

Sexual and Reproductive Health Needs of Women with Polycystic Ovarian Syndrome: A Scoping Review and Narrative Synthesis

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Abstract

Background: Polycystic ovarian syndrome (PCOs) is one of the most common endocrine disorders in women throughout the world affecting their sexual/ reproductive health (SRH). **Objective:** This scoping review aims to identify SRH needs of women with PCOs **Methods:** PubMed, SCOPUS, Google Scholar, MEDLINE, Science Direct, Ovid and the Cochrane Library were screened from 2000 to 2019. English or Persian peer reviewed and gray literature sources were included. In the primary search, 52 articles were obtained; and finally by narrative synthesis framework for quality assessment, and data analysis and synthesis 27 articles were analyzed. **Results:** From the 27 selected articles, 9 main themes were obtained i.e.: Complications and problems affecting patients, Lifelong effect of PCOs on reproductive patterns , PCOs and adverse reproductive and pregnancy outcomes, Information needs and preferences of patients about health outcomes and their application for treatment and management of lifelong health outcomes, Financial burden of disease, The effect of PCOs on life experiences and quality of life of affected women, Sexual disorders, Psychological concerns and issues, Femininity feelings and roles **Conclusion:** Comparison of the 9 themes developed in this study with SRH needs in women, revealed that some of the issues, such as psychological challenges, patients' femininity feelings and roles and financial burden of disease have been ignored in providing SRH services, and should be taken into consideration.

Background

Health with its different components is an essential part of human life (1). Today, health and welfare of women, who make up half of the population, is not only recognized as a human right, but its effect on the health of the family and society has also become increasingly important (2).

One of the important aspects of every woman' health during her lifetime is sexual /reproductive health (SRH) and related needs. According to the World Health Organization (WHO), reproductive health refers to physical, mental and social well-being related to the reproductive system and its function (3, 4).

The issue of reproductive health contains a range of health services throughout life from birth to death; its aim is to help individuals and families to improve their health (5, 6).

Without SRH, women will not be able to achieve their other rights too. according to published statistics on the burden of diseases, 22 percent of lost lives in women of reproductive age is due to the neglect of reproductive rights and related health problems (7-9). On the other hand promoting SRH has been considered to be essential in achieving the Millennium Development Goals (10) .

An important disease that affecting various aspects of women's health is Polycystic Ovarian Syndrome (PCOs), which is the most common endocrine disorder in women. This syndrome is a combination of Hyperandrogenism, chronic anovulation and polycystic ovaries, and is usually associated with insulin resistance and obesity. This syndrome has major effects on women's lives because of its high prevalence (varying between 2.2 to 26% in different regions) (11, 12).

PCOs research has shown that the quality of life of women with PCOs is lower in comparison to other women. Many aspects of women's health are affected by this syndrome which can significantly reduce the patients' quality of life (13, 14).

In recent decades, the focus on the quality of health services has increased significantly. But despite the significant success of health systems in promoting community health, there is still a considerable gap in achieving desirable conditions in SRH domain (15). Therefore taking a comprehensive approach to SRH, enables service providers to identify needs (16).

Many studies in women with PCOs have addressed different medical and health needs such as infertility, metabolic disorders, mental disorders and quality of life (14), but there is little evidence about sexual /reproductive health needs of women with PCOs. Therefore, the present scoping review study was performed to identify these needs in women with PCOs.

Methods

The present study is a “scoping review” about SRH needs of women with PCOs based on English or Persian peer reviewed and gray literature sources from 2000 to 2019. The method used was Arksey & O'Malley method (17).

2-1- Identification of research questions:

According to the research goals, the research question was chosen as follows: What articles have been published in journals since 2000 about SRH needs of women with PCOs?

Based on this question, the PCC method (population, concept and context) was used for review:

Population: Women with PCOs at reproductive ages.

Concept: Sexual and reproductive health needs of women with PCOs.

Context: Iranian and international publications.

2-2- Selection of the relevant databases

Data bases searched according to our study question were:

Elsevier, Guideline Central, Johns Hopkins Medicine, Oxford Journals, BMJ, Springer, Ovid, MEDLINE, Science Direct, ProQuest, Scopus, EBSCO host, Cochrane library, Pub med, Google Scholar; and Iranian data bases including: SID, Magiran, Irandoc, Iran Medex

2-3- Select studies

2-3-1- Exclusion and inclusion criteria

Criteria for inclusion in the study were: English or Persian peer reviewed and gray literature sources since 2000 about PCOs patients' SRH needs. Studies about other diseases or groups were considered as exclusion criteria. The following keywords were used: sexual and reproductive health needs; women; polycystic ovarian syndrome; health needs; health guidelines; health protocols; women's needs; women's health needs; reproductive health needs.

