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# **Patient-centered Fertility Care: From Theory to Practice**

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#### ABSTRACT

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**Background & aim:** Healthcare areas, especially fertility care (commonly accompanied with high emotions, as well as long-term and recurring treatment periods) could exclusively benefit from patient-centered care (PCC). Despite evident advantages of PCC, this approach has not been practiced as a routine procedure in current clinical environments yet, even in western developed countries. Therefore, this review aimed to evaluate the significance and different aspects of PCC, while emphasizing on patient-centered fertility care, its challenges, and applicable recommendations in this regard.

*Methods:* This narrative review was conducted on 29 relevant medical and clinical papers (published during 1990-2015) collected using various national and international databases (e.g., SID, Magiran, Medlib, Google scholar, Proquest, Pubmed, Wiley, Science direct, and Scopus). Key words and phrases used in this review were "infertility", "fertility care", "childlessness", "patient-centered care", "patient-centered fertility care" "shared decision-making", "infertile patient preferences", and "patient involvement in fertility care".

**Results:** According to the literature, implementation challenges of patient-centered fertility care were reported as different individual and organizational factors. These factors include lack of professional motivation to change, underestimating the significance of patient-centeredness by healthcare professionals, difficulty in translation of feedback into concrete measures, lack of time and financial resources, insufficient experience of healthcare professionals with regard to identification of needs and preferences of patients, traditional organizational culture, and common misconceptions.

**Conclusion:** Promotion of patient-centered fertility services requires the identification of infertile needs and priorities of individuals, designation of interventional and supportive programs based on sociocultural characteristics of the community to fulfill such preferences, and considering patients as the most significant stakeholders of each healthcare center. This review might provide important data for healthcare professionals and policymakers aiming to improve patient-centered fertility care.

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#### Introduction

Many young couples expect to be parents, which is a social matter in the majority of countries. However, one out of six couples may fail due to lack of fertility (1). Infertility is rated as one of the greatest stress sources in everyday life (2-4). The multifaceted nature of infertility affects

mental, social, physical, and emotional health of infertile couples (1, 5-6). In addition to the psychological impacts of infertility, treating it could also be associated with major emotional, physical, and economic effects, as well as periods of hopefulness and hopelessness (7, 8). Therefore,

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evaluation of infertility can be extremely stressful for most of the couples (9).

Medical progress made in this realm, as well as new methods devised for the treatment of infertility, have sparkled new hope for infertile patients; however, the emotional and psychological effects of infertility are still neglected by healthcare professionals. Only the biological and medical aspects of infertility have been duly taken into consideration (10). An exclusively medical approach has pushed the other aspects of infertility to the margins (11). While infertility does primarily deal with medical treatments, various studies have shown the significance of emotional and psychological aspects of infertility, which require greater attention and support (10, 12-18).

Despite the widespread prevalence of infertility and its numerous psychosocial problems (faced by infertile couples throughout all the stages of infertility), inadequate attention has been paid to the psychoemotional aspects of infertility in infertility treatment centers (19). Meanwhile, in addition to customary medical treatments and provided supports, identification of various needs of infertile patients, especially psychoemotional needs, is of paramount importance. Provision of patient-centered fertility care, specifically designed based on the needs and expectations of infertile patients, is regarded as the natural right of couples (18, 20-23).

Patient-centeredness is a key factor for highquality care and can be responsive to needs and values of patients (24). American Institute of Medicine (USAIM) defines this issue as providing care with respect to and directed at preferences, needs, and values of responding patients, while guaranteeing that all the clinical decisions are made based on the values of patients (25-31).

Patients can widely benefit from patient-centered fertility approach (24, 32-34), which might eliminate some of the emotional burden of infertility and its intensive treatment periods (32, 35). Patients are better heard and their opinions, notions, needs, and concerns are better identified through the application of patient-centered approach, which leads to a positive treatment experience. It also encourages patients to cooperate with caregivers, ultimately leading to

less misunderstanding and complaints by patients regarding the healthcare system (16).

Despite the importance of patient-centeredness in the area of fertility care, it is neglected and not optimally performed yet (29, 36). Many studies have been carried out regarding patient-centered fertility care, its barriers, and challenges across the world; however, these issues were not concertedly studied in a single study, especially in Iran. Therefore, this review of the literature aimed to evaluate the significance and different aspects of patient-centered care (PCC), while emphasizing on patient-centered fertility care, its implementation challenges, and applicable recommendations in this regard.

