



## CHALLENGES OF IMPLEMENTING PATIENTS' BILL OF RIGHTS: A QUALITATIVE STUDY

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### ABSTRACT

**Background and Objectives:** Assuring patients' rights is among the most basic duties of all health service providers. In order to fulfill this task, Iranian patients' bill of rights was compiled and communicated. However, its full implementation faces some challenges and problems. This study aims to explore the above-mentioned challenges through a multidimensional approach considering the views of patients, university teachers and students.

**Materials and Methods:** In this exploratory study, insights from key informants including 43 teachers, students and patients were gathered in grounded theory approach, and analyzed with qualitative content analysis method.

**Results:** Barriers to the implementation of patients' rights from the perspective of the participants in this study were classified in 3 main themes including health system characteristics, health care providers' personal and sociocultural characteristics, and patients' personal and sociocultural characteristics. Lack of a proper system of evaluation and control, incomplete information dissemination, undesirable justice in services, inadequate patient participation in decision-making, insufficient human resources, inappropriate work environment (physical and human relations), lack of an ideal system of dealing with complaints, personal problems of service providers, outdated knowledge of service providers regarding patients' rights and about Islamic affairs in addition to social, cultural and ethnic differences among service providers and among patients, are the most important obstacles.

**Conclusion:** Optimal implementation of patients' rights in health centers is related to multiple factors in the areas of economy, culture and society. So, oversimplification should be avoided and all the factors be addressed.

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### Introduction

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Assuring patients' rights is among the most basic duties of all health service providers. Respect for the role of patients in treatment and care, besides recognition of differences in culture, race, language, religion, age, gender and needs of people with disabilities, are considered as the main rights to which healthcare environments are expected to be sensitive. Patients' bills of rights were developed as a way to achieve these goals [1]. The bill aims to promote participation of patients and their families as members of the care team, thus assisting hospitals in fulfilling their functions [2]. Nowadays, health citizenship is known among patients' rights, whose realization strategies require patient and public involvement [3].

Nonetheless, implementing patients' rights faces obstacles and challenges. As literature shows, some of the main obstacles include potential conflict between patients' rights and the rights of health service providers [2], racial orientation [4], and the interference of electronic portals with confidentiality of patient information [5].

Iranian patients' bill of rights codified in 2002 and revised in 2009, focuses on receiving optimal health care as a right for patients, patients' access to adequate and desirable information, patients' right to choose and decide freely about receiving health services, respect for patients' privacy and confidentiality and their right to access to an efficient system dealing with the patient's complaints.

Despite the comprehensiveness of the patients' bill of rights, ensuring its full compliance across healthcare system requires measures such as socializing the idea of respecting the rights of all stakeholders and identifying and resolving obstacles to its implementation [6]. Previous studies report inadequate knowledge of patients, nurses, physicians, and medical students about patients' bill of rights, lack of enforcement, work overload of nurses and shortage of human resources, in addition to educational activities in hospitals, as the main challenges of patients' bill of rights implementation [7].

Studies also suggest that although most health care providers agree with the implementation of patients' rights [8], but patients [9-15] and care providers [16-18] consider the current state of patients' rights as weak or mean. Other studies show significant correlation between knowledge and experience of health service providers [19], different levels of awareness about the content of patients' bill of rights [20], and the divergent opinions of different groups of providers and recipients of services with regard to various aspects of patients' rights [21], and insufficient knowledge of the service providers about patients' rights [11, 19, 22-25]. In a separate study, the barriers of implementing the patients' bill of rights were investigated and the factors facilitating patient's rights were categorized as organizational factors, employees-related factors and factors related to the recipients of health services [26].

Defects mentioned in the literature about the challenges of compliance with patient rights as well as the weakness of the body of knowledge in the area mentioned, led us to carry out this study, so that applicable solutions may be sought.

## Materials and Methods

In this study, we used exploratory approach to challenges of implementing the patients' bill of rights. We referred to the key informants, according to Grounded Theory method and data were analyzed through qualitative content analysis.

Participants of the study were 43 persons selected through purposive sampling. For better accuracy, a wide range of participants' age, sex and education was covered. The participants consisted of 19 oncology clinic patients, 8 medical ethics teachers, and 16 senior medical students who participated in this research after obtaining informed consent.

The data were gathered through a questionnaire consisting of three parts: demographic characteristics with respect to each group of the participants and open-ended questions about the current state of patient rights observance and the obstacles to the implementation of the patients' bill of rights.

