefs, such as a parent's denial of the potential PCOS diagnosis (10%), exhaustion on behalf of the parent and the adolescent from multiple tests prior to the confirmation of a PCOS diagnosis (4%), as well as parent's and adolescents overlooking PCOS symptoms and perceiving them as a normal part of adolescence (10%) (Williams, 2014).

### Theme Three: Health Literacy

Nine studies reported on PCOS health literacy (Adjei, 2019; Amasha & Heeba 2014; Carron et al., 2018; Onwuzurumba, 2020; Santhi et al. 2021; Sasikala et al. 2021; Sehar, 2020; Sunanda & Nayak, 2016; Thabet et al., 2021). This theme included two categories (PCOS knowledge and sources of knowledge).

### PCOS Knowledge

Nine studies reported on PCOS knowledge which varied across studies. It was evident, the clinical healthcare setting had an impact on nurses' knowledge of PCOS, with outpatient departments, obstetrics and gynaecology having higher overall levels of knowledge in comparison to an emergency and paediatric setting; further factors included gender, experience of PCOS, age, university education, student's academic year, resources, social media and rank (Adjei, 2019; Amasha & Heeba, 2014; Thabet et al. 2021).

Significant improvements in the understanding of nurse's knowledge were reported after a PCOS educational intervention in three studies (Amasha & Heeba, 2014; Carron et al. 2018; Onwuzurumba, 2020).

However, the overall knowledge that registered nurses had of PCOS with or without an educational intervention was low such as 'only 2% of the nurses had average knowledge related to PCOS' Amasha and Heeba (2014), '1 (2.27%) of students had adequate knowledge, 37 (84.09%) of students had moderately adequate knowledge and only 6 (13.63%) of students had inadequate knowledge on polycystic syndrome' Santhi et al. (2021), 'most of the students (114) had average knowledge (76%)' Sunanda and Nayak (2016), 'majority of nursing students (60%) have average knowledge' (Sehar, 2020), 'most of the participants (82.9%) had an overall moderate knowledge about PCOS' (Thabet et al. 2021). Many registered nurses 'were unaware of the condition '(51.4%) and '80.0% of them reported they did not have any knowledge regarding PCOS' (Adjei, 2019; Amasha & Heeba, 2014).

Amasha and Heeba (2014) reported statistically significant differences (p<0.001) between the pre-educational intervention and post-educational intervention scores for PCOS knowledge for all the items in the program, with greatest increase observed in the nurses' knowledge for '*diagnosis*' (86.67%), '*meaning (definition)*' (86%), '*risk factors*' (85%) and '*causes of PCOS*' (80%). Gains in PCOS knowledge post an educational intervention were further reported in the Carron et al. (2018) and Onwuzurumba (2020) studies.

## Sources of Knowledge

Five studies reported on sources of PCOS knowledge (Adjei, 2019; Amasha & Heeba 2014; Onwuzurumba, 2020; Sunanda & Nayak, 2016; Thabet et al. 2021). Sources of knowledge included 'training programs', 'school', 'another health professional', 'healthcare providers', 'internet', 'social media', 'family and friends', 'school', 'academic learning', 'brochure / newspaper' and 'TV/radio' (Adjei, 2019; Amasha & Heeba 2014; Thabet et al. 2021) with a reported association between 'knowledge on PCOS and demographic variables such as source of information (Sunanda & Nayak, 2016). Educational intervention as a source of building PCOS knowledge appeared to have a positive impact on understanding (Onwuzurumba, 2020). Statistically significant differences were found between level of knowledge and quality of the source of such knowledge.

### Discussion

This review identified three themes in the existing literature on nurses' perceptions and knowledge in caring for a person living with PCOS being clinical manifestations, management, management, and health literacy.

#### **Clinical Manifestations**

Whilst menstrual irregularities and fertility are a recognised component of PCOS, there are several other clinical manifestations that can present. However, the name 'Polycystic Ovarian Syndrome' focuses heavily on the reproductive component of the disease, insinuating that "*polycystic ovaries are a sine qua non of the disorder*" when this is in fact inaccurate (Azziz, 2014, pg. 1143). This can be confusing to both patients, nurses, and physicians as it incorrectly denotes that polycystic ovaries are malignant tumours (Azziz, 2014). This is also consistent with findings from this review, which saw low to moderate nursing knowledge on PCOS clinical manifestations with some nurses not recognising polycystic ovarian morphology as a key indicator of PCOS (Carron et al. 2018).

