

'Patients' rights in Europe today', Speech by the European Ombudsman, Professor P. Nikiforos Diamandouros, to the Second Hygeia- Harvard Medical International Conference - 'Preventive Medicine in the 21st Century', Athens, Greece 3 June 2005

Speech

1. Introduction

I am delighted to have the opportunity to speak at this conference on Preventive Medicine in the 21st Century and I would like to thank the organisers, particularly Dr. Vassilis TSEMANIS, for inviting me to do so.

You are the experts on preventive medicine. Please forgive me if my understanding of it--as an Ombudsman and a political scientist -- is less than perfect.

I nevertheless hope it is not too crude an approximation to say that preventive medicine is about how to stop people becoming sick, in contrast to treating them when they are sick.

If that is so, then there is an interesting analogy with my work as ombudsman, initially here in Greece and, from April 2003, in the EU.

The basic function of an ombudsman is to investigate and report on complaints against public authorities, just as I suppose the basic function of a doctor is to diagnose and treat physical and psychological complaints.

In my case, the complaints are about maladministration by the institutions and bodies of the European Union.

I think of my work of dealing with complaints as "reactive", because I am responding to the problems that citizens bring to me.

But I also have a proactive role. This is partly about preventing maladministration from occurring, by cooperating with the Union institutions and bodies to raise the quality of administration and tackle systemic problems. Ombudsmanship thus also has a preventive dimension.

Another important aspect of my proactive work is to make citizens aware of their rights and of how to exercise those rights.



Although the ombudsman institution has a history going back nearly two hundred years, its global spread is more recent. In terms of numbers, it is a development mainly of the past quarter century.

This same period has seen the emergence and rapid spread, in both the United States and Europe of the idea of “patients’ rights”.

I am persuaded that the two phenomena have common social and cultural roots, that are connected to the widening and deepening of aspirations linked to the liberal version of democracy and to respect for human rights.

But, I will resist the temptation of a political scientist to pursue this line of inquiry further, intellectually attractive though this may be. Instead, I will focus more directly on the central theme of my presentation, which is the development of patients' rights in Europe.

2. The development of patients’ rights in Europe *Codes, laws and declarations about patients’ rights*

Let me begin by stating that, in Europe today, there are many national and international documents that declare, enact, or contain proposals for, patients’ rights.

At the national level, France was one of the first European countries to adopt a charter on the subject. The 1974 “Charter for hospital patients” (« *charte du malade hospitalisé* ») was not a legally binding text, but an annex to a ministerial circular.

Amongst current EU Member States to have adopted legislation are: Finland (in 1992), The Netherlands (in 1994), Greece, Hungary, Lithuania, Latvia and Portugal (in 1997), Denmark (in 1998), Belgium, Estonia and France (in 2002) and Cyprus (in 2005).

At the international level, prominent examples of documents about patients’ rights include:

- the *Declaration on the promotion of patients' rights in Europe* of March 1994. This resulted from an initiative of the World Health Organisation Regional Office for Europe;
- the *Ljubljana Charter on Reforming Health Care* of 1996 (also a W.H.O. initiative);
- the Council of Europe’s 1997 *Convention on Human Rights and Biomedicine* . Despite its name, this Convention also deals with patients rights in general; and
- the “*European Charter of Patients’ Rights*” , drafted under the auspices of an Italian-based NGO called the Active Citizenship Network.

I do not intend to present you with a comparative analysis of these sources, nor try to synthesise them into a comprehensive account of patients’ rights.

Instead, I shall first outline in general terms the different types of rights that are often brought together under the broad heading of “patients’ rights”.

Then I shall focus on individual rights and, within that category, on what I shall call “autonomy rights”.



Rights do not exist in a vacuum, so I shall link my analysis of autonomy rights to the changing social, economic and legal context of the relationship between doctors and patients and to a normative view of the appropriate terms of that relationship in today's world.

