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EDITORIAL

# Return to Basics: the Cases of Informed Consent and Lost Chances of Living

In the last twenty years, medical technology has 'run' so much faster than the law, that lawyers and lawmakers found themselves unable to follow up with science; they have taken a position not much different from that of the spectators of Formula, being in absolutely no position to compete, but, simultaneously, in a great danger of getting hurt themselves.

How can one get 'hurt' because of these developments? Inability to catch up with scientific developments, when lawyers are, though, in great need of an enforceable rule, is, of course, a direct injury, an injury of the legal profession generally; this injury, to say the least, exposes lawyers (once again) to the accusation of a clear and great distance from reality. Clients do not care for reasons, but only for results: that a contract for surrogate motherhood, entered into with the full consent of the parties, may or may not, later on, be declared invalid, is an instance where the law necessarily fails, at least as to its supposed quality of certainty and predictability. Another way of getting profoundly hurt is to forget what medical law is really about; insisting so much on research of these limited topics may even cause the grave mistake of thinking that a medical lawyer does not need a solid theoretical foundation and deep knowledge of classic medical law, seeing this law as outdated.

Not that an absolute creed in pure and abstract theory will save us. All these years, we have been watching endless debates of lawyers, philosophers, doctors, nurses and people from many other relevant professions as to when a patient is dead, which should be the procedure of removing organs for transplants, is a consented abortion of a two weeks fetus a homicide, is a life-saving blood transfusion upon an incompetent Jehovah's witness equal to rape, are all operations by an alcoholic surgeon who did not disclose his disease to the patients equal to assaults and batteries, is the care of an incompetent patient in imminent danger of dying legitimate because of an implied contract between the caretaker and the patient, is a severe mistake by the doctor a breach of contract, a tort or both? And besides the distance from reality of at least some of these favorite themes, there is also another major



source of concern: in all the conferences where the experts are called to offer their precious opinion, the lack of the important party of the panel, the patient, the person, the individual, means that the one voice we need to listen to is just not there. Even if we know that we cannot find one person to claim to be a representative of society, exactly as we know that the 'reasonable person'– standard for model conduct in negligence is a fiction, we can do better than nothing at all. At least in the common law world, which refuses to try anyone without a jury, this steady omission is clearly not correct.

All the theories of the world, I am afraid, cannot help us much, in solving specific problems in the hospitals or in doctor's surgeries. Last week, a three-year-old child was operated at the Children's Hospital of Hagia Sofia of Athens. The doctors just took the child from the mother, saying only 'we will do what is appropriate'; they did not allow her in the surgery, and afterwards, while she was congratulating her three-year-old for being so brave in there without her, one of the doctors complained: 'What are you talking about? The kid was screaming all the time, for Christ's sake!' And I will always remember my fellow, at the Harvard Center for Ethics and the Professions, a physician-ethicist, who secretively announced us during one of the seminars, that never mind all the doctrine of autonomy and respect for patients' rights; when it came down to telling the parents their child had leukemia, every member of the doctor's team looked at one another and discussed (in fact, argued upon) the one and most important thing: who amongst them will tell the parents the truth, and how. And then he added: 'we never talked about Plato in there'.

My fellow made us laugh in the seminar, and he laughed, somewhat guilty himself too; he did admit how far reality is from a thousand books on ethics. As such, this comment does not claim any reward of originality. I am using it, though, as a lead to another remark that medical law has to return, at least in part, to basics. Again, not that the law has to stop attempting to keep pace with the evolutions of medical science; I have already described some of the dangers of this route. But the dust of this exhausting race has to settle down and cease to blind us and hide the main problems of everyday situations of the doctor/patient relationship.

We have, to resist the temptations of modernity, up to a certain point, temptations, which force us to choose as a conference's theme 'genetic personal data and confidentiality' over, for example, 'informed consent', because the first topic is so much more 'a la mode'. After all, we are not haute couture designers, discussing latest styles and even they, as far as I know, live from the classic styles they sell, and not of the modern ones. Indeed, in this very journal you are reading from – which is, allow me to say, an excellent journal – in the last three years, nine articles were published on something in connection with 'genetic'; only one had to do with informed consent, only



one with medical malpractice, there was nothing on abortion or loss of chance (but, I do admit, there were six on euthanasia). But if medical law, all these years, has not come up with any solutions on the main themes of the doctor/patient relationship, solutions visible everywhere, in the surgeries, the hospitals and most importantly, in doctors'/patients'/people's minds, it does not 'have the right', it does not have the 'luxury' of discussing anything further than that. If it did, then we would have put the cart before the horse, which means precisely, that we will never go anywhere.

To prove what I allege here, that we look as if we have abandoned our research and thought of classic themes of medical law, in favour of what would 'sell' nowadays (for example cloning, genetic data, medically assisted reproduction, internet and medical law etc – and how many people's lives, throughout the entire world, do these subjects affect today?), I want, to offer two examples later on, : informed consent law and loss of chance (in a medical situation) law evolutions (or rather, the lack of them). Both cases deal with one to one relationships, doctor/patient, and I believe that every one of us at some point may be directly affected by the responses of the legal system to these two questions.

