A patient's right to know

(Adapted from McLean, 1989)

The patient's autonomy

A relationship between a doctor and a patient is based on the principle that the patient must have autonomy in making decisions. Such autonomy has been necessitated by two factors that override the obvious expertise of the doctor. First, the decisions to be made concern the health and life of the patient. Second, the patient and the patient alone knows what is right for him given his personal, family, social and economic status.

This right of the patient dictates the duty of the doctor not to overstep authority in the name or the interests of professional or technical superiority.

The doctor has a *continuing duty* to act in a manner consistent with the level of skill which can reasonably be expected of him but has MO right ***to do so unless*** the patient voluntarily agrees to it.

The patient's autonomy must be protected by the doctor even as he demonstrates technical competence. His task lies in helping the patient choose from various alternatives.

To make such autonomy meaningful, the doctor must provide honestly all the information that is necessary, including details on alternative means of treatment and the risks and benefits from the mode of therapy advised by the doctor. He must then allow the patient to make a free and uncoerced decision.

Only when such autonomy of the patient is protected by the doctor can he lay claim to moral and ethical practice.

Information disclosure

Although patients are not qualified to supervise the quality of medical care given to them, they are able to balance costs and benefits, especially when it concerns their own health and lives. They are also able to decide the extent to which they wish to delegate the responsibility for making decisions to the doctor. It is the doctor's responsibility to do all he can to help.

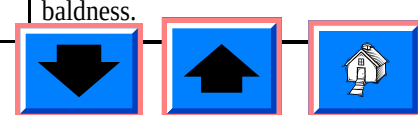
The doctor must especially provide all information (such as the possible morbidity and mortality from a procedure) which can reasonably be expected to influence the patient's decision.

When specific questions are asked by the patient or his near relatives, a full and fair disclosure must be made in response to them. It is not necessary, however, for the patient to have to ask specific questions for obtaining information. ***'Caveat emptor*** is not the norm for the consumer of medical services. The duty to disclose... is a duty to volunteer.. . the information the patient needs for an intelligent decision.' (Judgement in *Canterbury* ***v.*** *Spence*, quoted by McLean 1989)

The Bolam test (if the doctor acted in accordance with a school of thought accepted as reasonable by a responsible body of medical opinion, he was not negligent) has its drawback in referring the morality of an act by an individual to the views held by his peers instead of relying on the principles of morality.

The need to ensure that the patient understands the information provided: Since information is being provided to permit the patient make his own decision, it is up to the doctor to ensure that the information has been understood. Informed consent is neither informed nor valid if it is based on misunderstanding.

Apart from ensuring that the patient understands the pros and cons of a given step that worry the doctor, it is also important to provide details on aspects that the patient is deeply concerned. An example is the use of drugs in the treatment of cancer. Apart from warning the patient about possible compromise of his immune status and its consequences, it is also necessary for the doctor to dwell on nausea, vomiting, loss of appetite and baldness.



Legally incapacitated persons: What about the rights of children or the mentally incompetent? Let us consider the child who has not yet reached majority. It has been argued that for such patients, a paternal attitude by the doctor is essential - a necessary abrogation of the individual's right.

The fallacy of such an argument becomes evident when you consider the age at which a person becomes a major, becomes fully responsible for all his behaviour and is accorded all civil rights. The age - termed 'the magical age of majority' by McLean - has varied from 16 to 18 to **21** in different countries. On what basis is such a distinction drawn? Does it signify that an individual a day short of that magical age is incompetent to understand what is said to him?

Lord Denning provided wise counsel. '. ..The legal right of a parent to the custody of a child (in England) ends at the eighteenth birthday and even up till then, it is a dwindling right which the courts will hesitate to enforce against the wishes of the child, the older he is. It starts with a right of control and ends with little more than advice.. .' (Denning 1969).

Add to that the following: 'Parental rights to control a child do not exist for the benefit of the parent. They exist for the benefit of the child and they are justified only in so far as they enable the parent to perform his duties towards the child.. .' (Lord Fraser quoted by McLean).

And so it must be with doctors.

Morality demands that no blanket denial of autonomy to certain groups be made. The doctor must consider each individual case and determine competence to understand, weigh and judge. In so far as this is present, it remains the duty of the doctor to grant autonomy to make decisions to the patient and provide needed information.

Article VII of the United Nations document entitled *Rights of the Mentally Handicapped Person (197* 1) makes another point: Some mentally retarded persons may be unable, due to the severity of their handicap to exercise for themselves all of their rights in a meaningful way. . . Modification of some or all of these rights is appropriate. *The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.* '

The above discussion in no way infringes upon the need to keep the legal guardians (of children or mentally incompetent individuals) informed in order that they may form their own decisions.

Disclosure of information likelv to worsen the patient's health: The principle of *reasonableness* must govern the doctor's actions. Since the doctor's principal duty is to restore health to the extent possible, insistence on disclosure of all information - including that capable of potential harm - is counter-productive. Where the risks from such disclosure over-ride the rights of the patient to autonomy, withholding such information is justified on the grounds that it is done in good faith and with the patient's interests at heart. (Under such circumstances, special care must be taken to keep legally responsible relations of the patient fully informed.)