Varieties of rights

In contemporary legal and political debate, the language of rights is increasingly used to assert and to recognise the legitimacy of a wide variety of claims and interests.

Look, for example, at a modern document such as the *Charter of Fundamental Rights of the European Union*. The Charter was proclaimed at the Nice summit of the European Council in December 2000 and forms Part II of the Constitution Treaty for Europe. It constitutes the European equivalent of a Bill of Rights.

In the Charter, we find not only individual rights, but also statements of principle that could imply group or collective rights, such as prohibitions on making the human body and its parts a source of financial gain, and on reproductive cloning.

These prohibitions are included in Article 3 of the Charter on the "right to the integrity of the person".

I shall not focus on these principles, nor, for example, on public participation in debating the priorities, values and principles of public health care policies, which was the subject of a recommendation made by the Council of Europe in the year 2000.

That is not because I consider these questions as unimportant, but because the issues are different from those involved in individual rights.

The introduction to the 1995 version of the French Charter for hospital patients expresses well the approach that I am adopting: "[a] hospital patient is not just someone who is sick. He is first and foremost a person with rights and duties". (« *Le patient hospitalisé n'est pas seulement un malade. Il est avant tout une personne avec des droits et devoirs.* »)

I should add: that goes for all patients, not just those in hospital.

3 Categories of individual rights

In my view, the individual patient's rights fall into three categories:

- Rights to redress, including compensation;
- Rights of access to medical care; *and*
- Autonomy rights.

These three categories of rights are best understood as the concretisation of certain fundamental human rights.

I will briefly discuss the first two categories before focusing on the autonomy rights and the doctor-patient relationship.

Rights to redress



The most fundamental right to redress is the right to bring proceedings in a court of law. This is a traditional civil right associated with the principle of the rule of law. It can be found in Article 6 of the European Convention on Human Rights and Article 47 of the Charter of Fundamental Rights.

In the medical context, the right to go to court provides the most fundamental guarantee of the autonomy rights that I shall discuss later. It may also be an appropriate way to enforce certain rights of access to medical care.

The right to compensation if medical care falls below an acceptable standard also comes under this heading. I will not discuss this complex question in detail, but only to point out that there are basically two legal pathways to the provision of compensation, each of which has its own particular costs and benefits.

The first is litigation. As already mentioned, this is the traditional and fundamental pathway to justice. As the example of the United States illustrates, however, lawsuits about medical negligence can become big business, not always to the benefit of patients.

The second pathway is a compensation scheme, which may be based on no-fault liability. Such a scheme may be offered to patients as an alternative to court proceedings.

From my perspective as an Ombudsman, I will add that rights to redress are not just about damages or compensation. Complaints provide complex organisations, such as hospitals and public health care systems, with essential feedback on the quality of services.

Justified complaints are an opportunity not only to apologise for mistakes and provide compensation if appropriate, but also to help avoid similar problems from arising in the future.

Proper handling of a complaint, with a fair procedure, provides an opportunity to explain what has been done and can often satisfy the complainant.

Rights of access to medical care

As regards rights of access to medical care, the first point to note is that the general right not to be discriminated against applies in the field of medical care.

Non-discrimination does not require any particular level of service, but forbids unjustified variations.

In the European legal order, the substantive right to medical care is a social right, which requires government to ensure, directly or indirectly, the availability of adequate provision.

The right can be found in the European Social Charter (Article 13) and the United Nations' International Covenant on Economic, Social and Cultural Rights (Article 12), but is set out most clearly in the Charter of Fundamental Rights.

The first sentence of Article 35 of the Charter states: that "[e]veryone has the right of access to



preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.”

How government is to secure this right to citizens, and the general level of service to be provided, are matters of debate.

In this connection, I would like to draw your attention briefly to the case-law of the European Court of Justice concerning the conditions under which patients may claim re-imburement in their own Member State for treatment obtained in another Member State.

Although the legal basis of this case law is the freedom to provide services, it also has great significance for rights of access to health care in the European Union.

