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## Patients' rights in India: an ethical perspective

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### Abstract

*Patient autonomy is affected by a number of factors, including severity of illness, socio-economic status and dependence. Many patients find that they are not treated with due consideration and compassion, and also have no control over their own care.*

*In this article, we consider whether the Code of Ethics Regulations of the Medical Council of India protects patients' rights, by comparing the code with the charter of patients' rights of the Consumer Guidance Society of India. We then look at other developments in protecting patients' rights and the need for further work in this area.*

### Introduction

The low doctor-population ratio in India puts a tremendous strain on the available medical facilities and restricts the time available for doctors to interact with patients. There are thus valid reasons why doctors do not explain in detail to the patient, the diagnosis, the treatment planned, or expected prognosis. However, not providing such information to patients is a clear violation of their rights.

The Universal Declaration of Human Rights (1) grants us the right to life, liberty and security of person (1: Article 3). Additionally, we as human beings also have the right to a

standard of living adequate for the health and well being of oneself and one's family, including food, clothing, housing and medical care" and the right to support during the period of illness, disability, unemployment etc (1: Art. 25). The Declaration recognises "the inherent dignity" (1: Art. 1) and the "equal and unalienable rights of all members of the human family" (Preamble). In general terms, this implies that all humans, irrespective of gender, age, education, state of health or economic condition enjoy these rights. It is on the basis of these undeniable human rights that the rights of patients are based. The World Health Organization (WHO) defines patients' rights as those owed to the patient as a human being, by physicians and by the state (2). Patients' rights vary in different countries and are influenced by the patients' status, family, society and country-related factors.

The patient's right to have a say in his/her own treatment depends upon the model of physician-patient relationship. There are four models of physician-patient relations which define the rights that patients enjoy and the extent to which they do so (3). In the paternalistic model, the physician adopts the role of a decision maker and decides what would be good for the patient. In the informative model, the physician acts as an information source, and decision making is in the hands of the patient. The interpretive model has shared decision making; the physician helps the patient to interpret complex

medical evidence and its relevance to the patient's illness. The deliberative model is one where both the physician and patient deliberate on the best course of action. (4) There is obviously some overlap between the interpretive and deliberative models and different methods for classification of these models have been forwarded. The relationship could also be classified based on the physicians' profiles as shown in Table 1 with scores for its components (5).

**Table 1: Models of physician-patient interaction**

Model	Level of patient autonomy	Level of physician's decision	Level of moral deliberation
Classical paternalists	Low score	High score	Low score
Modern paternalists	Low score	High score	High score
Autonomists	High score	Low score	Low score
Deliberationists	High score	Low score	High score

Vaisman suggested that the deliberative model is the most suitable model for the physician-patient relationship, on the basis of the three key principles of ethics, as enunciated in the Belmont Report, viz. autonomy, beneficence and justice (6).

It is necessary to define what should constitute the basic rights of the patient. In the US, the right to medical records and right to privacy are considered as basic rights. A bill of rights known as the McCain-Edwards-Kennedy Patients' Bill of Rights was considered by the Congress in 2001, but it eventually failed to become a law (7). Any bill that attempts to grant enforceable rights to patients will affect the patient-physician relationship and would require the consent of patients and physicians.

The Association of American Physicians and Surgeons (AAPS) adopted a list of "patient freedoms" in 1990 which was modified and adopted as a "patients' bill of rights" in 1995 (8). A number of judgments in the US led to the formulation of patients rights' charters; these were subsequently developed into a code. While the Belmont Report and other guidelines laid down the rights of trial participants, a smaller exercise has been held to define patients' rights. The AAPS document guarantees patients the following:

- To seek consultation with the physician(s) of their choice;
- To contract with their physician(s) on mutually agreeable terms;
- To be treated confidentially, with access to their records limited to those involved in their care or designated by the patient;
- To use their own resources to purchase the care of their choice;
- To refuse medical treatment even if it is recommended by their physician(s);
- To be informed about their medical condition, the risks and benefits of treatment and appropriate alternatives;
- To refuse third-party interference in their medical care, and to be confident that their actions in seeking or declining

medical care will not result in third-party-imposed penalties for patients or physicians

The above clauses have been picked up from the original document which contains a number of clauses, all related to medical insurance, which is a burning issue in the US.

