# PATIENT RIGHTS IN PRIMARY CARE

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As everyone knows there are two tiers of provision of health care: state and private. Whilst government provides a good service at hospital and health centres, which is by right free for all, only private doctors provide Family Practices. WHO criteria for a family service advocate that, ideally, doctors should be life-time partners with the family, and that doctors should know their patients by name, and each patient able to mention by name his or her primary care physician<sup>1</sup>. For many private GPs this is still the case.

Health centres have however competed directly with the family doctor. This raises the issue of the family doctor not knowing the full medical history of his or her patients and having to share medical care with other, often unknown doctors, who may not make it their prerogative to communicate with the family doctor since the latter has been temporarily waived. As a result the right to one doctor directly responsible for the health of an individual is unknowingly lost.

In health centres patients are generally not seen by the same doctor. Although files are frequently kept, they miss out on an important aspect of patients' medical history and care - that provided by the private family doctor, which many patients will have. Conversely the family doctor not only does not have access to tests done at the polyclinic but finds himself having to repeat many of them.

Theoretically, a GP can send patients for investigations to a health centre but with the exception of a limited amount of basic blood tests, these have to be done through, and at the discretion of another health centre doctor. This, in my opinion is unethical and

going against the right to the doctor of one's choice. If this facility is to be offered, it cannot go against patient rights and professional ethics.

Another recent area of concern was the administration of vaccines through Local Councils. The Malta College of Family Doctors has expressed its concern to the Department of Health that doctors are not present during the administration of vaccines, and 'that the family doctor should be involved in any health-related decisions regarding his or her patients'.

Ironically, in case of death, health centre doctors ask patients whether they have a GP, and it is not the first time I am called to certify a cause of death after the health centre doctor has already been called in by the family. So if this procedure is convenient at the time of death, then why not for the health management of living patients. Patients have a right to be seen or to be followed-up by their GP for all conditions of health-related problems. This right should be made known to them through the system.

It is obvious that not only patients are unclear about their rights, but maybe also health care personnel are not clear of the right ethical procedures. Let me take diabetes as an example. Diabetes is a condition which can be adequately treated and followed up by General Practitioners many of whom hold diabetic clinics themselves<sup>2</sup>. Patients discharged from hospital needing monitoring of their blood glucose are as a general rule referred to health centres, even if they were admitted to hospital by a private GP. Since patients are not given a choice, they are not reassured that they will continue receiving free medicinals if their private GP continues to see them.

Moreover many patients may then be lured into the private practice of a so-called diabetologist, who of course never communicates with the General Practitioner. In the case of an emergency, it is the GP who is often called, and who then has to make heads or

tails, under emergency conditions, of a situation which he or she has not been following. All this because patients are subtly coerced into believing that their Family Doctor is not capable of taking care of their diabetes.

Although patients should be allowed to change their GPs whenever they feel best, it does not follow that one may shop around. Like most modern countries, we should, in my opinion, be thinking about patients registering with one or a group of doctors under a comprehensive scheme.

If the government cannot at this stage introduce a National Health Service similar to that in the UK or Canada, at least co-operation with private general practitioners on all levels of health management of patients is something attainable and in order.

## The Right to know and Informed Consent

Although there are legal implications of improper handling of informed consent, informed consent is not only about law, it is about what is morally right; it is not solely about consent, it is about adequate information.<sup>3</sup>

Although practices are changing, as a general practitioner I am still concerned to see patients, especially elderly ones, who are not told the truth about their condition. Terms like "laħam ħażin" are still frequently used to describe cancer. Although one has to respect culture and also the patient-specialist relationship, this occurrence is too frequent to be ignored. Everyone knows that the trend is towards more truth telling rather than paternalistic secrecy - if only because the patient needs to make an informed choice. This is especially the case when a patient refuses treatment, as one never knows whether that refusal would have occurred had the patient known the truth about his or her condition. Also, maybe more attention need be given to the truth when there is family pressure not to tell the patient of his or her condition, or

when the patient demands that the family are not told. Family members may also need to know if they are going to be the future carers responsible for the patient on returning home. Unless exerting their right not to know, patients need to know as much information as is reasonably considered enough in order to participate in the choices of their treatment.

### The role for teaching about Rights.

The right to adequate health care begs the right that patients know the limits of both private and state sectors. One is not in competition with the other. Patients must know that their family doctors need to participate in most if not all of their medical management if they are to receive optimum health care. Moreover, in my opinion doctors in health care centres should know whether people have a GP they wish to inform about test results, investigations and other matters discussed during their visit.

# **Questions of ownership**

According to the British Medical Association, the ownership of patient information is not the doctor's or the State's but the patient's. Patients therefore have a right to ask for any test results to share with whomsoever they wish - whether state or private. Patients thus own all that is put on their files and computers, and copies should be readily made available for the patients' perusal. It is ironic that hospital files still have a sign "not to be handled by the patient" on them.

# Patient rights and Professional Ethics

Is it time we start considering a national scheme for primary care with patients registered with GPs who dedicate their time solely to primary care and not part-time as is frequently the case. In Malta a doctor may be training for a specialised post in hospital in

the morning and do some primary care in the evening. They may feel this is their right - but is it in the interests of patients and *their* rights?