#### **Materials and Methods**

To conduct this narrative review, five steps were respectively performed as follows: 1) identifying the research question, 2) Choosing research methods for identification of relevant studies, 3) selecting and extracting the relevant studies, 4) classifying, analyzing, and summarizing the data and 5) reporting the results.

#### Identification of research question

For the purpose of this study, the main research question was "What were the most important challenges in implementation of patient-centered fertility care?"

# Research methods for identification of relevant studies

Extensive literature review was conducted through focusing on related medical and clinical papers (published during 1990-2015) collected using various national and international databases (e.g., SID, Magiran, Medlib, Google scholar, Proquest, Pubmed, Wiley, Science direct, and Scopus). In this review, the key words and phrases were "infertility", "fertility care", "childlessness", "patient-centered care", "patient-centered fertility care", "shared decision-making", "infertile patient preferences", and "patient involvement in fertility care". The qualified papers were quantitative, qualitative, or mixed methods studies.

#### Article Selection

The inclusion criteria of this review were as follows: 1) lack of fertility, 2) patient-centered care, and patient-centered fertility care directly or indirectly, 3) published during 1990-2015, 4)

written in English or Persian languages, 5) published in full text and 6) accessible through literature search.

In total, 228 articles were found, among which 29 met the inclusion criteria. The remaining 199 articles were excluded due to not being relevant to the research question or the purpose of this study, being replicated, and lack of access to the full text of articles. This narrative review was extensively carried out by first and fifth authors of this study under supervision of other three authors. Finally, the data were collected and classified under some sub-headings in the results section of the paper.

#### Results

#### Patient-centered care

PCC plays a pivotal role in demonstration of the quality of provided healthcare services (25, 34), and contributes great advantages to patients (16, 34). This approach attempts to encourage patients to actively improve their own healthcare process and to enhance the relationship between the patient and caregivers (26).

Harvey Picker, the founder of Picker Institute, was one of the indefatigable champions of PCC provision (37), and his institute was a pioneer in the production of valid surveys on PCC (38). Picker believed that healthcare should be provided in a way that could correspond with the well-being and problems of patients, coordinate with personal values and preferences of patients, and involve them and their family members in the decision-making process for their own healthcare program (37).

The current community is going through a fast-paced evolution and people are increasingly becoming eager to play an active role in designing their own personal life, and so are

patients of the current generation. They are willing to establish open communication channels with their healthcare professionals and prefer to have an active role in the decision-making process of their treatment. Moreover, they demand to be treated like a human being with a health problem and not a container of a disease (26).

An improved interaction between patients and their healthcare professionals helps achieving a more accurate identification of patients' problems and needs, as well as enhancing patient satisfaction regarding the provided services (39). This issue might promote to the higher understanding of patients in terms of treatment problems and possible choices, leading to better cooperation with the healthcare team with regard to medical instructions and recommended modification in their own lifestyle. On the other hand, this effective communicative approach could result in decreased level of stress and tension in patients (21, 39). Alternative terms for this care provision approach include patient-centered care, cooperative care, and cooperative medicine and health (26).

The World Health Organization (WHO) and Picker Institute introduced PCC as a multi-faceted concept in two recommended frameworks (Table 1), from which all beneficiaries in the healthcare system can benefit (40). Evidence suggests that supporting patients in terms of self-management and making informed decisions based on their treatment choices can definitely enhance the overall quality and security of care (34, 40). In addition, they lead to decreased healthcare costs and prohibited exhaustion of health resources (40). Not only does this approach boost the cooperation between patients and caregivers,

Table 1. Domains of patient-centeredness according to the Picker institute and WHO

Picker institute principles	WHO responsiveness model
Accessibility	Confidentiality of information
Information & communication	Communication
Partners & family involvement	Access to family & community support
Respect & autonomy	Autonomy
Organization of healthcare	Freedom to choose your own healthcare provider
Continuity of care	Dignity
Physical comfort	Prompt attention
Emotional support	Quality of basic amenities

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but it also leads to increased job satisfaction of healthcare professionals (34, 40).