Lord Templeman summed this up well: 'In order to make a balanced judgement... the patient needs to be aware of the general dangers and of any special dangers in each case, without *exaggeration or concealment.* At the end of the day, the doctor, bearing in mind the best interests of the patient and bearing in mind the patient's right to information which will enable the patient to make a balanced judgement, must decide what information should be given to the patient and in what terms the information should be couched.' (Quoted by McLean 1989)

Disclosure of therapeutic alternatives and disclosure of risks and benefits

It is mandatory for the doctor to explain in clear and simple terms other therapeutic alternatives to the course suggested by him and discuss the pros and cons of each alternative, summing up with his reasons for

advocating the one chosen by him. This is especially important when the course advised by him carries risks (to health and life) that may be similar to or worse than those attending alternative methods of treatment.

Two important principles:

When the unavoidable risks of therapy occur, negligence cannot be implied. 'We cannot accept the benefits of medical treatment without also accepting its risks' **(Denning 1954).** This principle assumes that the doctor was acting honorably for the benefit of the patient.

The risk factor in medicine is precisely why accountability is so important.

Some provisos:

The patient is not obliged to accept risks merely because the course advised is likely to help.

The patient is not obliged to run risks in the interests of the medical profession or advancement of medical science.

Non-standard treatment administered without approval and without the benefit of proven safety requirements is especially prone to challenge.

Medical and technical skills

The legal aspects:

Most challenges to doctors follow the patient's perception of deficiencies in the nature of care offered and the quality of technical skill displayed by the doctor.

Negligence is described and delineated by rules of law and is not commensurate with accepted professional conduct, encompassing as it does consideration of justice, need and other factors.

The professional competence of a doctor is measured, in the eyes of law, by comparison with that of others of similar standing under identical circumstances. The doctrine of reasonable ***skill and care is*** applied. 'The standard of reasonable care is not subjective... but objective, namely the standard of care which the court thinks a hypothetical standard individual, the reasonable man, would display' (Walker 1981).

The sophistication of the medical act is such that others skilled in the same branch of the medical profession are required to assess the standard of care that would have been offered by a reasonable doctor in a given situation and whether the person under investigation has fallen below the expected standard.

At the same time, knowing the reluctance of any professional group to criticise its own members for anything short of the most flagrant negligence or malpractice, it has been urged that fairness to the patient and judgement on the moral conduct of the doctor demand standards set not by doctors themselves but by law.

Doctors as expert witnesses in cases of alleged negligence:

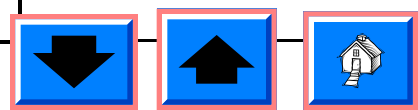
The doctor is expected to help the court arrive at a judgement, not make the judgement for the court.

His principal task is to opine whether the behaviour of the person under investigation met that of a reasonably competent practitioner.

The doctor as expert witness is, however, not competent to speak on the ultimate issue of negligence. That is a legal matter.

Consequences of shortage of resources:

Some claims for which the patients may argue may not be amenable to settlement. The inability of society to find sufficient resources to meet actual or potential demand will impose restrictions on an individual patient's rights. A case in point is dialysis for chronic renal failure. Given the sharply limited facilities available in the country, no matter how decisions on who shall be taken up for dialysis are made, some will be denied therapy.



Ensuring compliance with the law

It is not enough to recognise the truths enunciated above. It is also necessary to have in place mechanisms that can enforce the autonomy of the patient and make them function efficiently.

We have such mechanisms in this country in the form of the Medical Council of India and the various state medical councils, the Consumer Protection Courts and the courts of law. The medical councils have yet to prove that they do anything more than pay lip service to the principles of medical ethics. The courts of law are over-burdened by a huge backlog of cases to be heard and judged. These are matters of considerable concern to society at large, the medical and legal professions.

Epilogue

For those who scoff at ideology in medicine, Pellegrino and Thomasma provide an irrefutable argument: 'A philosophy of medicine is needed to help clarify medicine's goals in relationship to those of the technological civilisation. Medicine suffers from an abundance of means and a paucity of ends.' This makes especially good sense when you remember that means are no less important than ends.

As a consequence of all that is wrong in this field today, many in India dispute that medicine is a benign discipline. The assumption by doctors that technical expertise makes humane and moral practice unnecessary; unrecognised and unrectified wrongs in the medical profession; and the chain reaction set off by negligent and corrupt doctors who now hold positions of power have so unsettled public consciousness that recourse to litigation is seen as the only way of obtaining justice.

Unless we mend our ways, we may see the courts of law considering every interaction between doctor and patient as a legally binding contract and hold the former responsible on such counts as deceit, fraud, inadequacy of information, assault (trespass, battery), criminal and malicious intent. `When ethical standards do not generate uniform compliance by individuals faced with the mundane, everyday problems of life.. .the law steps in.. .to fill the recognised vacuum.. .so assure wherever possible, conformity to the ethical and moral ideal. '(Gregory 1981)

It will be a sad day when the profession of Caraka, Susruta, Hippocrates, Maimonides, Osler and Schweitzer needs the iron hand of law to maintain what was once the sanctity of the patient-doctor relationship.

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Sir William Osler on an ideal relationship between doctors

"An open mind in keeping with the free spirit of science, the ready acceptance of the best from any and every source, an attitude of rational receptiveness rather than of antagonism to new ideas and brotherly feelings should characterise a member of the most beneficent and universal guild that the race has evolved in its upward progress.. .."

"The word of action is stronger than that of speech."