This direct influence is also true on the (classic) medical negligence question; on this one, though, although the law has its 'holes' here and there, I think that we have a rather dense body of law to respond to our needs. Damages awards for medical negligence have, these last years, reached respectable sizes even in Greece, unfortunately famous for the lamentable awards for patient injury, has known at least one case where damages for moral harm reached 100 million dr., that is around 300.000 EURO (for the death of a 10-years-old girl, who contracted AIDS in Rhodes, due to inappropriate hospital blood testing – the award was affirmed by the Supreme Court. So, the case of classic medical negligence is not in a terribly bad situation, this does not mean that we do not have a long way to go anyway. I have found it very intriguing and attractive as well as terrifying for all the doctors I know and I have been threatened with, the model medical guidelines/standards of good practice, as they are proposed to be implemented in Germany[1]. If this trend persists, and in truth, I do not see why not, the whole picture of medical negligence will have to change. And it suffices to see how hard the defendant's lawyers, in the above tragic case, unjustly fought against the child's parents, to be instantly persuaded that this is definitely not a fair game and that not even the classic medical negligence, so many years after its 'birth' in the Western world, is a resolved issue.

Given the above, one may again find it a bit of, a luxury to turn to informed consent cases. If physicians had their ways in cutting through people for centuries – for their own good – I mean then imagine how strenuous a task



is to persuade them that it is not only people's bodies, which need their care, but also people's wills. Even lawyers sometimes do not fully grasp why it is *not* all right, if a surgeon performs a perfect operation, a heart transplant, say, of which Christian Barnard would be eternally jealous of, a heart transplant whose surgical lines are like a Renaissance painting, but a transplant to which the patient *has not consented in an equally perfect way*. At least practicing lawyers, who feel in their very souls what I said above, that clients care about results, not reasons, have as many problems with a pure theory of informed consent, the way Jay Katz was pioneering it, as doctors themselves.

Giving the example of a heart transplant, I did, somewhat deliberately, fall in the usual informed consent trap myself (apart from the necessary, because of the law, trap of speaking of informed consent and not informed choice): the trap that the doctrine has to do with physical interventions and that information means information about risks-so, statistics. But this is exactly where we are with the doctrine today, almost twenty years after Jay Katz published his famous 'Silent World of Doctor and Patient', a voice so loud, so clear, so unbelievably touching and yet fleshed in scientific argument, that one would think that the case for informed consent had to become status pretty soon.

And yet, it is not; and yet, more usually than not, patients who seek redress on grounds of uninformed consent do so, because they add one more count to a much more promising count for medical negligence, or they add it, because it is absolutely impossible to claim or prove medical negligence at all. And the law's standards look like 'an injury added to insult' by themselves, that is, exactly as Katz had seen the requirement of 'altered conduct'. This requirement is that the patient may sue, only if she suffered an adverse physical effect of a medical intervention and only if, had she known of something-in most cases, this is a risk, which must have materialized – of which she was unaware of, she would have decided against the intervention. And given all this, the court then will have to quantify and deduct from the award of damages, any amount, which represents losses because of the condition, which the patient suffers anyway, because she is ill.

To break all this down to reality, if you try chemotherapy, and you are not told, that in your case, radiation is an option with (all sorts of) results you may have preferred, the option of suing, typically available in (only) some jurisdictions, is in fact not desirable. Even if you surpass the formidable obstacle that in many jurisdictions, it is missing information on *risks* that counts, you are still left with the burden of proof that a reasonable patient would elect radiation (in jurisdictions where the standard is reasonable doctor, you are doomed to fight – and pay for – the battle of experts, if you find one for you), plus that radiation would hurt you less and give you more days upon



earth. And then there would be a comparison between the situations and you would be left with (whatever that would be) the difference. Now if you, just by chance, happened to find I think, the rare, lawyer who is a firm believer in client's informed consent in *legal* action, and she told you all this, before she sues, would you seriously support that this is a great case for winning?

Another example: the loss of chance cases. You are a cancer patient and your chances of living are 49%. Your doctor treats you negligently, your chances are reduced to 10% because of her negligence and you die. The court says: 'you (your estate, your relatives) cannot claim damages; your chances were against you anyway; you did not fulfill the 50 plus 1% burden of proof, so you loose. Too bad you were so sick in the first place! Had you been a *little bit* healthier, you would have made it. The law protects healthier patients more than the severely sick ones. And the law rewards doctors who negligently treat severely sick patients – the more sick you are, the less chances you have to live, the more the doctor may misread an x-ray, miss a lump or skip a test. He will start really caring, only when your chances are better than even, for then, the suit will be successful'[2].

Something in the system is very rotten. As a lawyer, I cannot look patients in the eyes and tell them that this is the legal truth for informed consent and loss of chance cases. And as a researcher, I urge people who care, in all professions, to return to the main principles of medical care, to the foundations of ethical practice and to try to change situations like the two described above. Until then, and with all due respect to all my esteemed colleagues, I will persist and be very skeptical about all thoughtful discussions about whether someone will steal my genetic data and give them to someone else, how the internet will affect my rights as a patient, if the widow of a man has the right to claim his refrigerated sperm from the sperm Bank and demand to become a mother and why researchers should not be allowed to use stem-cell material for their work (of course, they should). Please do not lose the entire picture for some, extremely important details.

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**Notes**

1. Dieter Hart: 'Medical Guidelines - Reception and Application by the law: the German example', EJHL 7(1):5-13, March 2000.
2. This is the case in the majority of the US states, Greece, Germany and the matter is hotly debated in France, Belgium and other countries.