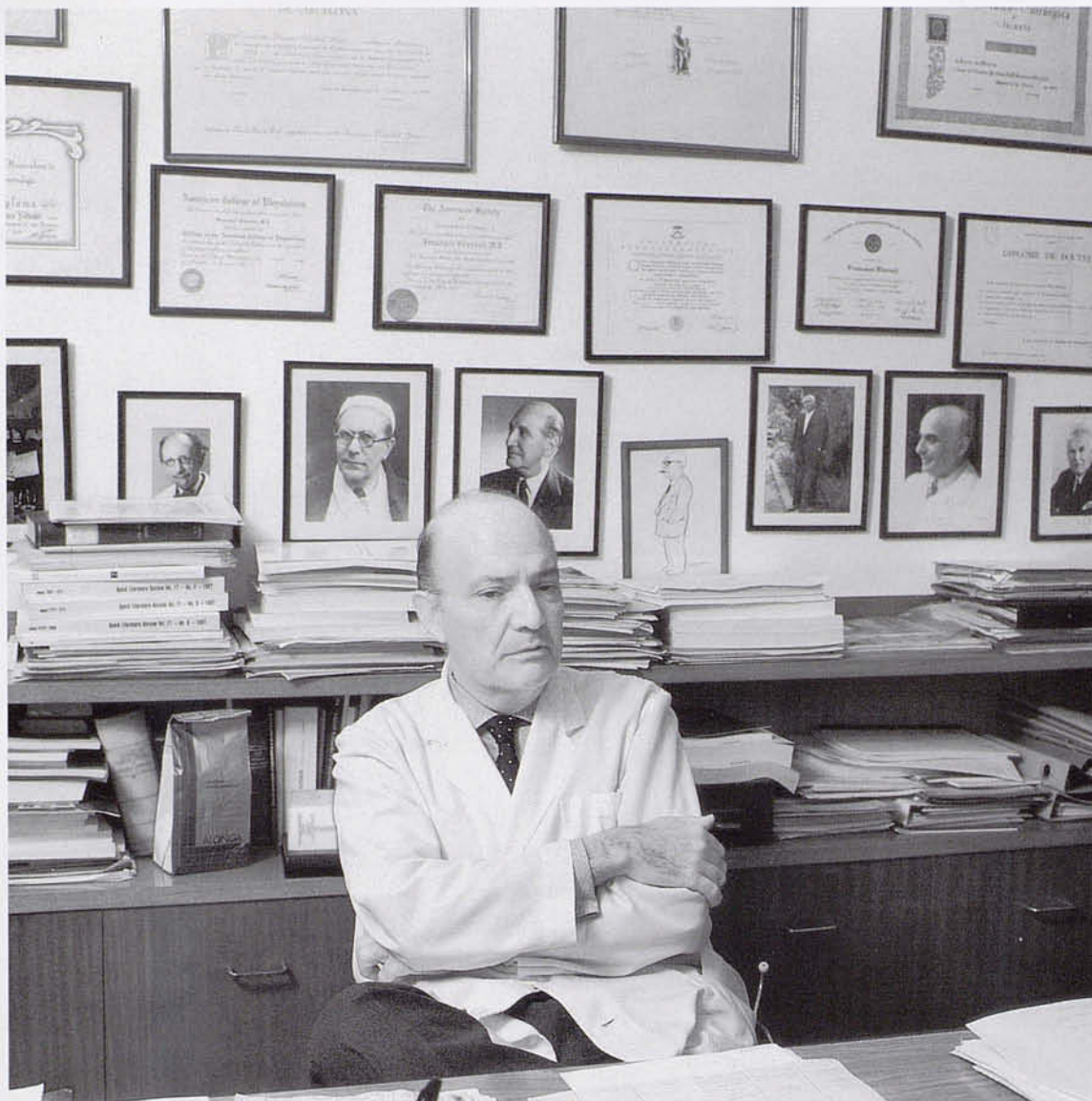




FRANCESC VILARDELL

THE RELATIONSHIP BETWEEN DOCTOR AND PATIENT HAS ALWAYS BEEN AT THE FOREFRONT OF MEDICAL ETHICS AND THE DEBATE HAS GONE ON UNINTERRUPTED ALL THESE YEARS. BUT UNQUESTIONABLY, THE MODERN WORLD, WHICH HAS UNDERGONE A RADICAL TRANSFORMATION THIS CENTURY, CARRIES WITH IT A SERIES OF DEMANDS THAT WEIGH HEAVILY ON THE DOCTOR-PATIENT RELATIONSHIP.

