

## INTRODUCTION

Health is universally recognized as an essential good. Health is man's greatest possession, for it lays a solid foundation for happiness. According to Buddha of all the gains, the gains of health are the highest and the best.<sup>1</sup> Health is not only a quintessential good for leading a happy life for an individual but it is also necessary for all productive activities in the society. Charaka, the renowned Ayurvedic physician is known to have said: 'Health is vital for ethical, artistic, material and spiritual development of man'.<sup>2</sup>

Like the proverbial elephant, health is difficult to be defined but easy to be spotted when we see it.<sup>3</sup> Health is often taken as identical with physical well-being or freedom from disease. But according to World Health Organization health 'is a state of physical, mental and social well-being and not merely the absence of disease or infirmity'. The definition provided by WHO underlines health as an integral part of what individuals need in order to realize their full potential and derive satisfaction from life. Health is therefore, not an end in itself but it is a means towards the fulfillment of the latent possibilities of us all and also a means of ensuring an acceptable quality of life.<sup>4</sup> In other words, health is axiomatic to human development.<sup>5</sup>

Health is placed inextricably at the heart of social and economic concerns. Empowerment of people comes from the freedom they enjoy, and this includes, among others, freedom from poverty, hunger, and malnutrition, and freedom to work and lead a healthy life.<sup>6</sup> Access to health care is critical to improving health status and good health is necessary for empowerment. Ensuring access to health care helps to minimize absenteeism, enhance labor productivity, and prevent misery. Government intervention in health is also argued for, due to the presence of high degree of asymmetric information in the health sector. Not surprisingly, throughout the world, governments have had a significant role in providing and regulating health services

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<sup>1</sup> SL Goel, *Primary Health Care Management*, Deep and Deep Publications, New Delhi (2004), p.2.

<sup>2</sup> Id.

<sup>3</sup> Michael Bury, *Health and Illness*, Polity Press, UK (2005), p.1.

<sup>4</sup> Diane Longley, *Health Care Constitutions*, Cavendish Publishing, London (1996), p.1.

<sup>5</sup> Id.

<sup>6</sup> Sen, A.K., *Development as Freedom*, Oxford University Press, New Delhi (1999).

and their role is particularly important in developing countries with large concentration of the poor.<sup>7</sup>

The role of law, however in the case of protection of health of an individual is limited. No law can guarantee an individual an absolute healthy life. Neither it can make a sick person healthy, cure disease or reduce suffering of an individual. But its importance lies in creation and maintenance of conditions in which governmental measures may be promoted or maintained. The role of law cannot be undermined in the regulation of medical institutions and personnel's engaged in healthcare as it is eminently the function of law to prescribe legal principles upon which failure by a healthcare personnel to discharge his or her duties properly may be visited with appropriate legal sanctions. Thus, the law helps in the removal of impediments in realizing healthcare.

The law's involvement in public health emerged in the nineteenth century. The health concerns of nineteenth century were much different from what we experience it in the current world. The sources of threats to ill-health in those days were largely beyond individual control and public initiatives on sanitation, vaccination, and medical treatment were able to make a considerable impact on the rate and causes of death.<sup>8</sup> While public health measures remain important even today, it has been said that 'much of the responsibility for ensuring his own good health lies with the individual'.<sup>9</sup> Hence, the State shifted its focus from providing safe drinking water and provision for effective disposal of waste, the supply of wholesome food, safety at work, controls on pollution and good housing to persuading individuals to examine their lifestyles. This raised new questions about the role of law in healthcare.

Health law encompasses increasingly diverse and complex concerns, including aspects of biomedical science, human reproduction and cloning, disability, infectious and non-communicable disease, and safety control for health services, foods and pharmaceuticals.<sup>10</sup> Changes in medicine directly affect not what humans can do, but how we think about what it means to be human; issues of social justice and resource

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<sup>7</sup> M. Govinda Rao, Mita Choudhury, *Health Care Financing Reforms in India*, Working Paper No: 2012-100 National Institute of Public Finance and Policy, (2012), p.1.