However, where there was nursing knowledge evident within this review, there was a heavy focus on menstrual irregularities and fertility-based symptoms as a primary indicator of the condition (Carron et al. 2018; Onwuzurumba., 2020; Sasikala et al., 2021; Thabet et al., 2021). This is concordant with the wider literature where physicians were aware of irregular menses as an indication of the possibility of PCOS and this symptom was their most frequently used diagnostic item for the condition (Saini et al., 2016; Yan et al., 2021). Research that surveyed 13 Norwegian General practitioners and gynaecologists found perceptions consistent with both the literature in this review and the wider literature (Fernandes et al., 2020). These physicians highlighted the need for fertility treatment to help people with PCOS get pregnant more easily, even though this may not be the desired outcome for every person who seeks assistance for their symptoms (Fernandes et al., 2020). This is also congruent with patient perceptions of care, where there was a heavy focus on fertility management, in conjunction with dismissal of concerns patients put forward in their consultations (Tay et al., 2022).

PCOS is an incredibly complex condition, and whilst it does have overt menstrual and fertilityrelated symptoms for many of those with the condition, a more holistic recognition of the condition is needed, to encompass the wide variety of symptoms a person living with the condition can present with. As per the research by Ricardo Azziz (2014), further education about PCOS along with the need for a name change to reflect the broader clinical scope of symptoms is essential.

Only three manuscripts in this review reported on nurses' knowledge on patients' psychosocial wellbeing (Adjei, 2019; Carron et al. 2018; Sasikala et al. 2021). Similarly, Saini et al. (2016) found obstetrics and gynaecology physicians were less aware of associated depression (49%), anxiety disorders (23%), and reduced quality of life (51%) experienced by people living with PCOS.

Similar findings on PCOS knowledge were evident in obstetrician-gynaecology residents, gynaecologists and endocrinologists in the United States of America and China (Chemerinski et al., 2020; Ma et al., 2021). It is evident, a discrepancy exists between the mental health burden of PCOS experienced by patients and the lack of healthcare professionals' understanding of the psychosocial, and emotional impact. Further education and resources in both supporting patients and educating nurses is warranted.

#### Management

Determining what is evidence-based best practice for nurses and other healthcare professionals in diagnosing and managing PCOS is paramount in supporting patients' health.

Currently, the International Evidence Based Guidelines (IEBG) for PCOS (2018) are considered as gold-standard evidence-based guidelines for PCOS management (Teede et al. 2018). Four articles in this review reported on functional lifestyle interventions in PCOS, with moderate knowledge across nursing students, registered nurses, nurse practitioner students and nurse practitioners; where improvements in nurses' PCOS knowledge was evident after undertaking a PCOS educational workshop (Carron et al. 2018; Huffman et al. 2017; Onwuzurumba, 2020; Sasikala et al. 2021). In the wider literature, endocrinologists, obstetricians, and gynaecologists noted the importance of lifestyle interventions as part of their patients' PCOS management plan, however many considered this as outside of their scope of practice, suggesting allied health referrals as appropriate for lifestyle management education (Chhour et al., 2021; Ma et al., 2021). Chhour et al., (2021) also highlighted that lack of time to gather relevant PCOS specific lifestyle information and consultation time constraints were the most common reasons for this deferral. These issues were further voiced by general practitioners as barriers in providing care to PCOS patients (Arasu et al., 2019).

Research showed many general practitioners favoured medications such as the oral contraceptive pill as their first intervention upon consultation, which was relatively consistent with the data in this review (Arasu et al., 2019; Carron et al. 2018; Fernandes et al., 2020; Thabet et al. 2021).

Other research points to the fact that medications should be first line for some symptoms of the condition such as fertility, anovulation, insulin resistance and acne, noting that oral contraceptives should only be used if patients aren't planning to start a family (Badawy & Elnashar, 2011; Jin & Xie, 2018; Williams et al., 2016). However, the IEBG (2018) caution about using medications as first-line treatment, due to their potential compounding impact on the mental health and wellbeing of patients (Norman & Teede, 2018).

The guidelines also note that many medications used for PCOS are not typically designed with the condition in mind (Norman & Teede, 2018). So, while they can be effective to varying levels, they should not be considered first line treatments but used only when needed in conjunction with correct lifestyle modifications (Norman & Teede, 2018).