As the study aimed to assess the challenges and obstacles of implementing patients' bill of rights, the items of patients' bill of rights clauses were added to the questionnaire to ensure the participants' awareness on the content of the document.

Challenges and problems of patients' rights were asked by this simple question: "what do you think, has hindered implementing patients' bill of rights?"

The data was analyzed by two members of medical ethics department, and the themes were developed. Data reached saturation point after analyzing data from eight patients, six teachers and 14 students.

## Results

Demographic characteristics of the participants, is presented in table 1.

**Table 1.** demographic variables of the research participants

| Variables      | Patients  | Students  | Instructors |
|----------------|-----------|-----------|-------------|
|                | N (%)     | N (%)     | N (%)       |
| Sex            |           |           |             |
| Male           | 3 (15.8)  | 6 (37.5)  | 6 (75)      |
| Female         | 16 (84.2) | 10 (62.5) | 2 (25)      |
| Marital Status |           |           |             |
| Single         | 5 (27.8)  | 11 (68.8) | 0 (0)       |
| Married        | 12 (66.7) | 5 (31.3)  | 8 (100)     |
| Divorced       | 1 (5.6)   | 0 (0)     | 0 (0)       |
| Education      |           |           |             |
| Illiterate     | 3 (16.7)  | 0 (0)     | 0 (0)       |

|                               |             |            |            |
|-------------------------------|-------------|------------|------------|
| Literate                      | 4 (22.2)    | 0 (0)      | 0 (0)      |
| Preliminary                   | 1 (5.3)     | 0 (0)      | 0 (0)      |
| Diploma                       | 6 (31.6)    | 0 (0)      | 0 (0)      |
| Associate Degree              | 2 (10.5)    | 0 (0)      | 0 (0)      |
| Bachelor or Higher            | 2 (10.5)    | 0 (0)      | 0 (0)      |
| Nativity                      |             |            |            |
| Native                        | 0 (0)       | 4 (25)     | 0 (0)      |
| Nonnative                     | 0 (0)       | 12 (75)    | 0 (0)      |
| The Mean (Standard Deviation) |             |            |            |
| Age                           | 44.5 (19.6) | 26.6 (2.5) | 46.1 (3.3) |
| Duration of Illness           | 1.5 (1.2)   | 0 (0)      | 0 (0)      |
| Work Experience               | 0 (0)       | 0 (0)      | 16.4 (2.9) |
| Medical Ethics Experience     | 0 (0)       | 0 (0)      | 4.7 (3.4)  |

Tables 2 to 4, depict the participants' opinions about the factors preventing the observance of patients' rights within three main themes including health system characteristics, health providers' personal and sociocultural characteristics, and patients' personal and sociocultural characteristics.

#### Health system related barriers

Human resources as the main assets of any organization, play a decisive role in efficiency and effectiveness and this emphasizes that inadequate human resources must be taken serious if the realization of patients' rights is to be warranted.

**Table 2.** Health system related barriers of patients' rights observance

| Barriers   | Instructors | Students | Patients |
|--|-------------|----------|----------|
| Inadequate system of evaluation and control for the implementation of patient rights | ✓           | ✓        | ✓        |
| incomplete information dissemination system  | ✓           | ✓        | ✓        |
| Failure to provide fair and thorough services  | ✓           | ✓        | ✓        |
| Lack of patient participation in decision-making                                     | ✓           | ✓        | ✓        |
| Lack of supportive public sector   | ✓           | ✓        | ✓        |
| Insufficient number of service providers   | ✓           | ✓        | ✓        |
| Improper structure of the workplace (physical and human relations)                   | ✓           | ✓        | ✓        |
| Lack of a mechanism of reward and punishment   | ✓           | ✓        |          |
| Lack of an efficient system of dealing with complaints                               | ✓           | ✓        |          |
| Unclear owner of the process of implementing patients' rights                        | ✓           | ✓        |          |
| Inefficient state laws   | ✓           | ✓        |          |
| Incomplete insurance system  | ✓           | ✓        |          |
| Inappropriate health economics   | ✓           | ✓        |          |
| Educational processes in public hospitals  | ✓           | ✓        |          |
| Partial health care services in public hospitals                                     | ✓           | ✓        |          |
| Multi- job doctors   | ✓           | ✓        |          |
| Lack of trained team of social work in the hospital                                  |             | ✓        |          |
| Financial relationship between physician and patient                                 | ✓           |          |          |

As the table 2 shows, "Insufficient specialized human resources and expert personnel in addition to its improper distribution in the country", "extensive workload of personnel as a result of patient turnover, overtime work for the sake of financial need and inevitable work instead of two people in a crowded and stressful ward" were some of the statements of the teachers concerning the issue, while the students mentioned some other problems such as "multi-job physicians (administrative and treatment positions) which lead to the waste of patients' time for executive affairs", and that "normally, a physician obliged to visit 70 patients within 2 hours, cannot demonstrate the true kindness and politeness in his behavior; nor can he give sufficient information to persuade the patient about the prescription". Inadequate human resources and lack of time hinders "full information provision to patients". So not only "decision-making processes are not free and informed", but also "in some instances, they make patients hurry up and decide under pressure".