MILAGROS PÉREZ OLIVA JOURNALIST



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Now 62, Doctor Francesc Vilardell Viñas has, since July 1987, been president of the Council of International Organizations of Medical Sciences, CIOMS, created at the beginning of the fifties by the WHO and UNESCO, to reflect and advise on medical ethics, the philosophy of medicine and other matters relevant to the profession, amongst them the training that doctors should receive and the moral obligations that should regulate their practice. Professor Vilardell is president of the World Organization of Gastro-enterology and has received various awards, amongst them the French Legion of Honour, the *Generalitat's* Saint George Cross and the Spanish Ministry of Health's *Encomienda al Mérito Sanitario*. In May 1981 he was called urgently to Rome, to join three other specialists watching over Pope John Paul II's recovery from his assassination attempt. Married and father of three children, he

is devoted to his work as head of the Digestive Pathology department of the Sant Pau Hospital, in Barcelona. The son and nephew of doctors, he was born in Barcelona in 1926 and graduated in Medicine in 1949. In 1962 he completed his specialist studies at the University of Pennsylvania (USA), with a doctoral thesis on the cytological diagnosis of stomach cancer. In 1963 he joined the Sant Pau hospital, where he continues working to this day. He enjoys a stroll in the gardens when in need of a moment of relaxation, never tiring of the harmonious arrangement of Domènech i Montaner's Modernist pavilions. Professor Vilardell has taken over the presidency of the CIOMS at a particularly delicate moment for the medical profession, which today has access to techniques that are capable of altering the course of human nature in a way which was unthinkable just a few decades ago. The sudden emergence of these technical possibilities

poses new ethical problems, but technological development takes place so fast that society has not even had time to reflect. For this reason, Doctor Vilardell's job at the head of the CIOMS involves such a great responsibility.

What are the particular aspects of the problem posed by medical ethics in today's society?

There's nothing new about medical ethics; the earliest references to society's concern for this subject date from 5,000 years B.C. And from then until now, all it's done is to develop. The relationship between doctor and patient has always been at the forefront of medical ethics and the debate has gone on uninterrupted all these years. But unquestionably, the modern world, which has undergone a radical transformation this century, carries with it a series of demands that weigh heavily on the doctor-patient relationship. This relationship has been



substantially modified over the last few years. One of the most important aspects has been the gradual generalization of a particular idea, that of the patient's autonomy, seen as the right to take part in the decisions that affect his health. This principle is based on Anglo-Saxon law, which defends the autonomy of the individual and freedom of choice as essential elements.

But freedom of choice and the ability to use his autonomy depend, in the patient's case, on his receiving accurate information from the doctor.

Of course. From what's been said, it can be deduced that this autonomy can't really exist unless there's informed consent, which means that, before any medical intervention, especially if it involves a risk, the patient has to be sufficiently informed so as to be able to decide whether or not he accepts the risk to which he is being submitted. This calls for a willingness, on the part of the doctor, to keep the patient informed. The problem is easier to solve in more advanced cultures than in areas whose culture doesn't correspond to the western model. Obviously, you can't hope for informed consent, for example, in the case of isolated tribes of Indians, who have no social or ethical criteria that are comparable to those of a developed society.

But that doesn't mean there's no patient-doctor relationship. What should be done in these cases?

It's suggested that one speak to the elders of the tribe, but in some cases, I think even this is premature.

You've spoken of autonomy and informed consent. Do you think that, given the existence of these two pre-requisites, one could justify passive euthanasia?

