CHAPTER

1

Introduction

Medical practice in India has reached both great heights and abysmal depths. There is no control on malpractice. The Indian Medical Council is a licensing authority and once a doctor gets a license to practice, he will continue to practice all his life, all over the country. Recently this has been amended to require renewal every five years, of this Medical Council Registration certificate to continue practice. Many states have also made it mandatory to have registered in that state.

In developed countries, this license is liable to be revoked, if the doctor does not undergo recertification with a certain fixed number of hours of Continued Medical Education (CME) every year. This law makes sure that doctors are aware of recent developments in their particular field. In India, there is no such compulsion. The Indian Medical Council and professional association like the Indian Medical Association or the Association of the Physicians of India or Association of Surgeons of India, etc. are academic bodies. They do not have any disciplinary powers. Similarly, the Indian Medical Council is unable to discipline medical practice in this country. As a result, doctors continue to treat patients with a very casual attitude resulting in unwarranted, inadequate or incomplete treatment, which is not only harmful but also dangerous in the overall interest of healthcare. In the USA, there is a Government Accountability Office (GAO) that oversees all medical practice. Such a department needs to be established in India

The introduction of patient's rights in this book is intended to correct this lack of accountability among medical practitioners and regulatory bodies. Patients who read this book may demand better quality of medical care. Physicians thus will become more cautious and learn to practice good

medicine when they know that the rights of a patient are widely circulated through books such as this one. It is with this intention of correcting malpractice that this book is written. There is of course the inherent danger that patients after reading this book may start claiming many things as a right from their physicians. However, no right can come without responsibility. It is mandatory on the part of the patient to gain confidence of the doctor by revealing all his private and personal problems that may have a bearing on his illness. Interpretation of these rights will have to be done on an individual basis.

It is hoped that this book will provide a basis on which the government, the administrators, hospitals and the judiciary will react to ensure that patients who come for medical treatment receive the highest quality of care.

In the United States, a republican representative introduced a bill known as the PATIENTS BILL OF RIGHTS. This was already passed by the house of representatives and the Senate in July 1999, and is now established as a law. Basically, it describes the relationships between the hospitals, the insurance companies and the patients. It seeks to ensure quality service by hospitals and insurance providers to the patients who pay for all these services. Certain provisions in the bill are dealt with in this book and pertain to the patient–hospital relationship. A brochure describing the rights of patients is given to the patient on admission to the hospital in the USA.

In India, the large majority of the population do not have medical insurance. It is true that in many other countries including US many people do not have medical insurance. An estimated 44 million people, which are nearly one-fifth of the US population, do not have medical insurance. In the US, medical insurance is necessary in order to pay for expense incurred in an illness. Compared to this, the cost of medical care in India is only about a small fraction of the cost in the US.

In order to streamline medical practice in India, attempts have to be made to ensure quality care by hospitals and by practitioners of medicine. Unfortunately because of the absence of any legislation or law on these issues, it is not necessary for doctors to update their knowledge in their field to practice. In

addition, there are no agencies enforcing quality of practice. It happens purely by litigation. Having had insight into these problems for the past four decades of practice in both government hospitals and private hospitals, I have come to the conclusion that the best way for ensuring quality of medical practice is to educate the patient. This thought also stems from the fact that education of the customer is the only means of ensuring quality of services in the consumer market.

When punishment for an offence is deterrent only then has the quality of services been improved. Despite Consumer Protection Act being extended to include all the medical practitioners including government doctors, the impact on quality of medical practice has not been very obvious. Doctors protect themselves by obtaining a malpractice insurance. On the other hand, the introduction of the Consumer Protection Act has made doctors more cautious and they tend to practice what is described as defensive medicine. The result of this is borne by the patient who has to undergo unnecessary investigations and pay the price for the same in addition to suffering the consequences.