<sup>8</sup> Jonathan Montgomery, *Health Care Law*, Oxford University press, Oxford (1997), p.23.

<sup>9</sup> DHSS, *Prevention and Health: Everybody's Business*, HMSO, London (1976), p.95.

<sup>10</sup> Grad F, "Public health law: Its forms, function, future and ethical parameters", 49 *International Digest of Health Legislation* 19 (1998), p. 24.

allocation arise more starkly and more compelling in the health care context than in any other; and health law introduces us to the problems confronted by another major profession, medicine.<sup>11</sup> Furthermore, international health law is increasingly recognized as integrally linked to most other traditionally defined realms of international legal concern.

Recognizing health care as a basic human right assumes that medical services are viewed as a natural right of all people and not a privilege of some fortunate individuals. It also confers certain responsibilities upon States. Foremost, the government must recognize the human right to health care and apply principles of social justice in legislation at the national level to support this right. Secondly, a national strategy on health care, including principles of accessibility, equality, and universality must be adopted and finally, it must drive a nation to develop a plan of action as a result of awareness that being uninsured and lacking access to basic health care leads to poor health outcomes for a society. These factors should serve as guiding components of any health care system modeled under the premise of a human right to health care for all. Health care policies must be developed in such a way that they will address the above points.

The design of a health care system in any country must be guided by the following key human rights standards: access, availability, acceptability, quality and non-discrimination. Human rights are used proactively as a tool for provision for better healthcare. The right to health care thus ensures that hospitals, clinics, medicines, and physician's services are accessible, available, acceptable and of good quality for everyone, on an equitable basis. The creation and functioning of WHO after World War II indicate that the protection and promotion of health represented one of the common values of States, and States shared responsibility in the working of a common institution, i.e., WHO in pursuit of that value.<sup>12</sup> It defined health in terms of an ultimate goal of perfection.<sup>13</sup> A noteworthy development for human rights and health policy was the UN's adoption in 1948 of the Universal Declaration of Human Rights (UDHR), which formed a comprehensive common vision of inalienable

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<sup>11</sup> George J Annas *et al*, *American Health Law*, Little, Brown and Company, London (1990), p. xxxi

<sup>12</sup> David P. Fidler, "International Law and Global Public Health", 48 *U. Kan. L. Rev.* 1(1999), p.15.

<sup>13</sup> Jonathan Montgomery, *Health Care Law*, Oxford University Press, Oxford (1997), p. 2.

rights.<sup>14</sup> Further, in recognition of health as a human right the said right appears in various other international human rights document.<sup>15</sup> It is also included in the statements of rights for specific groups of people, such as children and women.

Any reflection on the term 'health' in the international documents immediately reveals its complexity. The instruments prove that the idea of health is capable of wide and narrow application, and can be negatively as well as positively defined. We can be in good health and poor health. Moreover, health is not just a feature of our daily life; it can also appear on the political landscape. These international commitments nevertheless enshrine noble aspirations and examine the concept of health in both social and engineering model.

From the perspective of social model of health, the scope of health is vast. As Jonathan Montgomery<sup>16</sup> notes: 'the state of our health is fundamentally affected by our diet, the conditions of our environment, the way in which we live is organized, the lifestyles we adopt, and our own genetic heritage'. In contrast the engineering or mechanical model of health is concerned with the adequate functioning of the human body, preventing its breakdown and repairing it where necessary.<sup>17</sup> The promotion of health cannot be achieved by measures that derive from any single health discipline, nor can health measures be considered independently of the broader educational, social economic and administrative factors that are crucial to human development. Thus, inter-sectoral coordination is essential. As Adeoye Lambo<sup>18</sup> states:

It is now apparent that a more balanced consideration of the biological, social and cultural aspects of health is needed. Life is a process and not a substance, a living system based upon the primacy of continuity and inter-relatedness throughout the universe...If man and his family are to remain in empathy with the emerging necessities in the developing milieu, an adequate design of inter-disciplinary tools will have to be made to assist in this task of providing a total health package.

