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Iranian patients' perspective of patients' rights: a qualitative study

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Abstract

There is an increasing emphasis on "protecting patient rights", which has a great influence on the patient's well-being. This study aimed to explore patients' perspectives of patients' rights in the hospitals of Kurdistan University of Medical Sciences in Iran. This qualitative study used the content analysis method. The data were collected through in-depth interviews, conducted in Persian at the internal and surgical wards from 2012 to 2013. Consequently, interviews continued to be conducted on 20 patients, using content analysis, until data saturation. The findings highlighted aspects of patients' rights and five themes emerged from the interviews: having one's dignity respected, receiving care of the requisite quality, being shown financial consideration, receiving adequate information, and having a desirable and pleasant environment. The patients believed that for their rights to be upheld, it is necessary that together with the provision of enough facilities and equipment, they need to be respected and offered ideal healthcare services. This could be achieved by removing barriers and facilitating procedures.

Introduction

Human beings have physical, mental, social and spiritual dimensions, from which arise certain rights, whether they are in good or bad health (1). These rights cannot be achieved, defended and supported without assistance (2). Contemporary ethical thinking on "human rights" places increasing emphasis on the concept of "ethics" within different professions, especially those that directly involve human beings, and forces the

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authorities in these professions to take fundamental human rights into consideration to achieve citizenship rights, consider patients as vulnerable human beings with special needs, and stress their rights more seriously than before (3). Years ago, professional health practitioners, especially physicians, used to think that they could determine the patient's destiny just because they were aware of his/her health (4). However, in the light of the international community's growing concern about human rights, great emphasis is now being placed on "protecting patient rights" as well (3).

The World Health Organization (WHO) considers patients' rights as rights which individuals possess and which must be maintained by health service providers (2). Some of these are: right to appropriate and fair treatment and care, right to information, right to confidentiality, right to allow intervention only after giving informed consent, right to autonomy and freedom of choice, right to receive instruction on health, right to make complaints, and right to compensation (5). In other words, patients' rights touch upon legal and reasonable physical, mental, spiritual and social needs; these have been turned into medical rules and standards which a responsible treatment team must follow (6).

Nowadays, health systems take into consideration a "patient's bill of rights", which is announced at the administrative level, and healthcare personnel are urged to follow it. The content of these bills is almost the same: they all try to protect patients' rights (7,8). In most countries, such as Canada, the UK, the USA, Germany, Switzerland, Australia and Sweden, patients' rights are taken into consideration (8). In Iran as well, the Ministry of Health and Medical Education has issued a patients' bill of rights, which consists of 10 statements and is meant to be put into practice (9).

Most patients and doctors in the developed countries are familiar with patients' rights (10). Studies indicate that there are differences among different countries regarding these rights. Zolfaghar and Alvasvi concluded that 45% of patients in Turkey were completely unaware of their rights and did not know the concept of patients' rights (11). In Iran, Hooshmand and Joolaee stated that 73% of patients were moderately aware of their

rights (12). A study in Iran indicated that patients' rights were enforced inadequately (7). Moreover, Eshkevari et al concluded that patients' autonomy and freedom of choice are taken into consideration in 36% of cases, while secrecy of information and confidentiality are taken into consideration in 56% of cases (13). In a qualitative study, Joolaee et al reported that in the view of patients and their companions, the most important areas in which patients' rights are honoured include: being offered fair healthcare services, having their and their family's respect and dignity maintained, being given information on their disease and the activities related to it, and being provided with medicines and basic facilities in the hospital (1).

All in all, studies show that patients' awareness concerning their rights is increasing; therefore, if their expectations are not met, they react (13,14). Support is considered a necessary part of nursing activities. This includes helping patients to diagnose their disease, informing them about their rights, and protecting these rights and interests (5,7,14,15). Whatever the form of support and expectations, the patient is the locus of the medical team's activities. All medical activities should be characterised by a high level of attention to the patient because the need to follow medical procedures can increase the patient's vulnerability and need for comprehensive support (11,15,16).