Over the years, I have read several articles describing the frustration of doctors and of patients in an area where suffering is considered normal. In a hospital, the only ones apparently normal are the doctors or paramedical personnel. Having seen a lot of suffering, they tend to become insensitive and loose compassion for the suffering patient. Descriptions of such lack of compassion have been published in the scientific literature from time to time and I have referred to many of these to draw conclusions. Many scientific publications in peer reviewed journals carry articles on ethical issues in practice. It appears that over the last century the phenomenal progress in science and technology has placed an enormous demand for healthcare facilities. In India, health is not considered a major national problem. Little more than 2 to 3% of the national budgetary allocation is made towards providing healthcare under the Government. As a consequence, patients, who can afford, seek quality medical care in the hospitals and speciality centres.

Since demand for these has increased, many private hospitals have come up in the country.

These hospitals were built on the investment of businessman who could afford the cost. They have obtained a substantial reduction in land price from the government on the assurance of providing free healthcare to a certain number of patients. This is not really implemented. It was not clear at that time and it is not clear now what in India is considered affordable cost. For example, treatment of a heart valve problem in a government hospital may be one-quarter or one-fifth of the cost in a corporate hospital. The large majority of patients who suffer from illness particularly due to poor nutrition, unhygienic conditions and poverty, cannot afford treatment even in government hospitals. Most of them are probably dying for want of medical care. With the increased influx of affluent patients, the hospitals tend to rake in large sums of money. It is not wrong, if I say that in India some of the richest people are doctors. Great desire for wealth made doctors and hospitals barter skills for money. The effect of this was the demise of the traditional doctor–patient relationship. Hospitals and doctors became providers of services for a price. The Consumer Protection Act of India provided the patients an opportunity to seek monetary compensation with minimal cost. Again this increased the number of disgruntled, dissatisfied patients who seek justice for their grievances through the law.

An attempt is being made in this book to establish fundamental rights of patients; to my knowledge comprehensive collection of patient's rights does not exist in this form. Research has yielded more than 15 thousand published articles in scientific and other journals pertaining to the subject of patients' rights. This enormous number is in the English literature. I am convinced that similar or more such publications will be found in other languages as well. What is most surprising and heartening to see is that the authors of these articles are not patients? They are medical professionals, mostly doctors and nurses and paramedical staff. Encouragement can be drawn from these publications when it is realised that the protector of patient's right is the doctor or the medical personnel. However, since he is also the perpetrator of the

crimes against patients, it is logical that only he can take up this problem seriously.

These are described here as fundamental rights of patients. There are many columns particularly concerning human rights, rights of children, rights of women and rights of mentally ill person. Legal professionals have raised many of these questions in courts of law. A search of legal documents published in such journals will furnish details of the litigation from aggrieved patients. It has become common place to read at least one episode in daily newspapers pertaining to the breach of rights of patients. I have tried my best to cover all the rights, which I would like to have as a patient, and which I consider should be given to every one. This will go a long way in avoiding and in fact preventing litigations arising out of poor quality medical care.

There is reason to believe that patients are grateful to their doctors even when they are not able to give them much relief. Patients are willing to submit themselves to enormous difficulties in order to obtain or attempt to obtain relief of suffering. This trust is often breached by a casual and arrogant attitude. It is this that needs to be changed in the hope that an educated enlightened patient will ensure efficient and quality medical care for himself in the future.

I am reminded of a quote from Cornelius Ryan in his book "A Private Battle".[4] I quote **"whenever I walk through the doors of a hospitals I become sick with anxiety. Suppose something is done there that was totally unnecessary, the real problem not treated? You won't be able to protect or demand more time to think things out or be comforted by your own people. Because in hospitals, you don't make decisions governing your own life. You have got to trust the doctors to be right. And if they are not, you have gone through it all for nothing. The pain, the fear and the unfamiliarity of a world where sickness, not health is normal".**

Such observations by patients are numerous and has led many doctors and medical personnel to take up the rights of patients in their own community (Schutyser[19], Taylor[13], Chiles[8]). The World Health Organisation has published a

declaration on the promotion of patient's rights in Europe through its offices. These are only examples. A search through the Internet will lead you to thousands of such articles on the subject.

In India, several attempts have been made by government and non-governmental organisations to promote such awareness. A patient's charter has been published. Workshops have been held and a working group on formulation of citizens charter on the health services has been published by the Central Consumer Protection Council. Relationship between the doctor, patient and Consumer Protection Act has been described in a book form by Dr J Singh. The Janswasthya Abhiyan (an NGO), Peoples Health Movement in India(phmindia.org) and patientsrightsnow.org are some of the organisations and movements in recent years to promote awareness and demand legislation.