Improper mechanism of control and assessment and "not giving feedback to those who observe patients' rights and those who do not" is another barrier of patient's rights implementation. Unreliable system of dealing with complaints and "subsequently, lengthy processes, lead to compulsory withdrawal of patients from their complaints."

Moreover, as students stated, "inadequate insurance protection of physicians is another obstacle to put forth all the truth for patients in case of any error or patients' rights violation."

Governmental hospitals have their own limits for patient as a result of their massive clients, leading to violating some rights of patients. As an example, in students' opinion, "although it is a right for patients to attend in hospital coupled with their trusted people, lack of resources and crowded rooms and that if every patient has a companion, there is a real traffic, this right of patients is ignored." On the other hand, as a result of educational activities in governmental hospitals "and presence of others including students, interns and residents, some patients do not give full explanation of their history, and this may lead to diagnosis and treatment mistakes."

#### Health care providers- related barriers

Some barriers of patients' rights realization should be categorized in social, cultural, and individual characteristics of health care personnel. The main points in this part are shown in the table 3.

**Table 3.** Health care providers- related (social, cultural, and individual) barriers of patients' rights observance

| Barriers   | Instructors | Students | Patients |
|--|-------------|----------|----------|
| Individual problems of health care providers (job dissatisfaction, financial needs, etc.)          | ✓           | ✓        | ✓        |
| Ignorance of Islamic laws and customs among health care providers                                  | ✓           | ✓        | ✓        |
| Lack of appreciation for the rights of patients by health care providers                           | ✓           | ✓        | ✓        |
| Ethnic, cultural, and social divergence among health care providers                                | ✓           | ✓        |          |
| Outdated knowledge of some health care providers   | ✓           | ✓        |          |
| Harm of the dignity of patients as a result of some very intimate relationships between physicians | ✓           | ✓        |          |
| Lack of collaboration among physicians in relation to patients                                     | ✓           |          |          |

According to the students, "since many health care workers do not like their works, consider their jobs risky and boring, and think they have the right to reject work as much as possible," or in other words, "to prefer financial and personal benefits over the interests of the patient."

From the teachers' point of view, "not caring for patients' rights and their personalities," "belief in the incompetence of patients to intervene in the decision-making process of diagnosis and treatment," and "insufficient awareness of confidentiality issues" are among the individual barriers of patients' rights realization.

As the students have stated, some physicians' adherence to ethical principles is in question, "even if there are enough facilities, the organizational culture of medical centers prevents accepting patient's wishes. For example, a patient's idea of determining his doctor is understood as an insult for the treatment team." These have their roots in "culture of the community and weakness of mutual respect to each other's rights" and "not very positive attitude to one another", as it is said "despite religious beliefs, there is a kind of racism determining some behaviors of people." This means that "some physicians visit some patients better than the others because of a certain type of thinking." Students believe that "some people consider talking with patients useless and waste of time." The argue that "when finally, what we decide, is the right decision, why should we explain the procedure and its probable risks or reactions, which leads to our waste of time and creating stress for patients?"

Another point in students' words was "ignoring the religious beliefs of patients in medical examinations", which in turn, originates from "improper of awareness and commitment among physicians regarding these issues".

From the patients' point of view, "neglect of patients' needs", "not caring for personality and confidentiality of patient information for the sake of maintaining social status and personality of physician and medical team members" are other barriers of realizing patients' rights realization. They believe that "medical centers support their personnel extraordinarily to keep their own reputation".

#### Patients- related barriers

As table 4 indicates, "ethnic and linguistic discrimination", "social class gap", and "income level" are among the most influential parameters in this regard from the patients' point of view, who believe that "it is money and only money that works".

