Nephrology and society*

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‘Philosophy of progress and confidence in the future give way now to mistrust, caution and setback, leading to abstention and fear’

(Hans Jonas)

At first let me tell you that I am happy to be here, and this for several reasons. I was in Amsterdam 35 years ago when our association was founded and met for the first time. I was also the president of the 3rd EDTA congress in Lyon 30 years ago. It was a small, very convivial congress with 350 participants. Some of you may remember that we had a good time on the third day during the closing dinner in Château St Bernard near Lyon.

Thirty five years later, I am happy to see the three presidents assembled here, Prof. Berthoux (President of ERA/EDTA), Prof. Zuchelli (President of this congress) and Prof. Bernheim (past president) who all had been working with me in the past. I am happy that they did not forget their ‘patron’ as we say in French.

Why did I choose the topic of ‘Nephrology and Society’ for the opening lecture of the XXXth EDTA congress? I did so because I feel that during the past 50 years major changes took place in the relation between the medical world and society. In a rapidly changing world, the relations between the physicians (more precisely; the nephrologists) and their patients have been subjected to critical appraisal instead of confidence and acceptance by the public that we were used to in the past. New concepts appeared in the society which led to new rules and even to strict regulations.

Where do we stand now? Are these new trends beneficial or too restrictive? Do they permit further development of our speciality or do they become strangling? And if so, do we have the right to express critique or should we remain quiet, passively accepting these changes?

With respect to this question let us recall what nephrology has given to society. Even in the general public everyone is aware that in the course of the years dialysis and transplantation have saved hundreds of

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thousands of lives. Transplantation and dialysis have realized an old dream of mankind which has been expressed for more than 3000 years. Introduction of these treatments represents one of the great achievements of the present century.

Moreover, may I recall that some of us have lost their lives while treating their patients. As one example let me mention Vincenzo Ferioli. He was a fellow of Prof. Migone in Parma. In 1963, he came to Lyon, spent two years there, and became a close friend of our group. He was a marvellous man, full of enthusiasm and of energy. He returned to Parma and developed hepatitis with a malignant course. I am certain that many of you are aware of similar tragic fatalities in the nephrological community around the world. So as nephrologists I think we have a moral right to give our opinion on the above recent changes.

In a brief historical review let us consider the relation between nephrology and society as it has changed with time.

The period between 1960 and 1980 was, if I may say so, ‘the era of triumphant medicine’. Remember the pioneering achievement of the founders of nephrology, i.e. W. Kolf, N. Alwall, B. Scribner, J. Merrill, J. Murray, and J. Hamburger. Many other names could be cited. It was the time of medical adventure, bold and risky. These pioneering achievements were motivated by faith in progress and in its benefits for mankind. For this goal risks were accepted, because one was sure that, sooner or later, the harvest would be rich.

During this period, all members of the society shared such enthusiasm. Faith in professional skill and ethics was complete. The progressive improvement of results appeared to justify such co-operative attitude. This was the time of triumphant medicine, as I said, but it was also the time of too much triumphancy of physicians and surgeons.

Since 1980 (these dates are only approximate landmarks) followed what I called the ‘era of critical society’. Medicine was called into question despite its undeniable successes. The causes for this change in attitude are multiple:

- fear of the power of triumphant medicine
- change in the attitude of the mass media (recall for instance the repeated scoops on organ procurement)
- higher level of education of the population which is able to express (sometimes valuable) criticism

These tendencies go along with increasing awareness of the dangers of unlimited scientific progress. As our German colleagues know, Hans Jonas is one of the most vocal representatives of this tendency. This change in attitude has led to the following trends:

- the tendency to insist on evermore security
- the tendency to increasingly consider the bioethical aspects of these problems

- because of the difficulties in economic development, the tendency to impose pressures on the medical world to reduce cost of medical care
- and, as in other spheres, consumerism, i.e. the power of the consumer, has attracted much attention by politicians

These discussions are often conducted in an atmosphere which is dominated by distrust and fear concerning the progress of science. As a result the public indulges in the obscure desire to transfer the responsibility for professional activities to extra-medical administrative organizations.

Let us analyse some of these concepts in more depth. The aim to have maximum security i.e. ‘zero risk’, as desired by many, is impossible to achieve. All therapeutic modalities and particularly all new technologies involve a certain risk. Even consideration of the risk : benefit ratio breaks down if one aims at achieving zero risk. This dilemma led to the so-called ‘principle of precaution’, i.e. the idea to eliminate all risks, even those currently unknown. One must distinguish this from prevention which tries to eliminate known risks by adequate measures. Obviously, parts of society fell prey to the ‘security obsession’. This sentiment spread not only in the society as a whole, but, more worrying, also amongst decision makers, i.e. the administrative and political world. In such a climate innovation becomes risky and innovators may face heavy legal responsibilities.

The ethical concepts aiming at protection of human will and integrity are completely justified and regulations are necessary. This led to the establishment of bioethical laws (the Latin countries have been particularly fond of these formulations). But let me raise some issues here: is it wise to put into the rigid framework of laws an ever changing matter such as medical progress? Was it justified to issue such laws without the consultation of the public?

Today economy is of overriding importance. Nephrologists must participate in efforts to contain the cost of medical care. This is especially relevant for our costly treatment modalities, e.g. dialysis and transplantation. But this poses a dilemma. The nephrologist must remain a physician who takes care of his patients and who must deliver the best possible care. Everyone of us is willing to do so, but the danger lies elsewhere. As a result of powerful pressure of governmental regulations, we run the risk of becoming unconsciously ‘economy-minded’. More and more nephrologists spend an increasing amount of time to study extensively...
the cost of medical care instead of putting innovation into the first place.