On principle, no thinking, sensitive doctor feels that a patient of his should suffer. But the concept of suffering is very complex. A patient's stay in an intensive care unit involves the application of an aggressive programme of therapeutical possibilities. I don't doubt that many patients, in spite of appearances to the contrary, want these possibilities to be applied to them, want everything possible done to save their lives, even if they have to suffer severe inconvenience. I

sometimes feel that it's the families who create the difficulties, more than the patients themselves, when it comes to the application of high level medical technology. Now, there comes a moment when it can be said that the balance between the benefit, measured in terms of therapeutic effectiveness, and the harm, taken as the patient's moral suffering, is inverted, and comes down heavily on the side of the latter. Intolerable abuses have been committed in the exaggerated treatment of terminal patients. It's what's been called therapeutic determination. I think these extremes are unforgivable. Even the Pontifical Academy has announced that the right to a dignified death should be fully recognized.

But whose responsibility is it to take the decision to say 'stop'?

That's a very difficult question to answer. Very often, the doctor obviously doesn't tell the patient he's going to die, because he tries to keep his hopes up until the last minute. In fact, the doctor is trained and prepared to resist and to continue the struggle to save his patient's life so long as he has the means to do so.

But if the doctor doesn't tell the patient the whole truth about his situation, he is in fact taking a unilateral decision.

If the patient asks, he has to be told the truth. Always. And if nothing more can be done, some kind of agreement has to be reached with the patient. But I also understand that the doctor should want to leave room for hope. It's very difficult for him to give up the struggle. Sometimes there have been conflicts between medical staff and nursing staff, because the decision to abandon is far from easy. The nursing staff, who generally play a very active part in the care of the patient and build up a personal relationship with him, have sometimes been quicker than the families themselves to oppose the decision to move a patient out of intensive care. Psychologically, this is a perfectly understandable reaction, because they've made a great effort to save the patient's life and all that effort is lost the moment they give up.

One of the most hotly debated questions as regards health at the moment is the distribution of resources. Resources are limited and are devoted to certain ends



and not to others. What are your feelings regarding this problem?

Until now, no government has managed to get on top of medical expenditure. All cost estimates have been successively exceeded because the technology has developed according to its own possibilities, and has become more and more expensive. It was thought that the price would drop if production was increased, but mass production hasn't turned out any cheaper. Also, health department budgets haven't increased at the same rate as other activities. As well as this, life expectancy has risen in the industrial countries and that's made it necessary to devote large amounts of technological resources to the elderly, who are the people most in need of medical treatment. In my hospital, as in many others, we have far more patients of 80 coming in than twenty years ago. In those days, it was unusual to receive patients of that age. And of course, just because they're 80 doesn't mean we're going to deny them the treatment they'd get if they were 60. Besides, generally speaking, patients of 80 are in good physical shape nowadays and respond well to treatment.

This factor alone can unbalance the health budget of any country. But what's also happened over the last few years is that there have been great technical advances, which allow very expensive operations such as transplants. Many of these advances have been applied without first carrying out a proper cost analysis, which makes it difficult afterwards to sum up the efficiency of a technique from the point of view of cost/benefit, especially if it's a technique that's had brilliant results, as is the case with transplants. In some cases, like kidney transplants, the advantages have been clearly demonstrated, both in absolute and relative terms. It's cheaper to carry out a transplant than to keep a patient on dialysis. On the other hand, in the case of liver and heart transplants, the efficiency hasn't yet been clearly demonstrated. Although I think that, sooner or later, this will happen.

Hope is maintained through scientific progress itself. Before the discovery of cyclosporine, for example, the efficiency of transplants was more than doubtful. On the other hand, this immuno-suppressor

has now radically changed the outlook regarding the success of transplants.

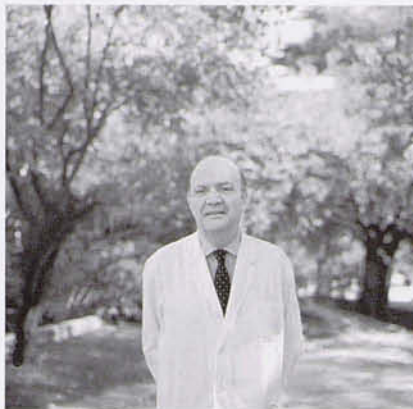
Of course. That's why it's so difficult to apply financial criteria to medical progress. The discovery of a drug may be enough to reverse the cost/benefit relationship of a highly sophisticated technique. And very often, the factors involved have nothing to do with medicine itself. For example, faced with the decision as to whether or not to authorize a particular type of transplant, a government might find that, as well as the rational aspects, it also has to consider emotional aspects involved in the decision, such as national honour.