Finally, it should be stated that the principles of humanity and respect for human rights apply to the entire world. In Iran, due to the moral lessons of Islam and the setting in cultural and human terms, special attention is paid to human rights, in general, and patients' rights, in particular. Several quantitative studies have been carried out on patients' rights; however, it is necessary to understand the concept of "rights" as seen by patients, based on their specific cultural and social setting. This study aimed to understand the perspectives of Iranian patients' on patients' rights in the government-run teaching hospitals of Kurdistan University of Medical Sciences.

Methods

Design

We used the qualitative content analysis method, which offers instruments for examining experiences and results in the acquisition of valuable and in-depth data from the samples (17,18).

Participants

The participants were selected using the purposive sampling technique. The participants were chosen from among patients admitted to educational–governmental hospitals, all of which have health insurance that partly covers medical expenses. Consequently, those recruited were hospitalised patients who were admitted to the internal surgical wards, were at least 18 years of age, did not suffer from dementia, had stable general health, and consented to participate in the study.

Data collection

The patients were given an introductory letter which mentioned the purpose of the study, assured them that the

information they parted with would be kept confidential, informed them that they had the right to abandon the study, and contained the informed consent form. The data required were collected through deep and semi-structured interviews. The interviews were conducted in Persian in the internal and surgical wards from 2012 to 2013. Twenty patients continued to be interviewed until data saturation. The interviews started with a general question on the patients' experience of how their rights were being observed in the hospital, after which further details were explored. The interviews took 45–60 minutes, and were recorded, transcribed and manually analysed.

Ethical measures

This research was ratified by the Ethics Committee of Kurdistan University of Medical Sciences. The method to be used and the objective of the research were explained to all the participants. The participants were all volunteers and written informed consent was obtained from them before starting the interviews. The names of the participants were converted into codes while transcribing the interviews, and the data related to each interview were stored safely. The participants were informed that they could withdraw from the study at any time.

Data analysis

The Graneheim and Lundman (19) procedure for qualitative content analysis was used to analyse the data. For this purpose, the researchers listened to the recorded interviews after data collection and studied the transcribed data to gain a general understanding. The contents of the transcripts of the interviews were studied frequently. The text was divided into meaning units and reviewed frequently. The meaning units were condensed, abstracted and labelled with a code. Then various codes were compared based on similarities and differences with the initial texts specified and final conclusions were made by the researchers for driving sub-themes. The opinions of experts and the panel of judges were elicited to investigate and confirm the contents of the interviews. Their viewpoints also directed the researchers to arrive at the deep meanings of the concepts put across by the participants and thence, to formulate the final themes.

Trustworthiness

Trustworthiness in content analysis studies, as in other qualitative studies, means methodological soundness or adequacy (17,18). To increase the trustworthiness of collecting data, data collection was carried out at an appropriate place and time, the participants were treated well, the complementary views of the co-workers were taken into consideration, the notes were revised with the patients' help, and other researchers' comments were utilised. In addition to interviewing the patients, we actively observed and made a note of their behaviour and interactions during the recorded interview so as to gain important information.

Findings

During the analysis of the data, five themes emerged with regard to the patients' views on "patients' rights". These were:

having one's dignity respected, receiving care of the requisite quality, being shown financial consideration, receiving adequate information, and having a desirable and pleasant environment (Table 1). The following quotations from the participants have been presented on the basis of what they indicate.

Maintaining dignity

Most of the participants mentioned the theme of "maintaining dignity", which consisted of two sub-themes: observing professional ethics and showing respect. They saw professional ethics as an important dimension of honouring patients' rights. In the words of one patient, "Doctors must establish a good relationship with a patient and keep the oath they have taken, even if the patient cannot afford to pay the hospital costs [code 3]." Another participant stated, "In the first place, a good nurse or doctor is characterised by a commitment to observing professional ethics and valuing human principles, so a good doctor or nurse is someone who is more committed to ethics [code 14]." According to another patient, "A medical team should prioritise the patients' well-being over money [code 6]."