The British Medical Journal, The Lancet, The New England Journal of Medicine, Medicine and Law and many other publications have dealt with the subject from time-to-time by publishing opinions both from patients and medical personnel. It is not within the scope of this book to provide an exhaustive bibliography of articles on the subject. I have listed, at the end, some of the articles, which I believe will have profound effect on the reader and will give an insight into the variety and source of such writings.

What is the patient's perspective of quality healthcare? In a survey conducted in Guinea, the community perspectives of primary healthcare services were reviewed.[12] The community perceived quality healthcare on the following points:

(a) Technical competence of healthcare personnel
(b) Interpersonnel relations
(c) Availability and accessibility of resources and services
(d) Accessibility of healthcare personnel
(e) Outcome of care

This perception is very characteristic of the minimum standards expected.

It is to be hoped that the professional organisations will rise up to the expected standards. Communication between medical professionals and patients is not easy. It requires compassion and understanding the basic skills in communication. Medical colleges and universities in many countries (Handfield Jones[11] and Kurtz[15]) have, in the recent past, included in the curriculum a course on developing communication skills for the students. Canadian medical schools demand certification in communication skills before issuing license to practice medicine. Similarly in Australia, communication skills have been included in medical school curricula. These observations by healthcare professionals and members of society in the developed countries are to be looked upon with great care. It is only after observing results over the past three decades that these organisations have decided that doctors and healthcare professionals need education in communication skills. This has risen out of the interaction between communities and healthcare providers. The inclusion of these in the curricula and demand for certification emphasise the need for developing communication skills among doctors and healthcare providers.

More recently, in the last two decades, scientific developments have changed the way doctors practice medicine. The availability of the Internet provides visual and verbal communication at a distance. Surgical techniques have become more sophisticated, complicated, expensive and hazardous. Doctors and hospitals do not clearly disclose or seek acceptance of these practices from patients and tend to lure the patients to select a more expensive and risky procedure. The obligatory consent taken at the time of admission of a patient to a healthcare facility is not legally valid. Hospitals and doctors do not share their results and are reluctant to share these with patients. There is no national registry to authenticate the quality of medical care in India.

WHAT IS PATIENT'S RIGHTS?

Patient's rights combine human rights with the contractual rights between a doctor and patient. It is necessary to under-

stand that the patient who seeks treatment from a doctor deserves to be recognised to have certain rights. In the absence of these rights, patients may receive both unnecessary and unwanted treatment. Both of these are detrimental to the patient and the profession.

WHY IS IT NECESSARY?

Patient's rights are necessary because the patient who comes to a doctor is suffering from an illness; he comes as a dependent of the doctor from whom he seeks treatment. His position as an individual is a very weak one. He lacks freedom to know and to decide what is good for him. He is also blissfully unaware of the quality of medical treatment that can be delivered to him. He is unaware of the cost of such treatment. Finally he expects that the doctor or the expert whom he sees will represent him in making a decision on his health. As explained earlier, such a vulnerable person in modern society will receive treatment that might be both expensive and unnecessary. Doctors, particularly in the present era, look upon patient as their source of income. Hence, they would be reluctant to advise the patient that he does not require or his condition does not warrant treatment. Extraneous influences such as money and a large practice dictate patient care in this manner.

In developed countries, particularly the United States and in Europe, public awareness of patient's rights took origin sometime in 1960. However, much of this was recognised in the human rights violation that occurred during the Second World War. Over the next three decades, various governmental and non-governmental organisations have done enormous amount of work to promote patient's rights. In many countries, it is already incorporated into laws. However, the international medical community throughout the world does not accept this uniformly.

There is not much effort made in making the public and the doctors aware of patient's rights. It is the purpose of this book to bring this awareness of the existence of patient's right to those who are dealing with such subjects.

WHAT IS THE DIFFERENCE BETWEEN PATIENT AND CONSUMER?