**Table 4.** patients- related (social, cultural, and individual) barriers of patients' rights observance

| Barriers   | Instructors | Students | Patients |
|--|-------------|----------|----------|
| Ethnic and socio-cultural divergence of patients                             | ✓           | ✓        | ✓        |
| Financial problems of patients   | ✓           | ✓        | ✓        |
| Patience and tolerance of patients or their companions regarding some events | ✓           | ✓        |          |

On the other hand, students acknowledging some "discrimination and unkindly behaviors" especially about "foreign emigrants", refer to "lack of proper acculturation" as one of the main causes of the problem, and argue that "if patients view their medical records, they expect everything to be explained for them".

### Discussion

Establishing favorable conditions in the hospitals in terms of patient rights is a multi-dimensional and complex process. The present study focused on the views of patients, students and instructors to investigate the barriers and challenges of establishing a favorable framework for patients' rights in medical centers. The barriers of patients' rights observance were classified in three categories: Health system related barriers, Health care providers- related (social, cultural, and individual) barriers; and patients-related (social, cultural, and individual) barriers. A considerable portion of the barriers are software dependent, which could be resolved through planning, process development, redefinition of relationships, and other managerial interventions. For instance, the inadequacy of control and evaluation system is expressed by all three groups of participants. These are among the main functions of all managers. So, any reform in health care provision with regard to patients' rights requires a plan and mechanism as a basis for controlling and evaluating the activities. If so, we can expect many barriers to be eliminated. To name some of them, this may lead to establishing a system of reward and punishment and a system of dealing with complaints, while on the other hand, could help confronting problems such as financial relationship of physicians and patients. It is sure that intrinsic and ethical motivation and commitment helps to remove the barriers, nevertheless, the need for a mechanism of evaluating activities and giving feedback on the right and wrong actions of health care providers from the patient' point of view, is felt and this is possible through assessing patient satisfaction and dealing with their complaints. Nevertheless, as the participants expressed, patients' complaints not only have not the full effectiveness, but also, have reverse effect, so far as it may cause the patient to be deprived from the previous cares. Moreover, the long process of dealing with complaints diminishes its effectiveness and efficiency. This is in concordance with the findings of Amini et al in Tabriz, who reported a lack of access to an efficient system of dealing with complaints [27]. Another notable remark is what has been expressed as the consequences of probable complaints of patients on the behaviors of health care providers. This is like what Kuzu et al, have reported in Turkey, that patients put off complaining against medical center, because they are concerned with its negative impact on the behavior of the care team [28]. So, formation of unofficial patients' rights committee is a solution proposed to follow up the patients' rights [29], through informing patients about their rights [30] so that they demand their legitimate rights.

Inadequacy of the system of information dissemination for public is declared by the participants, which has led to ignorance of patients to their rights. Studies show that patients receive little information about their rights [31]. We can argue that the patients' satisfaction of the hospital with regard to their rights in some studies [32] may be due to their lack of sufficient knowledge about their full rights [33]. Studies indicating a significant relationship between educational background and residential area of patients with their knowledge about their rights as patients [30] confirm this assumption. There is no doubt that patient cooperation in treatment process is influential in improving its effectiveness, but also the true cooperation is achieved only in the light of proper knowledge and awareness. Many researchers have reported insufficient knowledge of patients about their rights [20, 30, 31, 33]. So, it is necessary to design a mechanism for improving the knowledge of community. In other words, apart from training health care providers about patients' rights, the potential clients of medical centers, or the public, should receive adequate information on what they can expect from the state and health system. This leads to quality improvement in services [30], better professional ethics, less ethical controversies, and more law enforcement regarding patients' rights [9]. Use of different media including audiovisual media, worldwide web, social networks, and any public channel and at the same time, in field education through such means as booklets, brochures, and pamphlets, upon arrival to hospital, have been suggested. These can improve the ethical atmosphere without any considerable costs [20].

Insufficient human resource as an apparent challenge in health sector is among the structural barriers of optimum realization of patients' rights in medical centers. This defect imposes work overload on staff, making them weary and tired bodily and perhaps mentally. Moreover it leaves little time for them to communicate effectively with patients and give them full explanations needed, which in turn, prevents a suitable relationship to take place. This is similar to what Hooshmand et al have reported, mentioning sufficient staff and nurse-to-patient staffing ratios, along with factors such as providing facilities and equipment, as the main parameters facilitating patients' rights realization [26].