Another important dimension which most patients referred to was respect for the patient and honouring his/her dignity. This included themes such as listening to patients, establishing an appropriate relationship with them, and treating them as human beings rather than just patients. One of the participants said, "Not all doctors, but most of them do not even bother to listen to the patient, let alone establishing a good relationship with him/her and this is a disaster because doctors can only diagnose on the basis of the disease history [code 4]." Another said, "The personnel, especially doctors, don't behave well, which makes us feel inferior, insignificant and taken advantage of because we are treated like objects [code 12]."

Another theme that emerged in this study was that of respecting and valuing the patients' and their families' time. Almost all participants spoke of how the patients' and their families' time and energy were wasted - something which they equated to a failure to honour their rights. One of the participants said, "They hospitalise our patient, operate him and discharge him whenever they like to [code 4]." Another said, "Valuing the patient's time and avoiding wasting his/her time are really important to me, which should be considered by all the hospital personnel [code 1]." According to another participant, "We waited for a long time until the doctor came and examined me. We were under great pressure. How long should we wait unattended? [code3]" This complaint was echoed by a participant, who said, "The emergency ward was very crowded and we were not attended to until after a long delay, when the specialist doctor came to visit us. Later, twice I was sent for taking X-rays and both times the machine was not working. [code 5]" According to one participant, "I've been waiting for three days to be operated. I was taken to the operating room three days ago. To be honest, I was really scared and stressed out, and after waiting for 4 hours, they told me that the doctor will not operate. He hasn't turned up until now."

Quality of care

Most of the participants stated that they had the right to be provided with complete healthcare, which was considered under the theme of "having quality of care". The sub-themes of this theme included access to experienced personnel, facilities and equipment (such as sheets, clothes, medicines, and diagnostic and treatment equipment), as well as appropriate medical and nursing services. The participants said that access to specialist doctors and equipment was the most important. One of the patients stated, "Every Iranian should have access to health and medical facilities; however, for the most part, they have to go to Tehran and other big cities [code 15]." Another patient said, "We still lack facilities and experienced doctors in most cases" [code 18].

Patients thus feel that access to the necessary facilities and appropriate services is a significant factor when it comes to regard for their rights. The lack of basic facilities and medicines make specialised diagnosis difficult. Speaking about the lack of facilities, one of the participants said, "My family took a lot of trouble trying to procure a medicine that was finally found in Tehran, whereas it was supposed to have been available in the hospital [code 13]." Another patient said, "The food we eat isn't of good quality and I won't eat hospital food. My family brought me food from home [code 17]." One of the patients spoke in rather strong terms: "Patients' rights are nonsense; we are even deprived of a proper room and clean clothes [code 10]." Another said, "In the hospital where I'm hospitalised, there are few doctors compared to the number of patients. In addition, they are not specialists [code 15]." Yet another participant said, "The doctors are too busy and always have a large workload and a large number of patients. They have little time for their patients and are always pressed for time [code 2]."

Financial considerations

Another important dimension highlighted by the participants was that they had a low level of financial support, including insurance. One of the patients said, "Patients who have financial problems should be helped by some organisations [code 19]." Another said, "Those who are not financially able and are not supported by any insurance organisation need to be protected more so that they are not stressed out by the hospital and medical costs [code 4]."

Receiving information

Another theme that emerged from this study was the patients' wish to have the right to be aware of their disease and the treatment procedure. The sub-themes of this right, which were mentioned frequently by the participants, included the right to be seen by trained health personnel who devote enough time to the patient, explain the patient's treatment procedure to him/her and seek his/her cooperation in the procedure. Another important sub-theme was the right to receive complete information about the disease. Most patients felt that this right was not honoured properly. One of the patients said, "Nurses and doctors should frequently tell