2-3-2- Search results and quality appraisal:

At first, articles related to the research question were identified (52 articles). In the preliminary review, irrelevant articles were identified and removed. After applying the inclusion and exclusion criteria and removing irrelevant and repeated articles, 42 articles were selected. For quality assessment of the articles, PRISMA flow chart and data extraction guide of Popay was used which was adapted for checking robustness of both qualitative and quantitative studies. The articles were independently studied by two researchers for quality appraisal and relevance assessment and the related papers were identified. In case of disagreement, the article was judged by a third researcher (18, 19). Finally, from 42 articles, 27 papers were selected, of which 25 articles (92.6%) were published in English and 2 articles (7.4%) were in Persian (Figure 1).

2-4- Critical Appraisal

2-4-1- Methods used in studies

The methods used in selected articles were:

- Descriptive/cross sectional: 5 (%18.5)
- Mixed Methods: 1 (% 3.7)
- Qualitative: 6 (% 22.2)
- Cohort: 2 (% 7.4)
- RCT (randomized controlled trial): 1 (% 3.7)
- Systematic review: 2 (% 7.4)
- Review article: 9 (% 33.4)
- Meta-analysis: 1 (% 3.7)

2-4-2- Study places

Study places included four regions: the United States, Australia, Europe, and Asia (Table 1).

Risk of bias:

For minimizing the risk of bias, the double check process of validation was performed. Also the risk of bias in the included studies was assessed by Cochrane risk of bias tool and completeness of reporting outcome data (attrition bias), and selective outcome reporting (reporting bias). Also, by searching on different websites and platforms, we tried to minimize selection bias in the selection of articles.

Data analysis:

Data was analyzed by narrative synthesis method. It is used when statistical meta-analysis or another special form of synthesis is not feasible due to substantial methodological and clinical heterogeneity between studies identified. This method has four main elements: 1- Developing a theory, 2- Preliminary synthesis of findings of the included studies, 3- Exploring relationships in the data, 4- Assessing the robustness of the synthesis (19). In "developing the theory", we needed to have a clear understanding of sexual and reproductive health needs in PCOs women, so we began purposefully searching and exploring SRH needs and its categories. All articles were initially screened by two reviewers who independently reviewed titles and abstracts of the studies to accept or reject the full text paper. Thus after assessing the quality of the articles, the selected articles were identified. In the second step – "developing a preliminary synthesis of the findings", data was extracted from eligible studies and converted to primary codes. Reviewers discussed any disagreements in the data extracted, and referral to a third reviewer was done to resolve any disputes. In the third step

"Exploring relationships in the data ", primary codes were assessed by the reviewers and categorized based on the found relationships. Finally themes were extracted from the primary codes. In this way, the primary codes were extracted from the texts of the selected articles, and then the main themes were formed from these codes. For "Assessing the robustness of the synthesis ", the basic concepts extracted of articles were performed by three reviewers to be sure of the concordance of the obtained themes with the texts. Then the primary codes were categorized into specific categories.

Results

96 Primary codes were derived from reviewed material about needs, problems and complications related to sexual / reproductive health of women with PCOs. Then, 9 themes were extracted from these 96 Primary codes. Table 2 shows the themes extracted from the selected articles, with number of articles, and study methodology of related articles in each theme.

Theme A (Complications and problems affecting patients): With 5 primary codes, addresses issues such as hirsutism, hyperandrogenism, anovulation, acne, endogenous alopecia, menstrual disorders, cardiovascular complications, insulin resistance, diabetes, obesity and infertility.

Theme B (Lifelong effect of PCOs on reproductive patterns): With 17 primary codes, examines the importance and distinction of clinical symptoms in all life periods of women with PCOs starting from adolescence to old age.

Theme C (PCOs and adverse reproductive and pregnancy outcomes): With 11 primary codes, examines the association between disease complications such as menstrual irregularities, hyperandrogenism, obesity, Insulin resistance and increased serum LH levels with adverse outcomes in pregnancy, delivery and infancy such as preeclampsia, preterm delivery, gestational diabetes, abortion, neonatal LGA (Large for Gestational Age) risk, meconium aspiration, 5 minute Apgar score less than 7, and increased need for prenatal care and childbirth.

Theme D (Informational needs and preferences of patients about health outcomes and their application for treatment and management of lifelong health outcomes): With 9 primary codes addresses the educational and informational needs of women with PCOs with childbearing, prioritizing health needs, deciding on possible strategies for treatment, and choosing the best lifestyle.