Autonomy rights

The third category of rights, and those which I propose to devote most attention to, are what I call autonomy rights.

To talk about autonomy in the context of medical care may seem at best a polite fiction. The paradigm of the patient is a person who is suffering from an illness, or dysfunction, and who needs treatment in order to become well.

The process of treatment is in many cases almost the opposite of what we normally understand by autonomy. Think, for example, of an anaesthetised patient undergoing an operation.

Furthermore, there are many different conceptions of autonomy. Some of them have even been used to justify coercion, as Isaiah Berlin, the great Oxford political philosopher who recently passed away, pointed out in his famous 1969 essay on liberty.

To explain what I mean by autonomy and why the autonomy rights are fundamental to the idea of patients' rights, we need to examine the doctor-patient relationship.

In doing so, I shall draw on two well-known pieces of published work. The first is by Professor Edward SHORTER, holder of the Hannah Chair in the History of Medicine at the University of Toronto, on the history of the doctor-patient relationship. The second is by Linda and Ezekiel EMANUEL (*respectively now Professor of Medicine and Director of the Buehler Center on Aging at Northwestern's Feinberg School of Medicine and Chair of the Department of Clinical Bioethics at the National Institutes of Health, Bethesda, Md*), presenting four ideal-typical models of that relationship.

4 Rights and the doctor-patient relationship *Periodisation of the doctor-patient relationship*
Shorter divides the history of the doctor-patient relationship since the 18th Century into three periods, which he calls “traditional”, “modern” and “post-modern”. For reasons that need not detain us, I prefer to label the third period as “contemporary” or “late modern”.

The traditional period was characterised by an unscientific and largely unfounded therapeutic confidence on the part of doctors, which met with considerable scepticism among patients. As a result, doctors had a relatively modest social status during this early period.



The modern period begins with the gradual arrival, during the 19th Century, of a scientific basis for medicine, founded on the proper physical examination of patients, accurate diagnosis and finally the success of the germ theory of infectious disease.

Although unable to offer cures for many of the conditions that he could diagnose and explain, the doctor became, as Shorter puts it, a *“demi-god possessed of boundless authority over patients”*.

The doctor’s authority as a man of science was the foundation for what the Emanuels call the *“paternalistic”* model of the doctor-patient relationship.

In this model, the doctor determines what is in the patient’s interests, including how much the patient should know and indeed whether the patient should be told the truth about his or her condition and prognosis.

The patient’s role is, in essence, to follow the doctor’s orders.

The paternalist model thus focuses on the inequality of expertise in the relationship as a reason for giving the doctor, rather than the patient, autonomy in making decisions about what should happen to the patient.

The contemporary or late modern period began when scientific advances made it possible for doctors to cure patients with drugs, such as the sulphonamides in the 1930s and antibiotics after the Second World War.

Paradoxically, this spectacular therapeutic success has been accompanied by a decline in medical authority. In Shorter’s view, this results from the effect of the media on patients’ knowledge of medicine and medical procedures.

I am persuaded that the phenomenon should also be seen as part of a more general development in contemporary societies. Science and expertise are no longer accepted as constituting, by themselves, the legitimate basis for decisions that also involve values, or individual and social preferences.

This development is in turn connected to the wider cultural and political context defined by the growing ascendancy in the world of late modernity of democracy and especially of its liberal variant with its emphasis on both equality and liberty as fundamental to the ordering of our lives.

Two models of the contemporary doctor-patient relationship

In any event, the era of the doctor as a demi-god has passed and with it has gone the basis for the paternalistic model of the doctor-patient relationship, in which the doctor’s knowledge and expertise justifies authority over the patient.

A model for the contemporary period must be built on equality in the relationship and on respect for the autonomy of the patient.



I will put forward two possible models of the contemporary doctor-patient relationship, each of which is based on a different idea of what equality and autonomy should mean in this context.