It has been said that the development of medical technology leads to an increase in the demand for medical treatment. What do you feel about this?

In some ways that can be true. If society is offered the possibility of a particular course of action, however limited the advantages are, it'll be accepted immediately. Contrary to what a lot of people think, the more doctors a community has, the greater the need for medical attention and the more expensive it is. Medical technology hasn't made treatment any cheaper, it's simply created greater needs. For example, the creation of general practice clinics hasn't emptied the hospitals. Measures of this sort are a great benefit to society, as for example, in the early diagnosis of cancer, but they don't make medical treatment cheaper, which is what we're after. The logical thing to do would be to replace the technique in use with any improved technique that happened to appear. What happens in practice is that, instead of replacing the old with the new, both end up being used at once. Diagnosis techniques have got totally out of control over the last few years, and very often more tests are carried out than is strictly necessary. This is also a problem of training. Instead of being taught to find the correct solution to a problem with the minimum of resources, doctors are encouraged always to use the maximum number of possibilities at their disposal.

But sometimes, unless all the possibilities are applied, the patient may think he's not receiving proper treatment.

The patient sometimes insists on being subjected to even the most aggressive



techniques, because he understands that that way he has more chances of being cured. The media have helped to spread this idea and to raise medical technology to a mythical level. I remember when the first liver transplant was carried out in Barcelona, several relatives of patients who were beyond hope came to demand that they be given a transplant. Society is so used to resorting to technology for everything, and if you don't use it, the patient starts to think you haven't done anything.

To what extent do you think the proliferation of spectacular news stories about medical progress conditions patient's behaviour?

Are you referring to the excessive medicalization of society? Recently I think the idea of the right to health has been driven in very strongly. It's a dangerous concept because it's demagogic. No government has the resources necessary to guarantee the health of its citizens. I think it would be more reasonable to speak of the right not to be ill.

One of the fields in which, as president of the CIOMS, you intend to intervene is that of medicines. In what sense?

What the CIOMS is aiming at, with the agreement of the WHO, is the establishment of basic treatments that can be prescribed all over the world. For example, a vaccination or an antibiotic. It's a question of collaborating with the WHO in the design of a universally applicable formula, of seeing that certain active principles can get to every corner of the earth. But it isn't easy. There are countries that can't carry out a vaccination campaign that would save

thousands of lives because they haven't got a proper cold storage system, and on the other hand they've got two hospitals with the most sophisticated equipment, for example, computerized axial tomography machines. These countries would benefit more from having a sewer to avoid the spread of typhoid than from having a scanner.

One of the questions that has caused controversy recently is that of therapeutic experimentation on patients that hadn't been informed. What limitations should be placed on the doctor when it comes to trying out new drugs or surgical techniques?

In these cases, there should be absolute respect for the principles of autonomy and informed consent I mentioned earlier. Experimental treatment should in no way be carried out on patients who are unaware that the product they are being given is part of a programme of experiments. This is something which is quite clear. The CIOMS has published a sort of code of clinical investigation which includes experimental treatment and which clearly sets out the guidelines to be followed. First of all, no product can be tried on a patient unless it has some bearing on his illness. That seems obvious, but the principle hasn't always been respected. Secondly, the patient's informed consent should be guaranteed. The doctor should explain all the product's possible risks to him, bearing in mind that they are not always sufficiently well known and that it is very difficult to provide an explanation that guarantees its harmlessness. Third: all experimental treatment should be administered according to scientific method, with ade-

quate controls, which involves the formation of two groups, one to which the experimental product is administered and another which receives a placebo or other treatment, so as to be able to compare the results afterwards. And a product can't be tested unless there is a reasonable presumption regarding what it is it's going to cure. Also, if the product being tested affects an illness for which other treatments already exist, the results in this case can't be compared against those of a placebo but only against those of the previously existing product.

To avoid the superfluous proliferation of pharmaceutical products, before authorizing the marketing of a new product, some countries require proof, not only that it's good and efficient, but also that it's necessary because it's a substantial improvement on those already on the market. Do you think these criteria should be applied everywhere?