Theme E (Financial burden of disease): With 3 primary codes refers to the annual financial burden of PCOs, including \$ 1.35 million for menstrual dysfunction, \$ 533 million for infertility services, \$ 1.77 million for diabetes, and \$ 622 million hirsutism treatment.

Theme F (The effect of PCOs on life experiences and quality of life of affected women): With 19 primary codes, addresses the impact of physical, psychological, emotional, cognitive and social aspects of quality of life in women with PCOs. It also examines ways to improve the outcomes of infertility services in order to improve the quality of the women's lives.

Theme G (Sexual disorders): With 10 primary codes, explores the impact of disease, its treatments and complications on women's sexual function.

Theme H (Psychological concerns and issues): With 17 primary codes, examines the effects of disease complications such as obesity, menstrual problems, infertility, emotional disturbances and hirsutism on psychological aspects of women's health. It also points to patients concerns such as worries about physical symptoms, fears of future complications, and challenges of a chronic condition.

Theme I (Femininity feelings and roles): With 5 primary codes, examines the impact of the disease on social roles of patients as women and mothers, and their responsibilities.

Table 3 shows a sample of extracting primary codes from texts and then forming a theme (theme A).

Discussion

In this study, out of 27 selected articles, 96 primary codes were derived about the needs, problems and complications related to SRH needs of women with PCOs. Finally, 9 main themes were extracted from these codes. These 9 themes were compared with the 6 domains of SRH needs in "Assessment of Sexual Wellness Needs" questionnaire developed by UNFPA (2008) in Zimbabwe, which are: 1. Safe motherhood, morbidity profile and hygienic practices, 2. Family planning, 3. Sexual history and practices, 4. Sexually transmitted infections, 5. HIV and AIDS, 6- Sexual and gender-based violence ([20](#)).

In the present study, themes A, B and C are consistent with the first domain in UNFPA questionnaire which is “safe motherhood”. Themes A, B and C, respectively, investigate the complications of PCOs on health of women, the effect of disease on patterns women's life and the effect of disease on reproductive consequences.

In theme A, the articles mentioned that PCOs has various influences on reproductive system (21). Some complications such as menstrual disorders and infertility directly affect the reproductive health, also infertility and its consequences can affect the process of pregnancy and the care needed before, during and after pregnancy. On other hand, menstrual disorders affect ovulation, pregnancy, and also the choice and use of contraceptive methods (22-25).

In theme B, articles emphasized the impact of PCOs on reproductive symptoms of patients throughout their lives from embryonic period to adulthood, with significant complications of PCOs such as obesity, hirsutism, and anovulation. Therapeutic methods of disease, can affect the fertility of women in short-term and long-term. Also, the disease can affect the status of sex hormones, menstrual cycle and ovulation status, and cause infertility and fertility disorders (26-28). The point is that this theme refers to the chronic nature of the disease during women's reproductive life. Some symptoms such as acne, hirsutism and obesity are more likely to affect teenaged patients; conditions such as menstrual and ovulation disorders, obesity, and the choice of contraceptive methods affect reproductive aged women, and complications, such as long-term cardiovascular, and metabolic disorders, and increased risk of cancer more affect women in premenopausal and menopausal period (26) . Therefore, in planning for provision of SRH services, in addition to considering overall complications of the disease, the special problems in each stage of the patients' lives should be noted.

Theme C demonstrates adverse reproductive outcomes in women with PCOs, such as: pregnancy complications including: gestational diabetes, preeclampsia, preterm labor, fetal death, neonatal death, low Apgar scores, meconium aspiration, large for gestational age (LGA) and small for gestational age (SGA) newborns, and macrosomia (29, 30). According to the UNFPA reproductive / sexual health needs questionnaire (20), this theme was related with prenatal care, provision of health care during and after childbirth, and treatment of obstetrics complications. Rose McDonnell study mentioned that PCOs is associated with reproductive complications including: miscarriage, hypertensive disorders, gestational diabetes, and prematurity. Also the study indicated that PCOs has serious complications for women and their offspring with regard to long and short term reproductive functions, risk of chronic illness, and congenital anomalies, thus health care resources should be allocated accordingly to meet these challenges (31).

Theme D shows informational needs of reproductive aged PCOs patients regarding their fertility, childbirth and health service preferences. There are few studies on reproductive health priorities of women with PCOs, and their information about the complications and treatment of their illness, and its effects on childbearing. Investigating these gaps and informing about childbirth decisions and identifying health priorities is essential for women with PCOs (32, 33). Theme D is not related to any of the 6 SRH

needs domains in the UNFPA questionnaire (20). Therefore, it seems that management of the informational needs and launching educational programs is another necessity for patients with PCOs.