For reasons that I shall explain in a moment, I call the first model “consumerist”.

The consumerist model

Its main characteristics are the same as those of what the Emanuels called the “informative” model. The essence of their model is that the doctor’s role is to supply full information to the patient about his or her condition and about the available treatment options. The patient then decides which, if any, of the treatments to choose.

The doctor is thus a technical expert; on tap, but not on top.

The implications of this model are that the inequality of knowledge and expertise can be fully corrected through the supply of information and that autonomy for the patient consists of making an unconstrained choice on the basis of his or her own values and preferences.

The Emanuels criticised this model mainly on the grounds that it fails to capture an essential part of the doctor’s role, which is to care for the patient. Nor does it reflect most patients’ wants and expectations of their relationship with a doctor.

I would add some further considerations.

Even from a purely technical perspective, and I wish to stress the word “technical”, making choices about medical treatment is not like choosing between different models of car or washing machine. The complexity involved makes it more like choosing financial services, a field in which even the most liberal European states recognise that consumers (and this is why I call the model “consumerist”) need protection.

For this reason, I think the most likely outcome of the consumerist model would not be patient autonomy in the doctor-patient relationship, but that forces external to that relationship would establish new forms of paternalism.

This could take the form of public regulation of the doctor-patient relationship, in which a State bureaucracy sees itself as responsible for making decisions about patients’ best interests.

Alternatively, or perhaps additionally, there could be legal paternalism, in which lawyers and judges pursue their version of the patients’ best interests. This is likely to produce a more adversarial context for the doctor-patient relationship, with an excessive focus on rights of redress.

This in turn could lead to “defensive medicine”, in which the doctor’s actions are focused on avoiding liability rather than treating the patient.

In other words, a model that is based on a purely economic approach and on the logic of the



market only ignores, and therefore does violence to, an idea of autonomy that is linked to the ethical dimension of the patient as a whole person, as a human being and not a mere economic agent.

(Link to Talcott Parsons' later theory and need for balance between economic, cultural, political and social spheres)

To try to avoid these dangers, my second and preferred model is what I call the “communicative” model.

The communicative model

In this model, the doctor does not merely provide information but communicates with the patient and is willing to engage in a genuine dialogue.

Equality in this model is not equality of knowledge and expertise achieved through the flow of information, but equality at the fundamental level of the right to be an autonomous agent making choices about one's own life.

Respect for the patient's right to be an autonomous agent implies that the patient has the right to choose the balance in his or her relationship with the doctor between paternalism, information, advice, guidance and deliberation.

In practice, the doctor is the party who presumptively starts out with more power, based both on expertise and knowledge, and on the vulnerable situation of the patient who is possibly suffering from illness or dysfunction.

The burden should thus be on the doctor to take the initiative to explore how the patient wishes the relationship to function and to respect those wishes.

In doing so, the doctor should begin from the paradigm of the patient as an autonomous agent with the right to make informed choices about his or her medical treatment.

5 Fundamental patients' rights from the perspective of equality and autonomy

It is against the background of this model of the doctor-patient relationship, not the consumerist model, that we should understand the emerging international consensus that patients have certain fundamental autonomy rights.

These are: the right to give or withhold consent to treatment; the right to know the risks and benefits of proposed treatment; and the right to privacy.

The right to give or withhold consent to treatment

The right to give or withhold consent to treatment is perhaps the most fundamental of the autonomy rights.

In France, the principle of obtaining the consent of the patient before an operation was first clearly set out in the *Teyssier* decision of the *Cour de Cassation* in 1942, in the name of respect for the patient as a human being.



More recently, this right has been tested in cases on the so-called “right to die” and “living wills”, which usually state the patient’s wishes to be allowed to die in certain future circumstances.

The converse situation is currently before the Court of Appeal in the United Kingdom, in which Leslie Burke, a patient with a degenerative brain condition, insists that he should not be deprived of food and drink when his situation deteriorates to the point that he can no longer communicate his wishes.

