

The Patient's Family, between the Right to Know the Truth and the Medical Secret

The Patient's Family, between the Right to Know the Truth and the Medical Secret (Abstract)

This paper should be considered as the author's manifest against the overlook of a human right, the right of the family of the deceased patient to access the medical records of the latter.

The author's fight with the Romanian medical system started in 2003. After the tragic event of his parent's passing away, in mysterious and unclarified circumstances, he repeatedly claimed his access to the medical records, with no positive response up to present day.

The author inquired about how this problem is considered elsewhere. He found there are countries where this right is guaranteed by law. The examples of Hungary, France, Arizona and Washington states are commented here. In Switzerland, the family is given only an indirect access; nevertheless, members of the civilian society fight against that situation.

The author found that in Romania, the law of patient's rights does not grant the right in question. The civilian society does not take any position. And the medical system does not show interest for dialog with the latter, or does not even conceive that such dialog could exist.

The author brings arguments in favor of his opinion that being denied the right in question is an abuse of the Romanian medical system, against not only a human right, but also against the sacred right and duty of Man of trying to understand the Universe. Man can free himself of fear only by gaining such understanding. By opposing to it, the medical system keeps the man on his knees under terror and fear. Being himself a scientist, the author considers that being denied the right to scientific understanding of what happened with his parent represents a diminution of the researcher's statute, a negation of the interdisciplinary spirit and a self-placement of the medical system beyond the responsibility due to civilian society.

Keywords – human rights, patient's rights, access right to medical record, medical secret.

Instead of Introduction

I wish I would not had to write these lines.

Unhappy circumstances of life led me to this option, in order that the medical system of Romania be informed about my position.

I am indebted to Professor Dr. Vasile Astarastoe, for encouraging myself to publish this material in the Romanian Journal of Bioethics.

Why have I chosen precisely that journal?

My attention has been captured by a fragment from an editorial [6] written by Professor Dr. C. Gavrilovici, where I have found a reference to the ideal model of the relation between medical system and public in a "perfect society".

The system would be however perfect and in ethical parameters only in a society where the patients would wish to take decisions, would wish to be informed, the doctors would be able and wishful to offer them information, the patients would be able to understand those, to memorize them and, ideally, ... to adequately analyze the medical problems. This would be an almost perfect society...

The author has tried since the beginning of year 2003 to take a step towards the "perfect society", only to find with great sorrow that the above mentioned perfection is of chimerical nature: the patients DO NOT want to take decisions, the doctors ARE NOT willing to offer information, the state and the medical system ARE NOT willing to encourage the patients' initiative or the medical staff's "transparency" policy.

Since the tragic event of the passing away of my parent, George Pavel Vuza, in mysterious circumstances that are not cleared up to present day, I did not ceased to require, via several ways, the granting of my access to the medical records of the patient that have been drawn up by the state medical units, invoking in support of this the principles stated in the World Health Organization (WHO) document

Déclaration sur la promotion des droits des patients en Europe [11] as well as statements found in the laws of some neighboring countries.

In all memoirs addressed to various state organizations I stated precisely that my requests are founded on the desire of the scientist, of the researcher of natural phenomena, to understand from a scientific viewpoint the bizarre phenomena, for many times of a devastating dramatism, that marked the two months of my parent's suffering. I have made clear that, for that reason, I do not need a certificate, which would interpret the record data in a resumative way, from the perspective of the expertise and the momentary state of mind of a particular observer, but I need the objective data contained in the record, gathered through biophysical and biochemical tests, the only data that can be submitted to a scientific analysis independently of the subjectivity of a single observer.

My approach has been understood by NO ONE: neither by the state institutions, neither by the non-governmental organizations. I wish I am wrong, but it seems that the endeavor to approach the understanding of the tragic meaning of the existence from another perspective, rational and explicative and not only fatalist, is not in the spirit of this nation. In this people's conception, the doctor seems to dispose, "since our forefathers", of an absolute authority; he "knows what he is doing" and what he is doing is beyond any doubt, even beyond the scientist's skeptical-constructive doubt. Who does not accept this traditional view is stigmatized as not belonging to the nation. From this perspective I would consider that the distance to the "perfect society" seems still enormous; I nevertheless greet the opinion of the author of the editorial [6], as it is there where I have read for the first time in a Romanian publication about the view on an active, informed and responsible patient, a view that I endeavor myself to promote since three years.