On the other hand, the mere publicizing of patients' bill of rights as a legal document and a commitment for medical centers cannot be helpful unless its other requirements are met. Parsapoor et al in their report of implementing patients' rights in Iran, specify the strategy of Iranian ministry of health in this field as evaluating all rules and regulations of the health system, especially hospitals and clinics based on patients' rights and the principles of medical ethics by the Supreme Council of Medical Ethics [34]. At the meantime, to fulfill this duty, medical centers need to provide prerequisites, which have been listed as 53

indicators within 7 categories of education, research, supervision, process management, physical resources, organization, and human resource management [29]. So, extensive management interventions at the macro level and at different treatment centers are necessary to achieve desirable patients' rights observance.

Literature shows that although physicians and nurses are willing to act according to the patients' rights, they face limitations such as human resource shortage, little facilities, less competent staff, and insufficient public awareness, which lead to their poor performance [35]. It should be noted that any positive event in the treatment process, may take place just in case an active cooperation between treatment team and patients is created. So, just as patients' cooperation is our concern, physicians and other service providers need to be prepared and a suitable platform to be provided containing the required structures and contexts. To act as physicians and paramedics successfully and fulfill the difficult and vital tasks of them, they need physical and mental fitness. Otherwise it could not be considered as an opportunity for health promotion practices, rather this may be considered a hard and hazardous job, leading to job dissatisfaction and subsequently poor professional performance.

Incomplete knowledge and disregard of religious and spiritual perspectives in patient's rights are among the barriers mentioned by the participants in this research. This means that for patients' rights to be actually deployed, we should not forget the socio-cultural and religion-dependent factors [35]. So, an efficient intervention for better patients' rights realization is the staff empowerment through formal and informal education and training.

Another factor hindering proper patients' rights realization is outdated knowledge of health care providers as mentioned by the participants. Studies indicate a notable defect in knowledge of physicians, nurses, midwives and medical students with regard to patients' rights [19, 22-25, 33]. The causes of little awareness can be named as lack of time for study and reading, which is itself caused by numerous barriers, including economic inadequacy; unfavorable outlook of nursing profession; hard working conditions of hospitals like patient overload and personnel shortage; and lack of books and reading material and resources [2]. However, training and human resource enrichment and its effect on their better performance should not be ignored. It seems that the first and the most practical action, is to accommodate related topics in the curricula of different fields of study dealing directly with patients. Revision of nursing curriculum and conducting continuous education courses as the promoting factors of care quality, are among the suggestions of previous studies [17, 24, 34]. Educational interventions to assess the likely impacts of inclusion of appropriate educational programs in the curricula, confirms a considerable improvement in nurses' attitude toward patients' rights. Notwithstanding, not every acquired knowledge is embodied in attitude change and performance improvement, because the role of hidden curriculum is very important. Correcting the health care providers' perspective on patients is a very fundamental step to institutionalize patients' rights in hospitals. The right approach to patient, underpins human dignity. Studies show a gap in understanding, interpreting and maintaining human dignity in Iranian hospitals. Therefore, nearly no patient is satisfied with the quality of services received regarding his or her dignity and we can conclude the importance of staff awareness on keeping or hurting human dignity. Human dignity is repeatedly mentioned and stressed in the introductory passage of Iranian patients' bill of rights and the content especially the first chapter is set up in the same direction.

In summary, it seems that the implementation of patients' bill of rights in medical centers is not merely under the control or authority of medical centers or health sector alone. It is intertwined with different areas including economy, culture, and other societal parameters. In other words, the issue of institutionalization of patients' rights in health care centers cannot be helpful unless these rights are addressed and receive attention in every aspect of social relations. A person not benefitted about his or her rights in the social context of his life, is not expected to observe fully and with high quality the rights of patients as his or her clients. Or a student facing different controversies in the context of society and engaged with multiple economic and professional concerns especially when observing contradictions in the behavior of individuals around and inappropriate feedback of the organization toward them, could not adopt a desirable model for his professional career. So, the issue must be considered with its multifactorial nature and far from its oversimplification. In general, any success or failure of implementing patients' rights lies in awareness of rights, sufficient resources, and health care providers' accountability.

A limitation in this study was that the participating patients were only those with cancer. Furthermore, since the study was conducted in an educational hospital, to have any conception of the findings, the characteristics of this kind of hospitals should be kept in mind.

### **Conclusion**

Remarkable inadequacy of health system dealing with patients' rights is a multi-dimensional problem. Based on what has been explored in this study, the causes can be put in different categories and thus, different solutions should be adopted to address them. It seems that management interventions in macro and micro levels can facilitate the way through eliminating structural barriers on the one hand and improving knowledge and attitude of the health system staff regarding patients' rights and its importance on the other. Of course, public awareness of their rights is also necessary and determining.

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