In theme E, financial burden of PCOs in United States includes: \$ 1.35 million for hormonal treatments of menstrual dysfunction, \$ 533 million for infertility care, and \$ 1.7 billion for diabetes associated with PCOs, \$ 622 million for hirsutism treatment, with an overall value of care assessment for women with PCOs in reproductive ages being \$ 4.36 billion. Considering the cost of disease diagnosis and treatment, it can be concluded that preventing and screening for this disorder is a financially cost-effective strategy (34). None of the SRH needs domains in the UNFPA questionnaire (20), directly refers to the financial burden of disease. But given today's limited resources, it is essential to pay attention to this aspect of PCOs and in providing women with SRH services, the financial burden of each complication of the disease should be assessed, according to the age of the affected woman.

Theme F is not directly consistent with the domains of the UNFPA questionnaire but it is indirectly consistent with the domains of gender-based violence, and sexual behavior (20). It shows that PCOs affects women's lives from fetal period to death, increasing mortality rates and reducing women's physical, emotional, and social aspects of quality of life (35, 36). Also, the results of these studies showed that women with PCOs had serious health concerns which are often ignored in services provided by the health systems. Health service providers can play an important role in identifying these needs (37, 38).

Theme G examines sexual dysfunction in patients with PCOs. PCOs may affect female sexual function because of complications such as ovulation disorders, obesity, and hyperandrogenism. Studies have indicated PCOs has significant effects on sexual desire and stimulation of the sexual cycle, while hirsutism affects all sexual domains except for dyspareunia (39). Also, complications of the disease, such as anovulation, obesity and hyperandrogenism, affect the sexual function of women with PCOs in regard to desire, stimulation, lubrication, orgasm, satisfaction, and pain (40). Studies have shown that among the symptoms associated with PCOs, infertility and hair loss have more negative effect on sexual function (37). According SRH needs of UNFPA questionnaire (20); this theme matches with “sexual history and sexual behavior”. Thus, evaluating sexual function of women and educating about sexual problems by health service providers is essential in promoting the sexual health of patients.

Theme H studies psychological concerns in women with PCOs. The most common psychological concerns of women with PCOs include: fears about physical symptoms, financial burden of the disease, fears about future complications and chronic diseases. The most common worries and psychological outcomes are being overweight, menstrual problems, infertility, emotional problems and hirsutism. But most of the psychological consequences of the illness are underestimated and overlooked by health services providers (41). Therefore, patients need to receive special support to reduce their worries so they can improve their disease management by changing their lifestyle (42). While the psychological concerns and challenges of patients can affect their reproductive and sexual health, such as pregnancy, self-esteem, sexuality, gender and sexual violence; none of the UNFPA questionnaire domains (20) is

compatible with these concerns. On the other hand, women with PCOs are more susceptible to mood disorders and depression (43). In Zangeneh study, clinical signs of PCOs were associated with psychiatric disorders and it was recommended to consider these disorders in the diagnosis and treatment of PCOs (45). Therefore, it seems that these women, as soon as the disease is diagnosed, require screening for psychological disorders and referral to appropriate counseling centers, if needed. (44).

Theme I looked at the role of femininity in women with PCOs and noted that PCOs symptoms impeded patients' roles as women and mothers, and affected the meeting of their responsibilities. Women with PCOs have a small role in portraying women's part in general health (45). According SHR needs of UNFPA questionnaire(20); this theme is consistent with the sexual and gender-based violence domain. As mentioned, women with PCOs get mainly involved in the treatment of physical complications and slowly forget their social roles and femininity. Therefore, in assessing SRH needs, it is imperative to consider femininity feelings and roles of the patients.

There are two domains in the UNFPA questionnaire including: "Sexually transmitted infections" and "Human Immunodeficiency Virus and AIDS"(20); but in our studies to date, there have been no Special study that addressed these two domains in patients with PCOs. Studies have shown that HIV-infected women are increasingly exposed to insulin resistance and fat distribution and obesity, which is a common finding in PCOs patients. But the studies conclude that among HIV-positive people with severe abdominal fat and hypertension, there are no common features with PCOs (46).

Studies have indicated that with increasing age of patients, if there is no suitable management of the disease process, the risk of cancer is elevated. Rezayat study has shown that PCOs is a common endocrine disorder that, in addition to producing reproductive problems, is known to be a risk factor for breast and reproductive system cancers (including endometrial and ovarian tumors). Obesity and endocrine disorders that are caused by PCOs are two of the most important risk factors for women's cancers, including ovarian and breast cancers (47). Shaejabi study also highlights the increased risk of breast and ovarian cancers among women with PCOs, especially in long-term complications. Therefore, it seems that paying attention to and screening for cancers in women with PCOs is very important and should be considered as a major SRH need in them (48).

