

6 PATIENTS' RIGHTS: THE LAY PERSPECTIVE

CECILIA XUEREB

The doctor-patient relationship was historically based on trust rather than on monetary considerations. The family doctor, or the village doctor was a friend, a counsellor, a person of authority, a person to be honoured. The Welfare State brought about with it the socialisation of medical attention, and the right to proper medical care is nowadays recognised as part and parcel of the most fundamental human rights. The State which has the widest resources at its disposal and which is funded by the people's taxes has the obligation of providing the best kind of medical and health services, both therapeutic and preventive, that it possibly can. As a result, a consumerist mentality entered the medical field. The doctor became only one of the many and various social workers serving in dependence on, or in collaboration with insurance groups and social agencies and the patient became a consumer expecting high quality service. Health care is only one factor of the market economy. In many countries, this has resulted in the depersonalisation and in the dehumanisation of medical services.

In Malta, State provision of medical and health care exists alongside a reasonably strong private sector. The Government provides a free health service for all, which is covered from general taxation. Every citizen resident in Malta has a right to free health care, immaterial of income. Free medication is also guaranteed to those in the lower socio-economic strata. Generally speaking, patients can choose their general practitioner or their specialist or the hospital if they go privately. A patient can go directly to a specialist, privately, and then that specialist, who very often is also a public officer, takes the patient on in the public system. The idea of voluntarily joining private insurance schemes is gradually but steadily gaining ground. In this way one of the basic rights of

the citizen is adequately fulfilled: all medical services are available to all people independently of whether they can pay for them or not.

However the rights of the citizens go beyond the right to medical care to their rights in medical care, whether this is publicly or privately funded.

Most people in Malta regard their relationship with their doctor as sacred. While the family doctor is no longer the consultant on a wide variety of subjects, he is still looked upon with respect by most people. No matter how critical a medical situation can be, the mere presence of the doctor is for most people a great source of comfort. This has led to abuses by the public at large. They call in the doctor for house calls when they could very well have gone to the clinic themselves, or call out a doctor for a visit during the night or on a holiday when they could have done so at some other time. On the other hand, the patient needs to feel that the doctor considers him/her and his/her ailments important, and that he/she is prepared to give him/her all the time needed. This is certainly the case with most of our doctors and consultants whose bedside manners are impeccable. However it starts falling short further down the medical hierarchy: with nurses and paramedics and other hospital staff. While there are those among these people who are friendly and courteous and make the patient feel at ease and confident that he/she is in good hands, there are still several - I do not want to say many - others whose manners with patients seem to cater for the lowest levels: while they should make the beggar feel like a king, they in fact make the king feel like a beggar. Does it take much, for example, for a doctor who is seeing a patient for the first time to introduce himself instead of remaining a nameless face? The name gives the person an identity and it is amazing what difference this makes to the morale of the patient. The system whereby patients choose their own doctors who will follow them throughout their lives unless they want to change them, has remained a dead letter. Patients may find themselves being treated

by different practitioners every time they attend polyclinics.

Similarly the College of midwives had instituted a system whereby an expectant mother is followed throughout her pregnancy by the same midwife who would also deliver the baby. This system was discontinued: administrative criteria overcame personal and even, in this case, medical criteria.

Whatever the system it must remain primarily human.

Much has been said about informed consent and the right of the patient to refuse treatment, or to choose one form of treatment rather than another. Yet several doctors and people in the medical profession treat patients as some kind of morons who are unable to understand what is happening to them. They refuse to disclose to patients the real nature of their condition. I can personally recall the time when my own father was operated for the removal of the gallbladder: as a result of the operation he got the condition "ileus", or paralysis of the intestines. We only found out the real nature of his condition when the hospital authorities accidentally left his file where we could find it and we looked inside it. Not only should doctors inform patients, or their next of kin as the case may be, about the real nature of their patients' condition but these should be able to have access to their files and to all the data, medical or otherwise, which has been recorded about them.

The recent patients' charter issued by the College of Family Doctors adopts a very paternalistic attitude: patients' wishes in relation to any treatment or care proposed, including "any risks and any alternatives", are only "taken into account as far as possible". How far, one may ask, is as far as possible? Shouldn't the patient's wishes be taken into account and regarded as supreme at all times, even if these do not quite coincide with the wishes of the doctor? What is required here is that the person be given all the information needed for him to be able to take autonomous decisions.