I have not heard up to present any argument for justifying the absolute medical secret towards the patient's family, although I was very interested to hear at least one. In the papers on this topic that I could find, the medical secret towards the patient's family appears as a situation that is not logically argued, but decreed. Exactly as an order in the army, that is not to be discussed, but to be executed. From this emerged the name of "white army" that I used in conjunction with the medical system, when I publicly expressed some of my opinions. That is, a paramilitary power that has raised itself, by its own will, above the society, considering itself as free of the obligation to report to anyone for its actions.

I have not the least regret for having resorted to the "white army" concept. Three years have elapsed and the medical system of Romania has done nothing to show to me that the concept is not justified.

G. Scripcaru – *Bioethics between life sciences and human rights* [14].

By virtue of human rights, each individual has the right to appreciate the quality of his own life, the state being not entitled to impose a unique conception on the existence.

This is my personal appreciation on the quality of life in Romania, this is my own perception on the medical system generated along three years of failed attempts to establish a dialog with a system that not only keeps denying the son's right of finding the truth from the parent's medical records, but was not even willing to provide an explanation on the fact that something that is a guaranteed right in other European countries, in Romania is an interdiction.

Also in [14] one recalls the principle "knowledge is infinite, the man's duty of discovering the mysteries of the world being sacred". Would this assertion have only a propagandistic meaning? In other words, would the "duty" be "sacred" only for certain privileged representatives of human race, while the sacred duty of a son to find out the truth about his parent is equated to a bad action, since it is not the good actions that are forbidden by the law?

And again in [14] one estimates as a positive fact the "imperative" assertion by Romanian law 46/2003 of the right to confidentiality that guards the peace of the sleep of the brave. No exceptions being made, implicitly one deduces the keeping of the truth about the parent as a secret for the son. But the fact that peace of the sleep of the son is lost until the truth would be found does not create the slightest worry to anyone? (But who cares any longer in Romania about the situation of a scientist?)

In no way should be this paper considered as "a release of archaic feelings of always finding a culprit" [14], although I would be entitled to express my indignation against some blamable aspects I have remarked along the two months of the patient's suffering, in particular, the ease with which some incompetent and irresponsible medical personnel, by confusing the influence of ischemia on the nervous system with the symptoms of a degenerative disease, have labeled with "senile dementia" a man of a high moral profile, active and conscious until the very last days. Exactly as in [14], where it is written "the desecration of the medical act because of loss of the mystery aura surrounding the doctor runs into the risk of getting away from the soul of the patient who seems to be reduced to a plain medical record", my parent,

being urgently transported, against the family's will, to a state unit, has been "entered" into the computer database, "treated" mechanically (and with a certain aggressiveness I have reason to suspect from what I have witnessed, until truth would be revealed,) and then "eliminated" from the department reserved to live people, without the least concern from the part of that state unit of feeling obliged to provide an explanation to the family regarding what happened during the 10 hospitalization hours fatidic for the patient. One should compare this "treatment", evoking the inhuman and implacable mechanisms of a paramilitary power ("the white army"), against the humanitarianism and high moral sense of my parent who, while assuming high responsibilities in the juridical system (chief attorney of the Iassy region and then first assistant of the general attorney), did not hesitate to expose to danger his career and even his liberty for saving the liberty and sometimes even the life of innocent persons persecuted by the abuses of the communist system.