Conclusion

The findings showed that in many health systems designed to provide SRH services, the needs of patients with PCOs were not specifically considered and their needs were approached as ordinary women. The articles showed that the disease and its complications have a high financial burden that is often ignored in identifying and evaluating SRH needs of women. Also, the chronic nature of the disease effects mental status of the patients and the psychological consequences of disease, are often hidden and not paid attention to. The provision of services to women with PCOs lacks continuity and integrity, thus in identification and provision of SRH services to these women, there is a gap. According to evidence, since PCOs can affect the entire life of a woman, patients need different services, and health

systems should try to provide the best of services based on their limited resources. Therefore, studies such as the present study can offer that SRH needs in women with PCOs have to be addressed in a complete package in the form of protocols and guidelines that are based on the actual needs of the patients.

Limitations: The limitations of the present study were that, since many studies did not address the needs of women's reproductive / sexual health, we had to use all the data and articles published in this area, including qualitative/ quantitative methods, lectures, and guidelines. Also, due to this heterogeneity in the methodology of the selected articles, there was no meta-analysis possible.

Abbreviations

PCOs: Polycystic Ovarian Syndrome; SRH: sexual /reproductive health; WHO: World Health Organization; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses;

Declarations

Ethics approval and consent to participate

Permission to carry out this study and its design was obtained from The Ethical Committee of Tarbiat modare University (TMU), Tehran, Iran on 25 Septem 2017 with the code: IR.TMU.REC.1396.619

Consent for publication

Not applicable

Availability of data and materials

The data upon which the results are based, which are the articles studied, can be accessed through a simple internet search.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All the authors contributed to the concept and purpose of the study. MK drafted the first copy of the manuscript. EM, LM, LA, AP and SHSH revised the manuscript. LM carefully checked the manuscript for important academic content. All authors approved the final version of the manuscript.

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Tables

Due to technical limitations, the table is only available as a download in the supplemental files section.

Figures

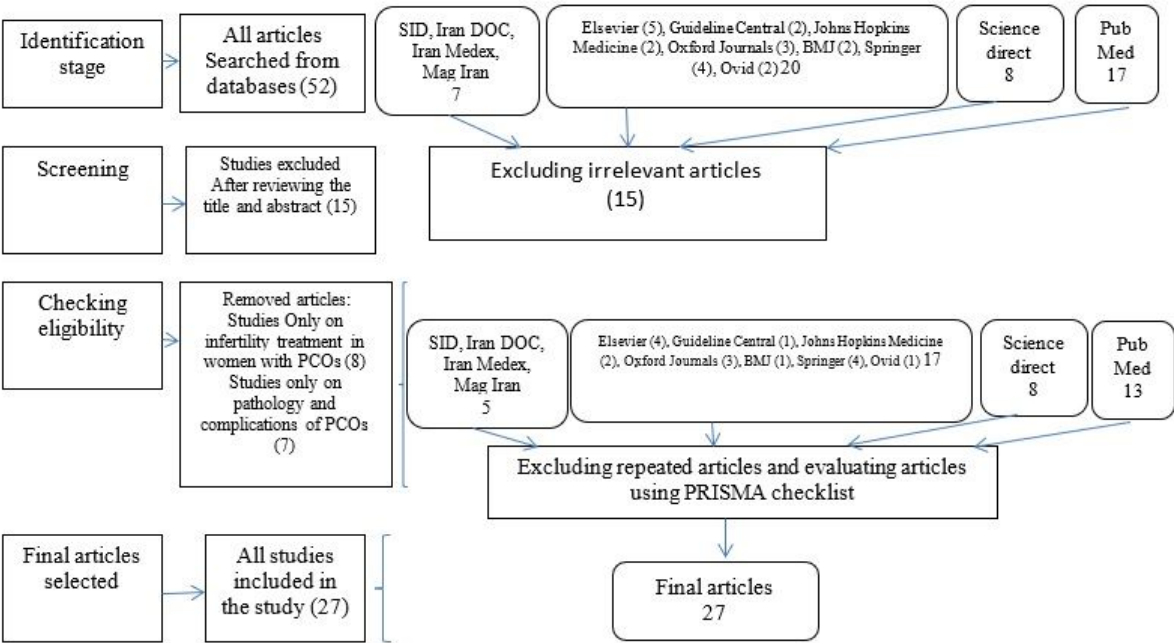


Figure 1: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart review steps

Figure 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart review steps

Supplementary Files

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