### Patients' rights in India

When one considers the conditions in India, the stark difference between the rights in the US and India is highlighted. The Medical Council of India published, in 2002, a Code of Ethics Regulations (COER) which deals with the duties and responsibilities of physicians in addition to certain rights of patients (9). It must be emphasised that this code does not represent patients' rights; those mentioned are incidental to the duties and responsibilities of physicians. A distinction must therefore be made between a duty-centric approach as represented by the COER and the rights-centric approach of the AAPS. A medical professional may have issues with the rights-centric approach of AAPS, but is duty bound to uphold the rights of patients that are incidental to his/her duties.

At the time of registration with the Medical Council of India (MCI), all medical practitioners are required to sign a declaration in Appendix I, stating *inter alia* as follows:

*"I shall abide by the code of medical ethics as enunciated in the Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations 2002." (Appendix 1, Declaration, clause k)*

The Consumer Guidance Society of India (CGSI) has a more comprehensive charter on its website listing eight specific rights of patients (10).

Interestingly, the CGSI's charter does not include the right to refuse treatment. Thus, if the physician decides on a particular course of action, the patient can at the most ask for a second opinion. Apart from this, the rights of patients are similar in the US and India.

However, there is no automatic respect for patients' rights in India, and if they are violated, the only recourse for patients is to approach the consumer courts. Violation of patients' rights is not a cognisable offence in India as it is in the US and some other countries. This experience is commonly reported in the media, in journals as well as in informal interactions by patients as well as their friends and close relatives.

The differences between the responsibilities described in the COER and each point of the CGSI's charter of rights may be worth discussing.

1. *You have a right to be told all the facts about your illness; to have your medical records explained to you; and to be made aware of risks and side effects, if any, of the treatment prescribed for you do not hesitate to question your doctor about any of these aspects.*

Physicians and surgeons rarely have the time or the inclination to discuss with the patient the diagnosis, the

treatment or the prognosis. In those rare situations where the physician is inclined to do so, the close relatives may attempt to keep the patient in the dark. There is little awareness that the patient's anxiety can increase manifold in the absence of clear information. This may be particularly true in case of diseases like cancer, where patients and relatives believe that there is little chance of recovery. In many cases the patient or relatives may not understand the modalities of treatment; in any case the physicians are rarely keen to discuss this with them. The COER does address this issue, as it enjoins all physicians to give factual information to patients and their relatives stating:

The physician should neither exaggerate nor minimise the gravity of a patient's condition. He should ensure himself that the patient, his relatives or his responsible friends have such knowledge of the patient's condition as will serve the best interests of the patient and the family. Best interest is often a controversial issue and cannot be the same for all patients. This may have to be evaluated on per case basis and differ from patient to patient. (2.3)

2. *When you are being given a physical examination, you have a right to be handled with consideration and due regard for your modesty.*

This right is most commonly respected, and physicians do their best to protect the patient from undue exposure. Most doctors also empathise with their patients and show due consideration. Patients are respected and treated with great care as a norm, yet, as an exception, violation of this right cannot be ruled out. However, this is not specifically mentioned in the COER.

3. *You have a right to know your doctor's qualifications. If you cannot evaluate them yourself, do not hesitate to ask someone who can.*

The unequal nature of the doctor-patient relation -- patients approach doctors when they are in need of help -- may make patients reluctant to ask their physicians for their qualifications or experience. However, the COER requires that doctors provide this information without being asked, as it states:

Physicians shall display as suffix to their names only recognised medical degrees or such certificates/diplomas and memberships/honours which confer professional knowledge or recognises any exemplary qualification/achievements. (1.4.2)

4. *You have a right to complete confidentiality regarding your illness.*

The COER supports patients' right to confidentiality:

Patience and delicacy should characterize the physician. Confidences concerning individual or domestic life entrusted by patients to a physician and defects in the disposition or character of patients observed during medical attendance should never be revealed unless their

revelation is required by the laws of the State (2.2).