Health is therefore, now a concern for almost every sector of society, not just the health sector. It is understood that appropriate developments must occur in agriculture,

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<sup>14</sup> See, Article 25 of the UDHR, 1948.

<sup>15</sup> See, Article 12 of ICESCR, 1966.

<sup>16</sup> Jonathan Montgomery, *Health Care Law*, Oxford University press, Oxford (1997), p. 3.

<sup>17</sup> Id. p.2.

<sup>18</sup> Adeoye Lambo T, "Total Health", *World Health*, WHO (1979), p.23.

industry, and energy if sustainable health improvements are to be attained. Thus, developments at the national and international political levels have promoted a more holistic perspective on health.

### **WHY RIGHTS OF PATIENTS?**

Medicine is essentially concerned with the relationship between doctors and patients and to a lesser extent hospitals and other institutions.<sup>19</sup> Between the doctor and patient there is an inevitable imbalance or disequilibrium of power. As Ian Kennedy<sup>20</sup> notes ‘the doctor has information and skill which the patient, who lacks these, wishes to employ for his benefit’. Among the powers possessed by the physician is the privilege to touch and even invade the body of another and as a consequence exercise control to a greater or lesser extent over that person. Moreover, the vulnerability of the sick makes them easily subject to violations of their rights and more affected by the shortcomings of social and health administrations.<sup>21</sup> The powers of the physician therefore, must be subject to control and scrutiny. By conferring specific rights to patients, the exercise of the doctor’s power could be set within the permissible limits by ethics and law.

There have of course, been doctors or healers in the past too and they held control over human health. The growth in healthcare during the twentieth century, both in terms of technological advances and social expectations means that a patient is more likely to encounter doctors, nurses and other healthcare workers on a professional basis. Over the years, especially after Second World War, medicine changed from what was essentially an art into a discipline increasingly grounded in science. The modern face of medicine is dominated by astonishing range of options like assisted reproduction; developments in genetic diagnosis and organ transplantation, stem cell research to name a few. But the discipline of medicine brings with it specific emotive and moral complications. For example, abortion, euthanasia, organ transplantation, assisted conceptions are ethical as well as legal issues and an entire philosophical subject of medical ethics has developed to study

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<sup>19</sup> I Kennedy, “Emerging Problems of Medicine, Technology, and the Law” in I.Kennedy, *Treat Me Right*, Oxford University Press, Oxford (1988), p.3.

<sup>20</sup> I Kennedy, *Treat Me Right: Essays in Medical Law and Ethics*, Clarendon Press, Oxford (1991), p.387.

<sup>21</sup> Leenen, HJJ, Gevers, JKM, Pinet G, *The Rights of Patients in Europe A Comparative Study*, Kluwer Law and Taxation Publishers, Boston (1993), p. vii.

them. There are common issues which permeate all the problems which underlie these modern techniques: respect for autonomy, consent, truth-telling, confidentiality, respect for personhood and persons, respect for dignity, and respect for justice. Today, well-informed patients are beginning to assert these rights in their private dealings with professionals in the health field. Hence, there is a need to advocate new and more positive concepts of patients' rights.

The public's interest in medical issues has risen in quantum leaps in recent times. Professionals such as lawyers, philosophers, theologians and doctors themselves have begun the process of discussing and analyzing the problems and dilemmas that arise in the practice of modern medicine.<sup>22</sup> Patients have also become more aware of their rights. There are indications that in the future medico-legal cases may not be restricted to the traditional medical negligence action, but may be opened out to the possibility of rights based actions brought by patients who wish to explore the legal relationship with their doctor.<sup>23</sup>

Developments in the systems of healthcare have implications for medical practice and the care of patients. Governments are paying increasing attention to medical issues for many reasons: in particular the growing burden of bureaucracy, especially in hospitals, new developments in computer technology, data recording and management techniques and the rapid advances in medical and health science and technology that have hastened the change in patients' expectations.<sup>24</sup> The State's pledge to 'health for all' movement stresses inter alia encouragement of individual choice and the opportunity to exercise it freely, and the commitment to build appropriate mechanisms to ensure the necessary quality of care. Hence, this thesis places all ethical and legal questions in the context of patients' rights.