Conversely, what is sauce for the goose is sauce for the gander. There are GPs who are audacious, for example, in surgical procedures. Recently a new patient of mine had a D&C done under the impression that it was going to be done by a specialist, and then finding to her surprise that it was her GP who performed the procedure. Appendectomies and haemorrhoidectomies are known to have been done by GPs. Although they may be quite capable of performing surgical procedures, all the normal ethical channels of informed consent and clear information of available choices have to be respected. And in my opinion, not all minor surgery can be done at Primary Care level.

Are we tolerating therefore more than we should? Why is it that some doctors, because they own a large clinic can advertise and others cannot? Why is it that some doctors practise in family-owned pharmacies when there is a law prohibiting this because of conflict of interests thereby violating patient rights? Why is it that insurance will pay for blood tests carried out in a private laboratory and not always for those carried out in the General Practitioner's own clinic?

A few years ago someone blew the whistle on a primary care physician who advertised laser treatment by another specialist in his clinic. Following a fine of Lm200 imposed by the Medical Council the advertising goes on.

Only last week the New England Journal of Medicine published an article in its Sounding Board column which showed concern about medical professionalism. I quote:

"Today, at the dawn of a new century, genuine medical professionalism is in peril. Increasingly, physicians encounter perverse financial incentives, fierce market competition, and the erosion of patients' trust, yet most physicians are illequipped to deal with these threats".

Although our problems are different to the American doctor, the same can be said of our society to some extent. The article calls on physicians to "speak out about their values" and concludes that:

"there is an essential role for professionalism in society that marketdriven and government-controlled health care alone cannot provide" proposing amongst others a negotiation within society.<sup>5</sup>

#### Conclusion

It is a WHO criterion that all medicine should start from primary care. The Malta College of Family Doctors has prepared a Patients' Charter. It is a neat document which explains to patients what should be expected from their doctor. I feel we need to work on such charters and create a more coherent health care system which works in co-ordination and co-operation.

Health care is about the 'care' or 'concern' that Heidegger's phenomenology<sup>6</sup> speaks about, whereby each Being comes into contact with other beings. It is about being-with and being-in-theworld. Heidegger warned against the levelling down of relationships when many beings come into contact with each other in masses. Theirs is not a being-with which projects itself into the full potential of human relationships. Rather it is a reduced form of contact which 'they' - the masses - bring about. With health care for the masses this levelling down is easily slipped into, depriving patients of the intimate doctor-patient relationship which they deserve. Patients have to be allowed to find their potentiality-for-being within a doctor-patient relationship; conversely the true becoming of a doctor is not merely in acquiring qualifications, but in coming into relationships; in being-with patients.<sup>7</sup>

This potentiality-for-being is the purpose of health care education and as such, therefore, cannot deprive the doctor of a full knowledge the ontology of patient, the physician and the doctorpatient relationship. The potential-for-being-in-a-relationship is the only road to avoid the levelling down of relationships found in mass-handling health centres.

The patient has a right to this full potential of the doctor-patient relationship which is fundamental to medicine To protect this relationship one has to protect the Family doctor who enters into direct relationships with individual members of families, and knows them, understands them and lives through their experiences. A right to health care is not merely a right to a service; it is a right to this phenomenology of medicine - the patient-physician relation which is not levelled down to routine examinations, tests and diagnoses. It is a right to a true long-standing relationship.

Governments should not compete with family doctors who know you from birth through to the age when you have your own children; doctors who know you by name and are almost part of the household. There are other ways which have been implemented successfully abroad for providing free primary health care through private doctors. The right to the doctor of one's choice provides for better long term relationships which in turn promotes better communication<sup>6</sup> - the basis of informed consent, fidelity, truth telling and all that patient rights are about.

#### References:

<sup>1</sup>AAFP Official Definitions Related to Primary Care. Reprinting No. 302, September 1994

<sup>2</sup>MacKinnon M., *Providing Diabetes Care in General Practice*, Third Edition, Class Publishing, 1998

<sup>3</sup>Faden R., Beauchamp T., *A History and Theory of Informed Consent*, Oxford University Press, 1986. See also, Beauchamp T., Childress J., Principles of Biomedical Ethics Third Edition, Oxford University Press, 1989

\*Medical Ethics Today, the Practice and Philosophy, British Medical Association Publishing Group, 1996, 44.

<sup>5</sup>Medical Professionalism in Society, Sounding Board, New England Journal of Medicine, Vol. 341, No 21, 1612-1616.

<sup>6</sup>Heidegger M., *Being And Time*, Blackwell 1995, (trans by J. Macquarrie & E. Robinson).

<sup>7</sup>Mallia P., A Criticism and Reappraisal of Biomedical Principles through the Phenomenology of the physician-patient relationship, University of Malta, 1998

<sup>8</sup>Rakel RE., *Establishing Rapport* in "Textbook of Family Practice", Ed: Rakel RE., 5th Edn., Saunders, 1995, 249-268