However, in Indian society where the physician may be required to interact with the entire family, and may be asked for information on the patient, physicians are generally willing to discuss the patient's problems with his/her relatives, violating this clause.

5. *If you are doubtful about the treatment prescribed and especially an operation suggested, you have a right to get a second opinion from any specialist.*

We may presume that doctors do not discourage their patients from seeking a second opinion on their advice. However, should a patient seek a second opinion, and if the same turns out to be radically different from the first, the patient is in a quandary as to which opinion to accept. The COER supports the right of the patient to take a second opinion, but adds as follows:

Differences of opinion should not be divulged unnecessarily but when there is irreconcilable difference of opinion the circumstances should be frankly and impartially explained to the patient or his relatives or friends. It would be open to them to seek further advice as they so desire. (3.4.2)

6. *You have a right to be told in advance what an operation is for and the possible risks involved. If this is not possible because of your being unconscious or for some other reasons, your nearest relatives must be told before they consent to the operation.*

There are multiple therapeutic options for some disorders. Unless there is a clear-cut advantage of one option over another, the patient should be given a choice of options. In fact the option used should be discussed and decided by the patient and the physician. A knowledgeable friend or relative may represent the patient, but someone from the patient's side should always be involved in the decision making process. The physician should also consider the economic burden of a particular therapeutic modality on the patient's family. The benefit of saving a life should be carefully balanced against the possible economic ruin of the family.

The COER states:

Before performing an operation the physician should obtain in writing the consent from the husband or wife, parent or guardian in the case of minor, or the patient himself as the case may be. In an operation which may result in sterility the consent of both husband and wife is needed (7.16).

7. *If you are to be discharged or moved to another hospital, you have a right to be informed in advance and to make your own choice of hospital of nursing home, in consultation with the doctor.*

A hospital may be justified in shifting a patient to another hospital or nursing home if the patient will not benefit from treatment at the hospital, if the services necessary are not available, or if the patient cannot afford the fees

(emergency treatment must be provided and the patient stabilized before such a shift). However, it is also believed that private hospitals sometimes shift seriously ill patients to a public hospital to avoid problems. However, this is not addressed in the COER.

8. *You have a right to get your case papers upon request.*

Many instances have been reported of hospitals and clinics denying this right to patients and their families, possibly as a way of preventing the patient from seeking treatment elsewhere, or even getting a second opinion. The COER states as follows:

If any request is made for medical records either by the patients / authorised attendant or legal authorities involved, the same may be duly acknowledged and documents shall be issued within the period of 72 hours. (1.3.2.)

Despite the rights given in the charter, it is widely believed that patients' rights in India are treated very lightly and are not honoured in most medical establishments.

Whether recognition is given to the patient's rights or not depends upon a variety of factors. We have identified the following issues based on our own experiences as physicians and also as patients and patients' relatives.

The patient's gender, age and education are decisive factors in the disclosure of information or choice for the patient. Female patients may be given less information, or choice about their treatment, though greater confidentiality may be maintained about them. If the patient is uneducated or not highly educated, the treatment meted out to them is pathetic. The authors' experience suggests that even when highly qualified people are ill, they are often treated with total disregard to their qualifications and experience. Patients from the higher economic strata get better treatment and have a higher autonomy than the less privileged, but this is only to be expected since money plays a significant role in ensuring better services. Patients may have more autonomy in urban compared to rural areas.

The attitude of the physician is a deciding factor in respect to patients' rights. The higher the status and education of the physician, the less autonomy resides with the patient. There are highly qualified physicians who share all information with the patient, but they are in a minority.