This is a political problem, not an ethical one, because at the heart of the question is the problem of resources. The laboratories are engaged in full-time economic competition. It's very difficult to prove that one product's much better than another, because the differences are usually so slight. You must remember that to show the validity of a product, it has to be tried on a large number of patients, and that from the discovery of a new product to the day it appears in the chemist's, more than ten years have gone by. That is to say, it's an extraordinarily expensive process. If, once it were over, the product couldn't be marketed because it was only marginally beneficial, the laboratories wouldn't take the risk. But there's another thing which I find



more worrying, and that's the problem of the harmful side-effects, which appear much later. Let's imagine a harmful side-effect that has an incidence of 1 in 100,000. The medicine has been tried on 10,000 patients, but the effect, that could be serious, won't be detected until the product has been administered to more than 100,000 people. And another very worrying thing is that the safeguards and controls applied to medicines aren't also applied to medical techniques and appliances. In the United States these *are* subjected to control, any new appliance has to be examined by a team of experts. Unfortunately, this control hasn't reached other countries and we come across a situation in which appliances that aren't authorized in the United States, for example, can be freely used in other countries, and the same thing happens with certain medicines. New inventions are constantly appearing that don't manage to pass the test of time, and by the time this is shown to be the case, they've already done the damage. About twenty years ago, for example, a gastric balloon appeared that made it possible to freeze the stomach and stop a haemorrhage. The results of the first tests were thought to be extraordinary and were received euphorically. Later it was discovered that it caused serious gastric injuries and the appliance was withdrawn from the market.

In vitro fertilization is a technique which the WHO describes as experimental, and yet it's used without any control whatsoever. Some feminist organizations have complained that in these cases women are being used as guinea pigs. What do you feel about the matter?

The Catholic Church has issued a directive in which it considers that this field of science has gone too far. In the last few years, progress has been such that there hasn't been time to reflect. So far as this and many other questions are concerned, I feel that the availability of the technical means to do something doesn't necessarily mean it has to be done. Ability and duty are two very different things. I think this field of investigation shouldn't be left to the doctor's free will, but should be subjected to a rigorous control imposed by society.

Do you share the concern aroused by genetic engineering in view of its possible use to manipulate man's genetic inheritance?
The possibility of altering the human genotype is, in my opinion, simply a matter of time. For that reason, the fears are not unfounded. And I agree with Federico Mayor, the new director-general of UNESCO, that, above all else, we have to defend the individual's right to his genotype. The human being has a right not to have his genetic code manipulated. Science is now at a crucial stage, that's why we're living a period of such uncertainty. That's why there's a legal vacuum that needs to be filled urgently. The only defence society has against this problem is legislation. National or supranational legal control. But that doesn't offer a complete solution to the problem, because no legislation can guarantee that there won't be abuses. I've heard conversations in which a single woman said that she'd love to have a son by herself and that she'd resort to a sperm bank and artificial insemination, which struck me as monstrous, because everybody has a right to a father and this child won't have

one, because one woman's selfishness can take advantage of medical technology. Technology isn't intrinsically good or bad, what's good or bad is the way it's used. For example, I seriously doubt whether it's legitimate that a woman who's been waiting ten years for a child shouldn't be able to resort to artificial insemination from her husband so as to be able to have one. The church doesn't seem to accept it but I feel it difficult to forbid.

You're a Catholic. Do you think the Catholic Church is keeping up with the times in these matters or is it lagging behind?

The Church can't help being conservative and in fact it's tremendously conservative. Now, in this question, the Church has been sensible enough to express its point of view, but without setting out any definitive rules. The directive regarding artificial insemination is merely intended to avoid the abuses that are taking place.

Do you think it should take a stand or do you think it should leave it up to its followers?

I think it's very difficult to establish limits and say "up to here it's moral and from here on it's immoral". In such delicate situations as this one, the Church chooses to say no to everything, because that's easiest. But I think that, in the long run, it's time that decides, and what's happened on other occasions is that it's set out with a radical "no" and has later changed its mind. Also, techniques are progressing rapidly and while we're thinking about it, new possibilities can arise that might solve some of the situations we now consider controversial. ■