A consumer in ordinary usage is a person who receives services for payment. A consumer has the right to choose an article of his choice. For the consumer, several rights are already incorporated in the Consumer Protection Act. He may seek compensation legally for deficient service. The person providing service is obliged to ensure that full information is given to the consumer about the product/service and to guarantee that such service or product will function according to the published or provided information. The consumer is an active beneficiary of this Act. He can choose quality and he has the freedom of choice. He is also aware of quality, cost, availability, and he is capable of representing his own interest in a court of law or before the consumer protection forum.

On the other hand, as explained earlier, patients are weak, vulnerable, dependent and cannot represent themselves. They are unaware of cost and quality that they should receive. There is no maximum retail price (MRP) for any procedure. When these differences are compared it becomes obvious that the patient is very dependent on the skills of the treating physician and his knowledge. Deficiencies in the management of patients by the treating physician is unknown and not disclosed. He is incapable of defending himself and protecting himself from malpractice except through a *knowledgeable* legal advisor. In most countries, lawyers are also specialists in such litigation. However, in India, in the absence of a patient's rights legislation, compensation is dependent on the knowledge of the concerned lawyer and judge. They may refer such cases to experts for an opinion. There is a motor vehicle accident tribunal that decides compensation for accidents. No such tribunal exists for medical negligence or similar cases. It is for this reason that awareness of patient's rights is necessary.

WHAT IS THE GLOBAL TREND?

In some countries in Europe and in the United States, there are laws in force to protect patient's rights. At the time of writing

this book, countries like Denmark, Finland, Greece, Iceland, Israel, Lithuania, Netherlands have laws incorporated for the purpose of enforcing patient's rights. In other countries in Europe, such as Belarus, Estonia, Georgia, Norway, Russian Federation, Turkey, Austria, Bulgaria, Czech Republic, France. Germany, Hungary, Poland, Slovakia, Slovenia, Spain, Sweden and Uzbekistan, patient's rights are incorporated into legal acts or laws in preparation. In some other countries like France, Ireland, Portugal, United Kingdom, Czech Republic, Slovakia, and Sweden, a patient's charter has been enforced. However, without legal rights, no patient can claim compensation or justice when his rights are not protected. With a view to protect the patient's rights, the United States Senate has passed the patients' bill of rights. When looked on from a distance it is obvious that the wave of recognition of patient's right is beginning to take it seriously in many countries.

These countries have reached this level of recognition and incorporation into law because of the basic infrastructure available. In all these countries, medical care is available to all citizens. The government is directly responsible for providing medical attention and to ensure the health of all their subjects. These countries also receive as tax, a certain part of the earnings of the individual to provide medical attention. Having succeeded in developing necessary infrastructure for healthcare delivery and having provided the required finances, these countries are able to implement the patient's rights. It must be clearly understood that in the absence of such developments in infrastructure and change in government policy towards healthcare, patient's rights will have no meaning. It is when the government is willing to consider seriously the need for healthcare to reach every citizen in the country, only then can they consider incorporation of patient's rights into laws.

The patient's rights movement in developed countries has come about after many decades of observation. This is due to the fact that in the beginning, there was only the conscious need for recognising patient's rights. This consciousness grew into compulsion, because of the phenomenal technological

developments in medicine. This was combined with adequate infrastructure development in the form of healthcare delivery facilities and the government's conscious funding and recognition of the need for a healthy population. As a result of the developmental programmes, citizens became aware of the need for adequate healthcare facilities and began to monitor the quality of care.

This was supported by improved regulation of delivery of medical care. Here the government and professional bodies stepped in to regulate and enforce quality. Professional associations are represented in governmental organisations for advice on the developments. This is obvious in the case of the United States where physicians are required by law to obtain re-certification at least once in 5 years. The re-certification requires putting in mandatory minimum number of hours of Continuing Medical Education (conferences, symposia, and lectures, etc.) to keep abreast of the developments in their speciality. In addition, they should continue to practice and keep up a minimum number of procedures (such as operations) to be eligible for re-certification. In addition, most professional organisations in the US have published minimum practice guideline standards[24] that every physician or surgeon should follow. If the concerned physician/surgeon/hospital does not conform to the minimum standards of quality, they run the risk of losing their licence to practice. Every physician even in India has to obtain a malpractice insurance to cover the cost of litigation and any compensation arising from such cases.