The disease suffered by the patient is a major factor that decides the autonomy of the patient; the poorer the prognosis, the less the autonomy. A physician might give all information to the patient if the diagnosis is one of appendicitis, but not if it is of pancreatic cancer.

There have to be reasonable limitations on the autonomy of the patient, and not all patients can be given full autonomy. For example, a patient with psychiatric illness should not be given more autonomy, and it is not given. It is not clear what happens if the physician has a psychiatric illness. After all, physicians come from the same society as patients, and there is no periodic

assessment of physicians' mental health. Internationally, there are many problems in mentally incompetent patients enjoying rights like any other patients. The United Nations Principles for the Protection of Persons with Mental Illness of 1991 has significant drawbacks and implementation is far from perfect (11). The COER states:

Medical practitioner having any incapacity detrimental to the patient or which can affect his performance vis-à-vis the patient is not permitted to practice his profession. (2.1.2)

One wonders whether this clause of the code is, or can be, enforced in practice.

### **Status of patients' rights**

Studies on patients' rights in India give a limited picture of the situation. Datye et al conducted a survey on patient-physician communication around HIV testing, and identified a number of gaps between practice and guidelines, and attribute it to the existing social and legal contexts of the physician-patient interaction in India (12). Physicians in India have always held disproportionate power over their patients, and classical paternalism in physicians' behavior is the rule rather than an exception (13). Gender has been defined as a decisive factor in physicians' dominance in their relations and communication with patients (14). India has a mixed medical practice with the dominant private medical practice alongside a tiered public health system. There is a deep mutual distrust between them which hampers standardisation of the quality of care and affects patients' rights as a whole (15).

At present patients' rights in clinical research are being closely looked at, with institutional ethics committees, scientific review committees, data safety and monitoring boards monitoring patients involved in drug trials (16). Despite the fact that there are a few patient advocacy groups, their role is limited to providing support to patients and making their lives easier, most of these groups do not involve themselves in patient advocacy to the extent required (17).

HIV positive (18) and mentally ill patients (19) present challenges that are specific and far reaching. The treatment meted out to HIV positive cases is repeatedly criticised in print, the audio-visual media and medical journals.

In addition to the existing support groups, one requires active advocacy groups; these may be made up of present and former patients, physicians and paramedical individuals. Their role would be to advise patients on the best therapy for them, how to choose between conflicting opinions and to ensure that they get the rights granted to them as citizens and human beings.

An ombudsman is being established in the form of the National Health Regulatory and Development Authority (NHRDA) that will monitor and enforce standards for healthcare delivery. The authority being established at the instance of the Planning Commission will regulate and monitor /audit both public and private sectors, and provide redress of complaints (20).

The National Human Rights Commission too has also taken up the issue, and is considering draft legislation seeking to protect the rights of patients and ensure that standardised treatment is made available to everyone (21).

Many aspects of patients' rights have not been studied and there is an urgent need to assess the extent to which the rights of patients are respected. There is need to evaluate the patients' perception of the physician-patient interaction and propose ways and means to improve patients' autonomy.

### The way ahead

The Medical Council of India or the Indian Medical Association could take a lead in redefining the rights of patients. It is necessary to put together the points recommended by the MCI and those suggested by the Consumer Guidance Society of India or such advocacy groups to prepare a comprehensive charter of rights.

Hospitals should have committees (on the lines of the institutional review board) that will ensure that patients' rights are protected in hospitals. These committees need not examine the routine working of the hospital, but should review all complaints from patients and direct physicians to take proper care to protect patients' rights.

The NHRDA is in the process of setting up a health ombudsman. While this initiative from the government is laudable, should we always look towards the government to solve our problems? It would be better if hospitals have their own systems rather than depending on the government.

These are some steps that could strengthen the rights of patients and ensure their implementation. In times to come, it is expected that common patients will have at least as many rights as given to patients participating in clinical research.

**Conflict of interests:** *The authors declare that they have no competing interests.*

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