The legal and ethical complexities of this kind of situation and of other special cases, such as children and psychiatric patients should not, however, obscure the paradigmatic case of the right of a conscious and competent patient to give or refuse consent to treatment.

The right to information

The right to information is the natural counterpart of the right to give or withhold consent to treatment. Put together, the two rights constitute the principle of informed consent.

This principle can itself be expressed as a right, as for example in Article 3 of the Charter of Fundamental Rights, which contains – as part of the right to the integrity of the person – the requirement to respect the free and informed consent of the person concerned in the fields of medicine and biology.

The right to control the flow of information about oneself

The right to control the flow of information about oneself is an aspect of the fundamental right of privacy.

As the European Court of Justice has expressed it: *“the right to respect for private life (...) is one of the fundamental rights protected by the legal order of the Community.(...) It includes in particular a person's right to keep his state of health secret.”*

This principle was also applied in 1998 by the European Ombudsman in a case where a European Commission official had contacted without permission a trainee’s doctor in order, as the official put it, to “clarify the situation” as regards a medical certificate issued by the doctor.

The requirements of privacy as regards the handling of personal information are made more concrete by European Union laws on data protection.

These laws require special protection for certain categories of personal data, including information about a person’s health.

6 Conclusion

I would like to make clear that my emphasis on the importance of the autonomy rights should not be understood as implying that the doctor-patient relationship can be reduced to a matter of legal rights and obligations that could be brought before a court.

On the contrary, within the communicative model, the deployment of the professional expertise and ethics of the doctor remains the very core and purpose of the relationship between doctor and patient.



In contemporary societies, however, the autonomy rights are a necessary condition for that relationship to function effectively.

Respect for these rights recognises the patient as an autonomous agent, who is entitled to make choices about his or her own life.

I do not believe that a legitimate model of the doctor-patient relationship can any longer be constructed without such respect and recognition.

As I have explained, I think the choice is between the consumerist model, which I regard as an unsatisfactory option, and the communicative model.

I will conclude with a final thought about the significance of the autonomy rights.

I argued earlier that the very nature of the consumerist model makes it vulnerable to bureaucratic and legal pressures that tend towards new, external, forms of paternalism.

I wish to stress that the communicative model does not, in and of itself, make these pressures disappear. It can, however, help resist them, if it is allowed to work effectively.

For this to happen, the autonomy rights are essential.

I would, therefore, suggest that we should understand these rights not so much as rights of the patient against the doctor, but as the foundation for the successful protection of the relationship between doctor and patient, to the mutual benefit of both parties.

Thank you for your attention.

References

Isaiah Berlin, 'Two Concepts of Liberty', in *Four Essays on Liberty*, London: Oxford University Press 1969.

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 1997, CETS No: 164.

Council of Europe Recommendation Rec(2000)5 for the development of institutions for citizen and patient participation in the decision-making process affecting health care, Adopted by the Committee of Ministers on 24 February 2000 at the 699th meeting of the Ministers' Deputies.

Circulaire du 20 septembre 1974, relative à la charte du malade hospitalisé.

Circulaire DGS/DH 95.22 du 6 mai 1995 relative aux droits des patients hospitalisés et comportant une charte du patient hospitalisé.

Arrêt Teyssier du 28 janvier 1942, (Dalloz 1942, Recueil critique, jurisprudence, p. 63)



Edward Shorter, "The history of the doctor-patient relationship" in W.F. Bynum and Roy Porter (eds.), *Companion Encyclopedia of the History of Medicine* (1993), vol.2, 783-800.

Ezekial J. Emanuel, and Linda L. Emanuel, "Four Models of the Patient-Physician Relationship," *Journal of the American Medical Association* 267:16. 2212-26 (1992).

Case C-404/92 P, *X v Commission* [1994] ECR I-04737

Case C-385/99, *Müller-Fauré and Van Riet* [2003] ECR I-04509.