Rights of patients can be divided into individual and social rights. The goal of social rights is to safeguard the participation of men in the achievements of society; whereas individual rights aim at the protection of the individual spheres and of liberty.<sup>25</sup> As to health, social rights are mainly expressed in the right to health care and

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<sup>22</sup> Andrew Grubb, "The Emergence and Rise of Medical Law and Ethics", 50 *The Modern Law Review* 241 (1987).

<sup>23</sup> Id.

<sup>24</sup> Id. p.v.

<sup>25</sup> Id. p.1

individual rights are expressed in the right to be treated, right to autonomy and right to privacy. This study delves deeply into both social and individual rights of patients.

### **OBJECTIVE AND RELEVANCE OF STUDY**

Physicians in India have always held disproportionate power over their patients, and classical paternalism in physicians' behavior is the rule rather than an exception.<sup>26</sup> Therefore, patients' rights in India are indirect rights, which arise or flow from the obligations of a physician or healthcare provider. For example, Indian Medical Council (Professional conduct, Etiquette and Ethics) Regulations, 2002 deals with the duties and responsibilities of physicians in addition to certain rights of patients. However, it must be emphasized that this code does not represent patients' rights and those mentioned are incidental to the duties and responsibilities of physicians.

The need for the study assumes more significance as in India; the rights of the patients are not reduced in writing in any statutory or codified form. Rights of patients in India basically emanate from the Constitution, human rights, consumer rights, code of ethics of medical and nursing profession. Though, the Government of India has enacted plethora of legislations on health and healthcare, these legislations are piecemeal and address its objectives without contextualizing them in the overall context of patients' rights. Further, these legislations unfortunately does not mention about the patients' right and the observance of medical ethics. At present in India, if rights of patients are violated the only recourse for patients is to approach the courts and there are no alternative mechanisms for adjudication of their grievances. Though regulatory bodies, scientific review committees, ethics committees and NGOs have tried their best in ensuring certain basic rights for patients, the studies have shown that their efforts have fell short of providing a comprehensive framework for the provision of rights for patients. With an increasing number of corporate hospitals, healthcare-related issues and research trials, there is a need to build a better mechanism for protection of rights of patients in our country. It is against this backdrop the topic, 'rights of patients' have been chosen.

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<sup>26</sup> Solomon S, Solomon SS, Ganesh AK. "AIDS in India", 82 *Postgrad Med J.* 545 (2006), p.546.

## **METHODOLOGY**

The study is doctrinal in nature. The materials available in the form of books, articles, statutes, judgments, governmental reports, studies and surveys conducted by government and non-governmental agencies relevant to the topic have been used for research. Though, the work is mainly focused on Indian law pertaining to the rights of patients, however in appropriate contexts the position of law and judicial decisions from other countries have been referred to.

## **SCHEME OF CHAPTERS**

The work of the thesis has been divided into seven chapters.

The end of medicine depends in great part on the understanding of the nature of health and illness. Therefore, in the first chapter, an attempt has been made to understand the concept of health, its philosophical nature, how far health is an enforceable human right, confusions regarding many of the public policy issues and also the ethical concerns that loom over the decisions made by medical practitioners while protecting the rights of patients.

Conventionally, patients' rights were protected through ethical rules or codes of conduct. These codes acted as guidelines that the medical professionals imposed in order to ensure that doctor's behavior towards their colleagues and their patients met appropriate standards. Though, doctors were under a duty to act in their patients' best interests, it was doctors who decided what those interests were. Thus, for centuries the focus of all the discussions on rights of patients has been centered on the 'particular obligation' of individual physician towards their patient's. Until 1970s, giving protection to patients did not include a meaningful role for the patient in the decision-making process. Reforms in health systems, progress in medical technology, respect for human rights, and other relevant factors like changing doctor-patient relationship have influenced patient's status in health services. The right of patients for the first time was announced in French National Assembly in 1973 by stipulating that 'every patient has the right to have his or her own bed'. Since then there has been major legal development in both international and national level. The second chapter therefore, provides a brief historical overview of the changing doctor-patient relationship and explains how patient's rights were protected through different ages. The chapter also makes an attempt to define the term 'patient'.