The issue of economy raises further questions: will medical progress, initially undoubtedly costly, lead to more economical treatment in the middle and long term? Economists calculate the immediate cost of innovation, but usually fail to take into consideration long-term saving from improved rehabilitation, reduced drug use, and diminished hospitalization.

Another interesting question: what is the cost of the ‘security obsession’? Industry knows that if you aim at zero risk the cost of the procedures required will become prohibitively high. Common sense forces us to adopt less extreme security standards.

Consumers in the era of consumer power, amplified by the power of the media, leads to the situation that many groups study and contest the quality of treatment delivered by physicians. They are backed by lawyers and have attracted the interest of politicians who pay increasing attention to this tendency, not the least because they want to avoid public contestation. This movement is further driven by the prospect of financial compensation. Examples of interest to the nephrologist include contamination by hepatitis C virus (the risk of which was unknown). Against this background the main legislative committee in France (Conseil d’Etat) issued a warning, ‘The concept of “no risk” and of compensation without fault lead to defensive medicine and loss of initiative in medicine’.

Having dealt with societal issues relating to professional activities let us now discuss their impact on medical progress with some examples. Recently there has been hope that xenotransplantation will fill the gap of human organ shortage. Important breakthroughs have been achieved: a transgenic pig heart transplanted into a primate survived for 65 days, compared to loss from hyperacute rejection after 2 min of a non-transgenic pig heart. This confronts us with the delicate questions: should we go ahead and use such transgenic pig hearts to bridge over the time until a human cardiac graft is available? These issues are currently hotly contested and professional opinion varies from a total moratorium to controlled human experimentation. F. Bach, a pioneer in this field, wrote a statement ‘individual benefit versus collective risks’, pointing to the hypothetical risk of porcine retrovirus spreading in the population. He asked for a moratorium.

D. Sachs, another leading scientist in the field, wrote ‘xenotransplantation—caution but no moratorium’. C. Groth wrote ‘forging ahead or grinding to a halt?’ D. Hardy, a well known transplant surgeon, stated ‘dilemma of porcine xenograft. Is there already an answer? He referred to the danger of porcine retrovirus transmission to man: indeed until now no harmful effect has been observed in patients injected with porcine cells for neurological disorders or correction of diabetes, or in burnt patients receiving porcine skin grafts. Patients treated with porcine liver perfusion in case of fulminant hepatitis have not shown any signs of viral infection either.

Xenotransplantation raises a number of questions. Some of them should be answered easily (Do animals have moral rights? Will xenotransplantation lead to social injustice?). Other questions are more difficult to answer (Will xenotransplantation endanger public health?); a careful study of pig cell transfer, or of pig skin graft in burns patients should rapidly solve this problem. It will certainly be a difficult matter to select a proper threshold of risk/benefit for a clinical trial in individual patients. I mention this ongoing discussion because here we also see the general tendencies mentioned above, i.e. ‘zero risk’ mentality and fear of the unknown. The discussion evokes a sense of déjà vu in someone who has participated in the early discussions concerning allotransplantation in the fifties and sixties. Happily then, solutions were more easy to find and allowed rapid progress.

Let us take another example: daily haemodialysis. This is a very old story. Prof. Bonomini (Bologna) was one of the first to deal with the subject. At the 1972 EDTA congress he presented a remarkable paper which documented the advantages of daily haemodialysis. This idea was taken up, since 1985 by Buonchristiani (Perugia).

In our group we have some results which confirm the superiority of this strategy. Comparing standard (4 h × 3) and daily dialysis (2 h × 6) in the same patient we confirmed that 2 h daily dialysis is possible using the usual AV fistula. The amount of dialysis delivered (Kt/V) is high. Daily haemodialysis is a physiological strategy with a TAD (time average deviation) value lower than with standard haemodialysis. We see rapid improvement of hypertension, left ventricular hypertrophy and nutritional state. This dialysis strategy can be used either in the long-term as a home treatment modality or for shorter periods as a rescue therapy. Yet, despite such excellent results, only a few groups around the world, no more than 15, have pursued this strategy. This is difficult to understand. Even the present meeting does not have a single session on this subject. Why?

One possibility is that nephrologists feel this treatment strategy is impossible to implement because of its high costs. Have we become ‘economy minded’? We should act the other way around: we should first prove that this strategy is useful and necessary, at least for some of our patients, and then we should try to limit the cost as much as possible.

Some other examples: haemodialysis generators have become ever more beautiful and attractive with marvellous colours, multiple security gadgets and impressive display of electronics. I do not want to attack industry which indeed is of great help to us, but the question must be asked: is this true innovation or does it reflect the above discussed ‘security obsession’? Reuse of dialyzers: I do not want to go into this difficult problem but I cannot help smiling when I look at this interesting dilemma between obsession with security and considerations of economics.

At the end let me summarize. We are under pressure from the media, from the public, government agencies,
the lawyers ... are we being subconsciously brain-washed? Are we still physicians or have we become cold-blooded economists and lawyers? Let me remind you of what J. Hamburger stated years ago: ‘Les médecins sont là pour exiger le respect de la vie, pour soigner les corps mais aussi défendre l’individu spirituel et ils doivent avant tout avoir un appétit de justice pour leurs patients, c’est-à-dire les défendre’. (The physicians are here to demand respect for life: to care for the body, but also to defend the spiritual being, and before anything else they must fight for justice for their patients, in other words they must defend them.)

As a closing remark, I do not want nephrologists to discard economy, ethics and so on ... (we must live with our time), but I want nephrologists to overcome these difficulties and climb as high as possible towards innovation despite the present difficulties. We must remember that innovation is the best solution to save more patients in the future.

After an era of complete and perhaps excessive freedom, we have now entered an era of strangulating regulations. I hope that with time the pendulum will swing back to a more middle-of-the-road position.