me about my disease and whatever they have done, but it's not so. Most illiterate patients don't even know their disease and their doctor's name, and no one gives them appropriate education [code 11]." Another participant stated, "A doctor should establish a relationship with the patients and give the necessary explanations, but unfortunately most doctors don't observe the patients' rights and don't care [code 3]." According to another patient, "I'm satisfied with the nurses and doctors with regard to their professional knowledge, but regarding a good relationship with patients, I'm not satisfied. I can't feel at ease and tell them my needs and talk about my problems freely. There's no communication between the personnel and the patients, there's no education about my disease, and I'm complaining about this [code 8]." Yet another patient said, "I didn't receive an education on my disease, its progress and treatment. I don't know what diet suits me [code 9]." Finally, one of the interviewed patients said, "If we know what will happen, we can decide what to do, but they don't tell us about our disease at all and don't consider us as human [code 4]." In addition, an important sub-theme of this theme was allotting enough time to patients to diagnose their disease and answer their probable questions. In this context, one of the patients said, "We're hardly given the right to ask any questions and if we ask, doctors don't respond or they even get upset and say that we're talkative. They don't explain. I think they're of a higher social class and we're not even important in their eyes [code 11]." Another participant said, "Here it's not important if someone is sick. Everyone wants to do their business and leave. No one asks who you are or what you want or even what the heck happens to you. And if we ask, no one responds [code 13]."

Need for a desirable and pleasant environment

Another theme that emerged from the study was the right to be hospitalised in a desirable and pleasant place. In the patients' view, the sub-themes of this theme included that they should have a relaxing place in the hospital to rest in and that the structure of the hospital wards should be appropriate. Most participants felt that the structure of the wards left much to be desired. One of the patients stated, "If they put fewer patients in a room, it would be a better place to relax in. If they planted trees and flowers in the hospital yard, it would be better for the hospitalised patients [code 7]." Another participant said, "I'm not satisfied with the hospital environment at all. The rooms are really crowded. There's a lot of noise and we're not relaxed at all [code 8]." According to another participant, "There's no peace by any means. For example, suddenly a cleaner comes to our room at midnight and makes noises and disturbs us. Unfortunately, nurses and even doctors speak loudly and disturb us when we're resting [code 1]." Another patient said, "Regarding the general environment of the hospital, it should be said that it's crowded inside the rooms and corridors and there's not enough peace. Regarding aesthetics, there has been no plan [code 20]." An important factor mentioned by the participants was the role of the hospital's personnel in providing the patients with a calm environment. One of the patients said, "The hospital

environment should be clean and aesthetically pleasing, and the nurses and doctors can try to provide a peaceful and desirable atmosphere for the patients to loosen up [code 17]." Going back to the question of the structure of the hospital and its wards, one of the participants said, "In our room, there are four beds. Due to limited space, our room is always crowded and we never relax [code 9]." Another participant said, "The hospital and the wards are not maintained well. The ward does not have enough toilets. They're not clean and I'm reluctant to use them. This is really frustrating [code 3]."

Finally, on the basis of the themes that emerged from the interviews, the study defined the observance of patients' rights as patient-centred and comprehensive healthcare, which can be offered through a cooperative process and effective communication, together with efforts to understand the patients. Meeting the patients' basic needs and protecting them extensively are essential elements of healthcare, and these goals can be fulfilled only in an appropriate and desirable environment, given adequate information about the patients and their needs, and at the same time, upholding their dignity and respect.

Discussion

The results of the study increased our understanding of patients' perspectives of their rights in hospitals and provided us with information on their unique experiences.

All the participants of the study had health insurance which covered their medical charges partially. In Iran, there are four main kinds of public health insurance, which cover more than 90% of the people. These are the Social Security Organization, The Medical Service Insurance Organization, The Military Personnel Insurance Organization and The Emdade-Emam Committee. The first one is for all people employed in the formal sector, except for government officials and members of the armed forces. The second is for government employees, students and rural dwellers. The third kind of health insurance is for military personnel, while the fourth is for the uninsured poor (20). The participants in the study had the first two kinds of insurance, which cover the same levels of service and costs.