I consider myself as showing understanding towards the terrible problems that confront the medical profession (not only in our country) and a certain degree of tolerance for the difficulties that result. It is not too demanding for me to transpose myself in the position of the medical personnel, taking into account that myself I come from a family in which many persons had medical professions. My mother, a disciple of the famous professor Gr. T. Popa, directed a laboratory for clinical tests until retirement. I know how much she had to fight with "the party" for obtaining the materials necessary for daily activities. I imagine the difficulties generated by the poor equipment that still confront doctors today. And above that, a new problem emerged, that of informational stress associated with the concept of continuous medical education (CME). The CME subject has first to face the huge assault of published material, without being certain that quantity is equated by quality. Today many papers are written not because the author has to convey something, but because he has to fill up his list of publications, this representing a flaw of the whole research, not only of medical research. The CME subject is therefore supposed to distinguish between authentic value and rubbish; however skimming over a material with less significance consumes the time and effort that could have been allocated to a more productive activity. Viewpoints are changing in medicine faster than the CME subject is able to assimilate. A new treatment is proposed as benefic and is followed shortly by alarming comments about side effects. To the CME subject it is difficult to distinguish the extent to which the presented facts are real or are the expression of interest conflicts. The arguments prevalent in medical literature are the statistical ones. Which raises skepticism concerning the accuracy of processing and the degree of significance of the samples. Even with a correct and not subjectively biased processing, one can obtain contradictory conclusions starting from different samples. Experimental arguments are obviously constrained by the limitations imposed to experiments on humans. Theoretical arguments displace the problem to the realm of other disciplines (mathematics, physics, chemistry), a fact that many times submits the CME subject's already overloaded learning capacity to an even tougher trial and, anyway, raises doubts about the accuracy of the used model. Unifying principles, similar to those on which Physics is founded, are still far from being foreseen.

Medicine is more and more running towards an informational chaos in which the CME subject feels himself more and more lost (how many new protein and enzyme names that molecular biology impinges on him should he be obliged to learn?). I imagine him, after a work day during which he was confronted with exhausting cases, with the lack of resources, with the failure of some treatments, with the wickedness of the colleagues, arriving at last at home, where a pile of CME is waiting for him, but tiredness overcomes him and he gives up, falling asleep with the thought that, after all, that what is already written will happen to the patients, who is to get away will get away, who is not...

The only way to overcome such a social problem apparently without solution is within an active collaboration between the medical system and the factors of competence and progress of the civilian society. But such collaboration is hard to imagine in the lack of transparency and of reciprocal availability to approach the difficulties openly. As long as the absolute medical secret, even by its symbolic value only, would maintain the barrier between "us" and "them", the society would not get out of the feudal stage where the medical profession dominates over a population partly frightened, partly indifferent, but entirely ignorant.

In the following, by "medical secret" I shall understand only that aspect of it that restricts the access of the family of the patient to the medical record of the latter.

A paradigm as old as the medical system and secret

The patient is brought to the doctor by his family. Suddenly screams and other worrying noises are heard from medical room. Shortly after the family is announced: “The patient has deceased. You may take him”.

“What happened?” – “We cannot tell you that. It is medical secret”.

The family will get away in great grief highly augmented by the thought: “The doctors have taken his life”.

Who could comfort the family that it was not the doctors’ incompetence that brought an end to the patient’s life?

“Fill a complain request and submit it to the Medical Board” suggests the State.

“The doctors acted right and no errors have been found” is the Medical Board’s answer to the complain.

“But we have heard screams” protests the family.

“What have you expected, doctors always protect each other”, replies Common Wisdom.

Would a solution be ever found for this apparently unsolvable issue?

George Bernard Shaw

All professions are conspiracies against laymen.

The right of access of the family to the patient’s medical record in some countries

Apparently, Hungary is one of the countries where the patients and their family have conquered the most extended rights. Act CLIV of 1997 on Health [1] guarantees the unconditioned access of the family and the legal representatives to the deceased patient’s record.

[1], Section 24 – *The Right to Become Acquainted With the Medical Record*

(11) In the case of a patient’s death, his legal representative, close relative, or heir shall have the right, upon written request, to become acquainted with health data that is, or may be, related to the cause of death, and data that is related to the medical treatment preceding death, furthermore to inspect the medical record and to be provided by copies thereof, at his own cost.

In Arizona, the law [2] introduces the concept of *health care decision maker* and enumerates the persons that possess such a quality as being in the first rank of the persons entitled to have access to the medical record of the deceased patient, together with other categories of persons that include the patient’s close relatives.

12-2291. Definitions

3. "Health care decision maker" means an individual who is authorized to make health care treatment decisions for the patient, including a parent of a minor or an individual who is authorized pursuant to section ...