It is only when such stringent quality control has been in place that these countries are willing to consider legislation to protect patient's rights. Without these basic foundation, steps any attempt to legalise patient's rights will lead to disastrous consequences in healthcare delivery.

PATIENT'S RIGHTS IN INDIA

At present, there is scant awareness that patients have rights. Both doctors and patients are unaware of the rights of patients.

There is no separate act or rules formed under this head in parliament. However, we are several steps behind Europe, US and other developed countries in this area. In order to legalise patient's rights, there is a need to do the following.

(a) Improve the infrastructural development both in the government and private sectors in healthcare. Provide more hospital beds, doctors, clinics, nursing and medicines and conform to international standard in healthcare delivery. There are agencies such as National Accreditation Board for Hospitals (NABH) and the Joint Commission International (JCI) which evaluate the practice standards in hospitals and certify them. Once this certificate is obtained, hospitals tend to become more expensive. These agencies also monitor the quality of care periodically. They however do not have powers to enforce any compliance.

(b) In order to achieve (a) above, the government needs to change its attitude towards healthcare. There is need to recognise that healthy citizens provide a stable economy for growth. An unhealthy sick population will drain the per capita income towards healthcare, if governments are subsidising this sector. An unhealthy population can only deliver poor quality service. So in order to achieve (a), the government should change its attitude and give more importance to health. They need to develop the necessary infrastructure, establish healthcare insurance for all and allocate adequate funds for healthcare infrastructure.

(c) There is need for regulating medical practice. With so many systems in medicine, and so many people practising medicine, there is a need for a regulatory body with teeth. It should have the powers and the ability to enforce discipline in all systems of medical care. They must enforce proper licensing both the medical profession and the paramedical personnel. There is need to enforce existing laws in the pharmaceutical industry and to regulate dispensing of medicines as well. The NABH and the JCI are only regulatory bodies that certify hospitals. They have no powers except, to withdraw certification. Unfortunately, these agencies do not adhere to stringent international

standards (explained later) and are known to ignore sub-standards.

(d) There is no law on re-certification of physicians in India. This needs to be done in order to ensure that physicians (and surgeons, gynaecologists and other specialist) undergo a minimum number of hours of Continuing Medical Education periodically (at least every 5 years). A method of mandatory re-certification should be introduced. Names and addresses of physicians who do not qualify for re-certification must be published through local mass media or through the government Internet portals. This was introduced some years ago but is not enforced.

(e) Healthcare delivery organisations (hospitals, nursing homes, clinics) should have similar licensing. They should ensure that physicians employed by them and who are using these facilities conform to re-certification requirements. They must evolve their own mechanisms for monitoring quality of care in their establishments. They must also provide avenues for grievance redressal for patients. They must develop a robust communication system that helps in avoiding litigation. The Medical Council of India (and state medical councils) requires every physician to sign a declaration referred to in Appendix I, at the time of registration. The statements are generally forgotten just as the Hipocrates' oath in due course of time. This is not peculiar to India, as I have experienced myself in foreign countries how doctors behave towards patients and how patients without insurance are treated.

(f) Finally, healthcare must become universally available to all classes of citizens. The government must generate funds for or provide mechanisms for funding basic and tertiary medical care.

It is only when all of the above steps have been achieved can one seriously attempt to establish patient's rights as an act of parliament. In the absence of the above infrastructural

development, administering patient's rights will become seriously one sided. This will result in further complicating quality healthcare delivery. Physicians will not only be cautious, they will then not undertake their responsibility with enthusiasm. It is, therefore, very premature at this time to seriously administer patient's rights. However, recognition that patients do have rights will be the first step towards achieving better infrastructural facilities. Although it may take a decade or two before patient's rights are incorporated into laws, this will be a first step in the process. This first edition was published in 2001. It has been quoted in litigations and judgements yet, two decades later, we still do not have a legal system to administer patient's rights.