Respect for the patient also implies keeping appointments. While the same Charter mentions that when a patient keeps appointments made for him/her he/she is helping the doctor, it only provides that “patients should be satisfied with the waiting time in surgery”. What criteria constitute satisfaction? It is one thing if there is no appointment procedure, but what about those doctors/specialists who do not time their appointments properly and allow patients to wait for over an hour before they attend to them. Obviously accurate calculations cannot be made since not all patients would require the same amount of time. The patients or clients of one particular gynaecologist, mostly pregnant women, have been known to wait for as long as two and a half hours, and this in the most uncomfortable of conditions, since the crowd in the waiting room necessitated that the women in question wait outside, seated on the steps of the clinic. Seeing to a simple fracture in the emergency department at St Luke’s just ten days ago took from 1.30 in the afternoon till 5.15, while an appointment with the consultant a week later which was scheduled at 9.00a.m. only materialised at 10.45. Is this reasonable, I ask?

Another big source of irritation for patients is long-term appointments. Prompt attention to requests for nursing or medical assistance is, or should be, one of the rights of patients. We have by now got used to being given appointments for six or more months ahead . This does not matter in the case of routine visits, but what happens in the case of an emergency? A patient who has already been treated by a particular person feels safer if he/she is attended by the same person who knows his/her history. Doctors should make allowances for such emergencies. Very often they make themselves inaccessible and although they themselves would never refuse to see such a patient, it is often the receptionists at clinics that have the task of putting people off. In Malta we do not have the system of group practices: but the least that could happen on such occasions is for the doctor or his clinic to refer the patient to another doctor whom the doctor him/herself trusts. Such trust might then be passed on to the patient.

All this can in fact be summarised in the fact that the patient expects to be treated with respect as an intelligent person. Closely linked with respect of the patient as an intelligent being is respect for the patient's dignity, privacy and confidentiality of his condition. Not all patients like to be turned into 'a case' and made the object of study. This happens because our major hospital is a teaching hospital - but I feel very strongly that the patients' permission should be required before they become an object of demonstration to medical or paramedical students. Also, how dignified is it to find an old person tied up to his/her bed or chair simply because there is not enough staff on the ward to see to the safety of the persons concerned?

Good gentle manners and a gentle soft voice should be the rule rather than the exception. I have known members of the nursing staff mock their patients, especially the elderly, in front of outsiders. Although the patients themselves might not realise what they are being subjected to (and sometimes they only pretend not to notice), their next of kin will certainly do - and closely related to the rights of patients are the rights of patients' families. Although I would not like to generalise and say that this is common practice, I have witnessed it myself on more than one occasion. Although some patients may be irritating, I hardly call such behaviour keeping a sense of humour.

I cannot end my paper without a word about the rights of patients with mental problems and their families. Traditionally these patients have been regarded as objects of charity. There still exists widespread prejudice in this regard, especially if the patient needs to be institutionalised. Organisations like the Richmond Foundation have done much to minimise the prejudice and the resulting social stigma but unfortunately these still exist. Patients with mental illness are just like any other patients and have the same rights as any other patients. They have a right to be treated with dignity and respect, to be given information in words they can understand about their medication; and about their diagnosis; to have some

choice of treatment; assurance of confidentiality; and to have a say in how the services they use are planned. They have a right to decent living conditions: for basic things like being allowed to wear their own clothes, use their own personal possessions and toilet articles, have some secure storage space, privacy when they want it, and to be able to complain about any abuse they feel they have received without fear of recrimination.

After having said all this, however, and in spite of all our moaning, I must say that the general opinion about our medical services, both public and private, is very high. Unfortunately it is usually the unpleasant exceptions rather than the efficient day-to-day service that makes the rounds among the public. We are proud of our personalised service which we must be very careful not to lose: rather it should be made even more personalised. We must not allow routine to justify shoddy treatment. We appreciate the fact that both our doctors and our nursing staff are over-worked with extremely long hours when they are on duty. It is easy to say that, like us, they are human: but each patient expects to get the best possible treatment as is his/her due. And I am afraid that in this case it is up to the medical profession to live up to the patient's expectations rather than the other way round. A patient's state of health will make him even more irritable and more demanding. What is so sad is the fact that it is usually those patients who cannot stand up for themselves, the patients with no connections, the less fortunate, who become the victims of an inefficient medical service.

Bibliography:

Häring Bernard: *Medical Ethics*. St Paul Publication, 1991

Reich Warren Thomas: *Encyclopaedia of Bioethics* vol.4 ed., Macmillan 1995.

Annas George J.: *Origin and nature of Patient's Rights*

Koplov Louis E.: *Mental Patients, Rights*.

Brody Howard: *Duties of Patients*

Beauchamp Tour L.: *Paternalism*

Morgan Edith: *The Rights of People with Mental Health Problems*. Paper given on the occasion of seminar on Mental Health, Malta 5.10.1996