12-2294. Release of medical records and payment records to third parties

D. A health care provider may disclose a deceased patient's medical records or payment records or the information contained in medical records or payment records to the patient's health care decision maker at the time of the patient's death. A health care provider also may disclose a deceased patient's medical records or payment records or the information contained in medical records or payment records to the personal representative or administrator of the estate of a deceased patient, or if a personal representative or administrator has not been appointed, to the following persons in the following order of priority, unless the deceased patient during the deceased patient's lifetime or a person in a higher order of priority has notified the health care provider in writing that the deceased patient opposed the release of the medical records or payment records:

1. The deceased patient's spouse, unless the patient and the patient's spouse were legally separated at the time of the patient's death.

2. The acting trustee of a trust created by the deceased patient either alone or with the deceased patient's spouse if the trust was a revocable inter vivos trust during the deceased patient's lifetime and the deceased patient was a beneficiary of the trust during the deceased patient's lifetime.

3. An adult child of the deceased patient.

4. A parent of the deceased patient.

5. An adult brother or sister of the deceased patient.

6. A guardian or conservator of the deceased patient at the time of the patient's death.

It is worth observing that the law of the state of Arizona admits the presumed consent of the patient, with the only exception when there exists an interdiction explicitly formulated by the patient.

The law of the Washington state [15] also guarantees the exercise of *all* rights of the deceased patient by his legal representatives (in particular, the right to access his own medical record).

70.02.005 Findings.

(2) Patients need access to their own health care information as a matter of fairness to enable them to make informed decisions about their health care and correct inaccurate or incomplete information about themselves.

70.02.140 Representative of deceased patient.

A personal representative of a deceased patient may exercise all of the deceased patient's rights under this chapter. If there is no personal representative, or upon discharge of the personal representative, a deceased patient's rights under this chapter may be exercised by persons who would have been authorized to make health care decisions for the deceased patient when the patient was living under RCW 7.70.065.

In France, in the confrontation between civilian society and medical secret, the former has won victories, however the battle is ongoing; at least this is to be understood from the up-to-date law texts.

The law 2002-303 of 4 March 2002 [9] has been announced as a revolution of the French medical system. Concerning the medical record, the new facts are contained in the fragments reproduced below.

Art. L. 1110-4. – (...) Le secret médical ne fait pas obstacle à ce que les informations concernant une personne décédée soient délivrées à ses ayants droit, dans la mesure où elles leur sont nécessaires pour leur permettre de connaître les causes de la mort, de défendre la mémoire du défunt ou de faire valoir leurs droits, sauf volonté contraire exprimée par la personne avant son décès.

Art. L. 1111-7. – (...) En cas de décès du malade, l'accès des ayants droit à son dossier médical s'effectue dans les conditions prévues par le dernier alinéa de l'article L. 1110-4.

It is nonetheless true that, after less than two months, the decree 2002-637 of 29 April 2002 was issued that amended the text of the law.

Art. 7. - L'ayant droit d'une personne décédée qui souhaite accéder aux informations médicales concernant cette personne, dans les conditions prévues au septième alinéa de l'article L. 1110-4 du code de la santé publique, doit préciser, lors de sa demande, le motif pour lequel elle a besoin d'avoir connaissance de ces informations. Le refus d'une demande opposé à cet ayant droit est motivé. Ce refus ne fait pas obstacle, le cas échéant, à la délivrance d'un certificat médical, dès lors que ce certificat ne comporte pas d'informations couvertes par le secret médical.

This shows once again how tough is the mute fight between medical system and civilian society and how difficult is to conquer a territory dominated by a heavily established mentality. In *La nouvelle démocratie sanitaire* [10], Hervé Nabarette quotes Yvonne Lambert-Faivre's comment, which summarizes the essence of the problem in a few words told with courage and consciousness.

L'accès du malade à son dossier médical et hospitalier a longtemps été quasi tabou, pour de *mauvaises raisons* déontologiques, psychologiques et juridiques. En effet, le secret médical était conçu comme un "droit" du médecin opposable au malade. Celui-ci était maintenu dans *une ignorance infantilissante* de son état "pour son bien". Surtout, l'inaccessibilité du dossier médical jetait sur les dysfonctionnements hospitaliers et sur les fautes médicales un voile qui *éludait les mises en responsabilité* des professionnels de santé.

That we are witness to a real fight also follow from this fragment from [8] *L'information et le consentement du patient*.

L'article L 1111-7 nouveau du Code de la santé publique prévoit le droit à l'accès direct au dossier médical. Introduit par la loi du 4 mars 2002, *ce droit était revendiqué de façon constante par les malades et leurs familles*.