As shown by the results of the study, the patients believed that respecting the dignity of the patient is among the major features of patient-centred healthcare systems. Many studies have had a similar finding (1,12,13). The right to receive healthcare with respect and attention was one of the main themes that emerged also in a qualitative study conducted by Joolaee et al (1). The study conducted by Waterworth and Lucker (16) stresses the results of the present study in the context of the importance of respect for and attention to patients and the need to give these priority. Bucken and Bucken (21) noted that honouring patients' rights to provide healthcare characterised by respect and empathy had to be different from the past, when it was based on the individual will of healthcare providers. According to these researchers, the support and attention provided to patients by doctors, nurses and other healthcare providers should be based on

national and international principles and rules that clearly outline patients' rights and specify ways of observing them. It is important to have rules and principles that specify certain punishments for healthcare providers who ignore the rights of patients. Bills of patients' rights usually set out patients' expectations and rights without clarifying the healthcare providers' duties. Thus, the practical obligations of those practising medicine are not specified (21). The authorities and policy-makers probably need to adopt approaches that are more creative than sticking the patients' bill of rights on the walls of hospitals and medical centres.

In this study, the participants felt that the main element of patients' rights is the provision of good quality of care, which was associated with other themes such as effective communication, cooperation, comprehensive support, and fulfilment of their mental and spiritual needs. In their opinion, receiving care of good quality meant more than the mere physical presence of health personnel and routine medical and nursing activities. They were interested in the improvement of healthcare. Mrayyan (22) believes that quality nursing is based on nursing standards. The criteria of good-quality nursing care include: sufficient skills, a caring attitude, effective communication, efficient organisational and managerial systems, and effective cooperation among the members of society (16). Therefore, physicians and nurses should acquire knowledge and skills to provide quality care to patients.

A large number of scholars have highlighted care as the essence and basis of nursing. In this regard, Tschudin (23) states that, "Although care is not unique to nursing, it is regarded as a unique activity in this field." The main elements of everyday nursing care include experience, emotion, kindness and communication. They could all be summarised in one word, which is "care".

As shown by the participants' responses, the lack of necessary resources, whether qualitative or quantitative (such as time and manpower), was an important issue which was seen by many as obstructing the provision of appropriate healthcare. In their study on patients' understanding of appropriate healthcare, Larrabee and Bolden (24) concluded that in the view of patients, good healthcare is based on the patient's needs, associated with respect and warmth, patient-centred and, timely and appropriate, and should be provided by a skilled person. Other studies mention the right to receive appropriate healthcare, which emphasises the essence of care and not just its appearance (1,12,22). Appropriate and effective policies can create appropriate circumstances for the observance of patients' rights. Informing patients about their rights and responsibilities can effectively influence the observance of these rights. Joolaee et al (1) stated that a greater effort is required to stabilise patients' rights and improve their cooperation when taking health decisions related to them. It is not possible to observe patients' rights merely on the basis of ethical principles. Laws, instructions and mechanisms are necessary for the purpose. Nursing textbooks lay much emphasis on the content of healthcare; and providing

good-quality nursing care is one of the main rights of patients. Two important factors affecting patients' rights are a lack of information forthcoming from the people, patients, nurses and physicians, as well as unclear statements. In addition to the efficiency of the healthcare provider, care includes dimensions such as attention, respect and warmth, which are not measured using the typical methods.

Providing good-quality care to patients relies on ethical attitudes in healthcare providers and is possible only following comprehensive practical education in the nursing departments of universities (11,25). An insufficient number of healthcare providers, especially nurses, and an excessive number of patients can also affect the quality of care. Implementing patients' rights is the responsibility of all the personnel of the healthcare delivery system. It is a matter that is sociocultural and contextual in other ways as well, and a strong will and commitment are required on the part of the healthcare personnel.

There is always a gap between the expectations and rights of patients. However, policy-makers should be aware of the people's perspectives and expectations. A modicum of awareness can help them coordinate the perspectives of patients and the codification of their rights.