Patients may currently rely on Human Rights guaranteed under the Article 21 of the Constitution of India. They may also complain to the Medical council under the Professional Conduct regulations of 2002.[39] They may approach the consumer forums for the redressal of grievances. They may also approach the courts using past judgements under similar cases. They may refer to the Charter of Patients' Rights for adoption by the National Human Rights Commission (NHRC).

WHAT STEPS CAN BE TAKEN IN INDIA?

With the above drawbacks, already discussed steps that can be taken in this current status need clarification. Primarily, medical profession and the government need to recognise that patient's rights are important.

In a society where national literacy averages 74% (or thereof), the recognition of patient's rights becomes even more meaningful. It is common knowledge that the illiterate and the poor receive poor quality of service. For this reason, alone recognition, that patients do have rights will correct to a large extent malpractices in healthcare delivery.

Government and non-governmental organisations (NGOs) should take up these issues and bring about awareness among the people. Even in the absence of laws protecting these rights, this one step will go a long way in improving the quality of

healthcare. The mass media (newspaper and television) should be used for educating the public on these issues. It is particularly important to observe that such facilities extend to even more remote areas, and provide a far greater reach.

METHODS OF EDUCATION

1. Primarily communication between patient and doctor needs to be improved. As noted in other countries (Canada and Australia), medical graduates have to undergo a course and even be certified in communication skills before receiving a license to practice. Therefore, medical universities and schools (there are more than 335 in India) must introduce a course in communication in the curriculum.
2. Medical graduates and paramedical staff (nurses, hospital employees, and technicians) should undergo periodically a course on communication. They must also be taught to recognise and respect patient's rights.

Secondary schools where most people receive basic education should introduce a structured course on human rights and patient's rights. This is best introduced in the 12 to 18 years age group where learning ability is much better. It may be included in the subject of social studies which is now a compulsory subject in most schools.

Advanced courses in communication, in sociology, law, history, etc. must include a course on patient's rights. Such educational structure will help to develop an understanding and recognition of patient's rights at all levels.

COSTS

As a first step, recognition that patients have rights will be free of any expenditure. However, as a rule, nothing comes free. Funding will be required for mass education to set up governmental and non-governmental agencies for implementation of the educational programmes.

In terms of costs of medical care, this step in the long run will bring down the costs. Patient's participation in his own

healthcare has been shown to be cost-effective in developed countries. It is a fact that costs containment in healthcare delivery was one of the compelling reasons for recognising and implementing patient's rights. One of the major benefits will be a friendlier attitude between doctors and patients resulting in reducing unnecessary investigations and treatment. The resulting savings in healthcare delivery can only be imagined.

BENEFITS

The benefits of recognition and implementation of patient's rights are numerous. Primarily it improves availability, affordability of quality of healthcare delivery. There will be an improvement in infrastructural facilities like expansion in healthcare facilities.

- There will be legislation of licensing of healthcare workers and organisations.
- Healthcare will become less expensive and will reach those most in need of these.
- There will be better and friendlier doctor–patient relationship.

There will be awareness among the people for the need for a healthy living and to seek medical care early rather than late.

NEGATIVE ASPECTS

There are strictly no negative effects in recognising or implementing patient's rights. However, at the present moment in India, it is time to take steps in implementing or incorporating these into laws. Administering patient's rights at present will require development of infrastructure as discussed earlier. There would be litigations for which no laws exist and it would have a costly effect on the already inadequate and poor quality of healthcare delivery.

On the other hand, recognition that patients do have rights and that sometime in the future these would be converted to

legal rights would have very beneficial effects both immediately and in the long run.

The National Human Rights Commission (NHRC) has placed through the Ministry of Health and Family Welfare (MOHFW), Government of India a draft proposal of patients' charter for implementation by all state governments.[35] This draft was sent on 30th august 2018. It is only a recommendation and is not yet incorporated as law. However, since many of the provisions come under the fundamental rights under the constitution, this draft does not preclude patients from exercising their right to address grievances to the appropriate legal channels. The draft proposes establishment of hospital, district, state, and central government grievance redressal bodies. Currently, therefore, there is no separate patient's rights act. Patients can seek redressal through the hospital appointed grievance redressal body, consumer forums, and courts.