Medicine is an ethical profession and a doctor is deeply confronted with complex and sensitive medical issues coupled with the increasing public demand in decision-making process in the modern day advanced technological era. Though, in the past, it was acceptable for doctors to base their decisions on conscience, intuition, received wisdom, and codes of practice, changes in the nature of the doctor-patient relationship and in the accountability of doctors have demanded a more formal and explicit approach to medical ethics. Doctors are increasingly required to explain and justify their decisions to patients, other health care workers, the media, regulators, and the courts, and to each other. In order to do so they need skills in ethical reasoning combined with an understanding of the law and knowledge of professional guidance. Hence, the third chapter focuses on various theories relating to medical ethics.

The 58<sup>th</sup> session of the World Health Assembly in 2005 defined universal health care as providing access to key promotive, preventive, curative, and rehabilitative health interventions for all at an affordable cost.<sup>27</sup> However, the goal of a comprehensive, high quality medical care that is freely available to all on the basis of medical need is difficult in the face of steadily increasing costs. Also, limited funding puts pressure on health providers and medical professionals and inevitably results in some patients being denied the medical treatment which they need. Hence, the fourth chapter focuses on the question whether a patient has a 'right' to receive medical treatment? Once a patient overcomes the hurdles of scarcity of resources, the law's focus turns to the quality of medical care offered to the patient. Thus, the chapter also examines the role of physician in ensuring quality care to patients.

Values inherent in fundamental human rights are notions of respect for the individual and for self-determination, on which the rights of patients are founded. The imperative of individual autonomy in healthcare requires that patients cannot be compelled to accept treatment which they do not want, no matter how painless, beneficial and risk-free the treatment may be and no matter how dire the consequences of refusal of treatment. The legal principle of consent is the conceptual mechanism through which the patient's right to self-determination is guaranteed and safeguarded. Thus, the fifth chapter examines the ethical underpinnings of the whole concept of consent and also the essential elements which have to be satisfied in order for a

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<sup>27</sup> M. Govinda Rao, Mita Choudhury, *Health Care Financing Reforms in India*, Working Paper No: 2012-100, National Institute of Public Finance and Policy, March- 2012, p.2.

competent patient to give a valid consent. For a significant category of patients, informed consent is unattainable due to lack of mental capacity or maturity. These incompetent patients may be temporarily, or even permanently, incapable of exercising an autonomous choice regarding healthcare and thus, alternative means of authorizing treatment must be adopted. The chapter also discusses as to who makes healthcare decisions in respect of incompetent patients and on what basis.

For proper diagnosis and treatment it is essential that in the course of treatment, a patient discloses truthfully to the physician about his illness. This may sometimes involve disclosure of personal and sensitive information to the doctors and it is the duty of the physician to maintain the confidence of his patient. In the modern day, most of the information acquired by physician is recorded and preserved at the hospitals and these medical records are no doubt regarded as the property of the hospital by law. There are circumstances in which medical professionals are encouraged or even required to report their observations or patient test results to third parties, sometimes law enforcement officials, in which such a breach of duty has come to be seen as acceptable. Of late, the medical community, the courts, and society have been struggling in particular with whether the breach of the duty of confidentiality by a physician is permissible or to be encouraged. The sixth chapter firstly, examines the concept of privacy. Secondly, it demonstrates the ethical and legal justification for protecting patient confidentiality. After having established a right to medical confidentiality, the chapter looks into the numerous exceptions to the right which exist due to the need to balance an individual's privacy against competing social needs. Finally, even though medical records are considered as an exclusive property of hospital or health care institutions; patient's right to gain access to their medical records is also discussed.

Finally, the thesis concludes with the summarization of the entire chapters. It put forwards some constructive suggestions and recommendations for effective protection of rights of patients in India.