The issue of patients' rights has been a controversial one since the last decade. Health rights are specified in patients' bills of rights. These bills of rights usually mention patients' rights without clarifying the responsibilities of healthcare providers. Thus, no practical obligation is specified for anyone (3). The Iranian Patients' Bill of Rights was approved by the Ministry of Health and Medical Education in 2009 and has five axes.

- A patient has the right to receive optimal healthcare.
- Patients must be provided adequate information, in a proper manner.
- A patient's right to have a free choice and autonomy of decision-making must be respected in matters concerning his/her health.
- Health services should be based on respect for the privacy of patients and respect for the principle of confidentiality.
- Access to an effective system of complaints is a patient's right (25,26).

The first statement in the Iranian Patients' Bill of Rights, says, "A patient has the right to be provided with appropriate care and treated immediately, with complete respect and without considering racial, cultural and religious factors." It is clear that there is no trace of realism in this statement because it does not guarantee the fulfilment of patients' expectations with respect to their rights. A patient can harbour many expectations, but what remains vague is who will respond to these expectations (1,25).

The Iranian Patients' Bill of Rights has nine principles in common with the bills of other nations.

• The right to appropriate care and treatment, which should be of high quality and offered without any discrimination

- The right to medical information related to the disease status
- The right to privacy in relation to health and therapeutic information and to have healthcare providers maintain confidentiality
- The right to allow any health/ therapeutic intervention only after giving informed consent
- The right to decide independently on the type of healthcare service to be availed of
- The right to a hospital environment that offers privacy
- · The right to peace
- The right to express objections and complaints
- The right to fair compensation (25,26).

When one compares patients' rights in Iran with those in other countries, it is clear that Iran's Patients' Bill of Rights could be more comprehensive with the addition of the right to independent decision-making on the type of healthcare services to be availed of, the right to a hospital environment that offers privacy, the right to peace, the right to express objections and complaints, and the right to fair compensation. If these elements were incorporated, we could expect effective and efficient service delivery to people in need.

Since there is no appropriate forum for patients to voice their views on their rights in Iran and there is no responsible non-governmental organisation, establishing such organisations is necessary, so that the patients' voices can be heard by the authorities and their opinions considered while designing a bill and instructions aimed at protecting their rights. Further, patients' lack of adherence to the recommendations of treatment teams result in poor outcomes and lead to the sense of lack of optimal healthcare services. Therefore, other than expecting their rights to be upheld, patients should, as far as possible, adhere to the recommendations and prescriptions of the healthcare system that guarantees their rights.

Limitations of the study

As this was a context-based qualitative study, the generalisability of the results is limited. Therefore, more studies are necessary for further exploration of patients' rights, especially among patients hospitalised under different systems and in different wards. Moreover, it would be helpful if additional studies were carried out to explore the various aspects of patients' rights as perceived of by nurses and physicians.

Conclusion

The results of this study show that patients believe that for their rights to be upheld properly, adequate facilities and equipment need to be complemented by respect and the provision of ideal healthcare services. They do not have an adequate knowledge of their rights, which makes it difficult for them to know how to go about things and how to exercise different aspects of their rights. The patients' viewpoints are important because their ideas can be utilised as a basis for further research and to design a bill of rights that is

appropriate for their needs and expectations, with Iran's social, economic and cultural context as the general backdrop. Further, it is essential to understand the patients' opinions on their rights as it would not be possible to satisfy them otherwise. Their satisfaction could be increased by removing barriers and facilitating procedures that help in upholding their rights.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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Table 1. Summary of themes and sub-themes

Main themes	Sub-themes
Having one's dignity respected	Receiving care from professionally ethical personnel
	Being respected
Receiving good-quality care	Having access to experienced personnel
	Having access to adequate facilities and equipment
	Having access to appropriate medical and nursing services
Being shown financial consideration	Receiving financial support
Receiving adequate information	Being given complete information on the disease
	The right to be trained and being given enough time
	Having one's questions answered
Having a desirable and pleasant environment	Being in a place in the hospital that is relaxing
	Structure of wards should be appropriate

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