#### Health Literacy

In this review, it was evident that the level of health literacy held by nurses on PCOS and its management, was not sufficient to be conducive with the best practice guidelines. Similarly, the overall knowledge held by other healthcare professionals on PCOS is lacking, thus resulting in inconsistent support and management by clinicians, and consequently, poorer interactions and outcomes for PCOS patients (Piltonen et al., 2019; Tassone et al., 2018). While the level of education in formal training is insufficient in providing up to date education on PCOS, the level of experiential knowledge also was seen to impact the level of care provided (Dokras et al., 2017). The source of knowledge gained by clinicians and patients alike is critical when looking at not only the level of understanding but the quality of such knowledge. Sources of knowledge reported in the wider literature were similar to those of the literature in this review (Adjei, 2019; Amasha & Heeba 2014; Carron et al., 2018; Huffman et al., 2017; Onwuzurumba, 2020; Santhi et al. 2021; Sasikala et al. 2021; Sehar, 2020; Sunanda & Nayak, 2016; Thabet et al., 2021; Williams, 2014).

It is important to note that health professionals such as nurses and physicians were one of the primary sources of information for patients' trying to understand PCOS and its management; followed closely by the internet, friends, and family (Abu-Taha et al., 2020; Jabeen et al., 2022; Jena et al., 2020; Kaundal et al., 2023). Additionally, patients reported support groups and conversations with others experiencing the condition as good sources of information (Holbrey & Coulson, 2013). Many patients stated they felt more informed about PCOS with up-to-date information accessed through the internet (AlSinan & Shaman, 2017). However, there are issues with information collected by patients online, as there is no easy way of ensuring the information is credible (Holbrey & Coulson, 2013). In the Gibson-Helm et al. (2014) study, more than half of the patients who received a PCOS diagnosis stated they were not provided with any information sources and a further 20% who were provided information said it was inadequate. There is a deficit in nurses' and clinicians' health literacy on PCOS, further training on up-to-date evidence based PCOS diagnosis and management is paramount.

#### Strengths

There are several strengths that support the validity and rigour of this review. The literature included in this review didn't exclude any country, context of care (primary, secondary, and tertiary healthcare settings), or degree/level of nursing qualifications which provided a wide scope of PCOS knowledge amongst the nursing profession. This research also identified that better support for nurses on PCOS identification and management needs to be integrated at a multi-tiered level from an organisational, governmental, clinical, and academic lens. This review has provided further insight and opportunities for improving nurses' knowledge on PCOS through ongoing research, education, and practice.

### Limitations

Some limitations evident in this review despite a rigorous systematic process being undertaken have been identified.

Some studies included did not attain a high JBI critical appraisal score, however due to the limited published literature on this phenomenon, no studies were excluded based on a low JBI score. In addition, the researcher selected broad characteristics in the curation of the research question, due to limited research on PCOS that included a nursing focus. The researcher has, in the past, been employed at a clinic specialising in PCOS, and so may hold potential inherent biases. However, the researcher kept a reflective journal on these biases and has enlisted the support of a research supervisor without a background in this area to mitigate any potential biases throughout the review.

### Words of Wisdom

It is evident from both this review and the state of the science on this phenomenon that women's health is frequently misunderstood and under researched. Due to the limited literature within nursing research on PCOS and the deficits in the existing literature, further high-quality research should be undertaken to build on the understanding of PCOS from a triadic lens. These individuals are already underrepresented in the literature and are known to have poor health outcomes, thus the need for a greater understanding of how they experience PCOS and the supports they receive would help direct future practice and educational interventions to deliver more equitable supportive individualised care.

## Implications for practice

Not only does this review contribute to the literature on women's health but it assists in guiding nursing policy and practice.

The research identifies the deficits in the knowledge of nurses on PCOS, making clear where the focus of resources and work are most needed. Additionally, the literature that utilised educational interventions showed statistically significant improvements in knowledge in posttest data, therefore reinforcing the need to support nurses at all levels to further their understanding of PCOS is paramount.

# Conclusion

Deficits in the knowledge and perceptions of nurses were identified and congruent with those of other healthcare practitioners, with educational interventions proving to be beneficial to improve knowledge and understanding of PCOS. This necessitates further educational support for nurses and further development and distribution of care protocols to improve the lives of people living with PCOS.

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