Safety, effectiveness, efficiency, equity, timeliness, and patient-centeredness are six domains of quality of clinical care (25, 26). Despite evident benefits of PCC, such care is not yet practiced as a routine in current clinical environments, even in developed western countries (26). Although the American Institute of Medicine accentuated the six main aspects of high-quality healthcare in 2001, only two aspects of safety and effectiveness were consequently taken into consideration and patient-centeredness has been neglected (41). One of the current challenges of healthcare professionals is combining all the essential components of high-quality care in daily healthcare services. Some of the most important factors for beneficial, physical, and emotional healthcare services provided for patients are cost-effectiveness, safety, patientcenteredness (16).

#### Patient-centered fertility care

All types of healthcare services that are associated with great emotional consequences and long-term treatment plans (e.g., care provided for patients suffering from cancer or rheumatoid arthritis) can benefit from PCC (35). Fertility care is another instance of such sensitive areas (34, 35). It is clear that all those infertile patients (almost 55%) in search for treatment support are dealing with long-term processes of either diagnosis or treatment. This long period leads to great damages and psychosomatic burden, persisting from a few months to even years. Therefore, infertility and its treatment process can affect the quality of life of couples and might harm their psychosocial well-being, sexual satisfaction, and marital relationship.

Meanwhile, about 23% of couples have no desire to continue with the treatment process due to its great physical and emotional burden (41). Lack of healthcare personnel empathy and inadequate attention to psychological aspects of treatment have been mentioned by patients as reasons of ending the treatment process (42). Therefore, given the remarkable dropout rates of patients, the stigmatizing character of infertility, and lack of willingness of patients to complete their treatment process due to its mental and physical damages, infertility treatment centers

should make an attempt to provide PCC services more than ever (34, 41).

Studies conducted on fertility care in the recent decades have mainly focused on improving the effectiveness of reproductive medicine with regard to hormonal ovarian stimulation, embryo culture methods, genetic screening before implantation, pregnancy rate, prevention of high-order multiple pregnancies. Although there is no doubt regarding the importance of above-mentioned factors, it is worth mentioning that the quality of fertility care goes bevond pregnancy consequences or effectiveness. Effectiveness is only one of the six aspects of quality of care, and patient-centeredness is often forgotten in this regard (36). Patient-centeredness is one of the most important factors for demonstration of the quality of fertility care (16). Investment of infertility treatment centers in promotion of experiencing the relevant care by patients might lead to the resolution of emotional tensions and physical damages caused by infertility treatment. This could help the couples successfully achieve their treatment objectives. On the other hand, prevalence of PCC approach can have salutary effects on job satisfaction of healthcare professionals (43).

# Different aspects of patient-centered fertility care

As mentioned before, Picker institute provides the most comprehensive PCC approach merging interpersonal organizational aspects of care. This approach consists of eight aspects, which could alleviate fear and anxiety of individuals. Dancet et al. employed Picker Institute methodology to provide a deep description of PCC based on the viewpoints of patients regarding infertility treatment. In the aforementioned study, in addition to the confirmation of recommended aspects of PCC (by Picker institute), the researchers were able to recognize two more care aspects, including the competence of medical personnel and their viewpoints and the employed communication method (44). Ten aspects of PCC are presented in Table 2 in the form of an interactive model. Patient-centeredness of infertility care depends on six system factors and four human factors, as well as their interaction with

Table 2. The interaction model of patient-centered infertility care

#### **Patient-Centered infertility care**

#### System factors Information Competence of clinic and staff Coordination and integration Accessibility

Continuity and transition



#### **Human factors**

Attitude of staff and their relationship with patients Communication

Patient involvement and privacy

**Emotional support** 

one another (45).

Physical comfort

#### **Challenges**

Although evident merits of PCC have been recognized before, the implementation of this approach is not easy and feasible. In this regard, challenges are influenced by different individual and organizational factors (38), including lack of professional motivation to change, problem in translating feedbacks into concrete measures, and lack of time and financial resources (35). One of the barriers to the realization of this approach is that healthcare professionals in fertility care centers underestimate significance of patient-centeredness (41, 46) and, consequently, fail to accurately assess their own performance (41, 47). Another challenge faced by these centers is the common organizational culture of individuals (41). For instance, more attention has been paid to the quality of outcome measures (e.g., effectiveness and safety) of fertility care (32), while the mindset of healthcare professionals personnel is more "provider-focus" than "patientfocus" (48). Moreover, healthcare professionals lack the necessary experience regarding the identification of patients' needs (26, 49). Healthcare professionals inaccurately believe that patient-centeredness means responding to every request of patients, which leads to increased healthcare expenses (38). Therefore, it is necessary to take measures for changing professionals' attitude toward PCC (41, 50-51).

#### **Discussion**

PCC is a key component of care in each healthcare setting, particularly in infertility care (44). Benefits and practical implementation of PCC are still not clear to healthcare providers (38). Accordingly, the healthcare system is fundamentally designed based on the viewpoints of healthcare providers and is mainly directed by

the decisions made by caregivers and healthcare professionals on the quality of provided care services (21, 26).

PCC is a kind of paternalistic approach to patients. In the current system, patients receive imperfect, inefficient, and ineffective care that are not usually integrated. Moreover, due to the common attitude of healthcare system, patients still play a passive role in the treatment process and cannot benefit from necessary means for self-management with regard to their own health status (26). Meanwhile, infertile couples emphasize the importance of their autonomy, appreciate informed shared decision-making (21), and express their desire to receive PCC (44).

If Healthcare is designed based on the viewpoints of patients, more cost-effective cares with enhanced quality, safety, and accessibility could be provided for individuals. Additionally, patients are placed at the center of healthcare teams' attention in the PCC approach (26). In fact, synchronized and integrated services, tailored based on the needs of patients, can positively affect clinical outcomes, well-being of patients during treatment, treatment compliance, treatment success rates, and quality of life of patients (26, 44). In this regard, the most recent challenge is the application of this approach where patients and healthcare professionals are of the same status in the healthcare team. Certain changes should be applied to care system if healthcare professionals aim to give a central role to patients. This is also necessary to move from the classical model of professionalism toward a customer-centered model (26).

Application of PCC approach is definitely accompanied with more attention to patients through the provision of optimum responses to patients' expectations and empowering them. Therefore, if we want to shift to this approach, it is necessary to identify the needs and preferences of patients, provide interventions to recognize the

strengths and weaknesses of healthcare providers, promote the communication skills of healthcare personnel, and prove adequate trainings programs for medical personnel.

Application of PCC certainly increases the quality, efficacy, and cost-effectiveness of the healthcare programs in infertility care centers (21). Other key factors for achieving PCC are engagement of a responsible leadership, a clear constant communicative strategy of healthcare organization, sufficient resources, a supportive culture in terms of change and education, active participation of patients and families at different stages of care, a supportive workplace, systematic assessment and evaluation, quality organization, and of information supportive technology (48).Implementation of PCC in infertility centers should be considered as a criterion for evaluation and performance comparison of all centers with one another. In addition, it must be used as a criterion of performance assessment of healthcare pro-fessionals in these centers and a basis for rewarding them. These selection criteria could help patients make informed choices regarding fertility centers, in which high quality, efficient, and appropriate services are provided (38).

#### Strengths and limitations of the study

Despite the evaluation and summarization of various available studies in the present research, since it is a narrative review, other researchers might reach different conclusions by reviewing the findings of different studies. Another limitation of this review was the inclusion of just English and Persian articles, which led to exclusion of the findings of other studies. Therefore, it is recommended that further comprehensive studies (especially systematic reviews) be conducted in this regard.

Other major drawbacks of this study were extensive evaluation of various databases in this review, as well as reviewing and screening the 29 included articles by two of the authors (the first and fifth authors) under the supervision of other three authors. According to the results, this was the first narrative review of literature conducted in the area of patient-centered infertility care.

#### Conclusion

Promotion of patient-centered fertility services requires the identification of needs and preferences of infertile couples, designing interventional and supportive programs based on sociocultural characteristics of the community to fulfill such preferences and needs, and considering patients as the most significant stakeholders of each healthcare center. This review might provide some insight into important information for the healthcare professionals and policymakers aiming to improve patient-centered fertility care.

#### **Conflicts of Interest**

The authors declare no conflicts of interest.

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