In Switzerland, the information I dispose of up to this moment shows that the access of entitled people to the medical records of the deceased patient is allowed, however not directly but intermediated by medical personnel that would examine the records and communicate only their conclusions to the interested

persons. This limitation of the access right is severely criticized by Mauro Poggia, an expert in medical laws, during a debate organized by the Medical Foundation Louis-Jeantet. I have allowed myself to include his complete statement [5] here, as I consider it as a strong reinforcement of my own point of view.

Question : Après un décès, les proches ont-ils accès au dossier médical du patient décédé ?

MP : Le problème du secret médical après la mort, est un sujet éminemment important quand on y est confronté, évidemment. Il faut savoir que pour le tribunal fédéral, le secret médical perdure au-delà de la mort du patient. Donc, le médecin lui doit le respect du secret médical au-delà de sa mort. Je le sais parce que j'ai fait trois recours au Tribunal fédéral pour tenter de faire changer cette jurisprudence. **Je trouve inadmissible que l'on considère que le médecin n'a pas le droit après le décès de son patient de donner des informations, même aux proches.** Donc, on a décidé à Genève, et le tribunal fédéral, c'était dans le cadre d'un recours qui lui permettait uniquement de dire si c'était acceptable ou non acceptable, le Tribunal fédéral a dit qu'il était acceptable de faire ce qu'on propose à Genève, c'est-à-dire de choisir un médecin en tant que par exemple fils d'une personne décédée. Ce médecin va recevoir le dossier, le consulter et ensuite, sans permettre à son interlocuteur de le lire ou d'en prendre des photocopies, va lui indiquer ce qui s'y trouve. C'est un système qui est **totalemtent boiteux** puisque le médecin que l'on va désigner pour regarder le dossier n'a jamais obtenu de quiconque l'autorisation de regarder le dossier de la personne décédée. Pire encore, on va même jusqu'à demander à l'héritier qui voudrait voir le dossier, d'autoriser le médecin qui était le médecin traitant de la personne décédée, à transmettre le dossier à ce nouveau médecin que l'on parachute de je ne sais où pour que l'on puisse le regarder. Donc, c'est une solution très boiteuse. On considère qu'il peut y avoir dans le dossier médical des informations sensibles que la personne décédée n'aurait pas voulu qu'elles soient transmises. Je pense pour ma part, et j'ai fait une proposition pour notre nouvelle loi de santé genevoise dans ce sens. Je pense qu'il faudrait inverser la règle et l'exception. **La règle, c'est que l'on veut que nos héritiers aient accès à notre dossier médical, ce d'autant plus lorsque l'héritier met en cause le médecin ou l'établissement hospitalier comme étant responsable du décès. On a des cas absurdes où l'on considère que l'hôpital est responsable du décès de son père, mais on n'a pas accès au dossier pour pouvoir démontrer qu'il y aurait une responsabilité médicale.** Alors je pense qu'il faudrait inverser la règle et l'exception. Et, à moins qu'il n'y ait dans l'anamnèse des éléments qui permettent de penser que la personne défunte n'aurait pas voulu que ses proches, et encore faut-il définir les proches, aient accès à son dossier médical, il faut l'autoriser et cela devrait être la règle, parce qu'aujourd'hui **personne ne comprend que l'on utilise le secret médical pour protéger finalement le médecin. Parce que quand la personne est décédée, c'est le médecin ou l'établissement public que l'on veut mettre en cause qui est protégé.** Autre est la question, si l'on veut avoir accès au dossier médical dans d'autres buts. Par exemple, pour prouver que de son vivant, la personne décédée aurait donné des biens alors qu'elle n'était plus capable de discernement. Là, la question est beaucoup plus délicate. Mais je dirais que lorsque l'on veut démontrer qu'il y a eu, ou pas, faute médicale à l'origine du décès, **opposer un secret médical ne fait que générer des souffrances inutiles.**

What is the situation in Romania?

We have seen above examples of how the problem of the access of the deceased patient's family to his medical record has been regulated by law in other countries. In those laws one precisely defines the conditions under which the access right is exercised and the categories of persons for which this right is guaranteed.

In Romania, this issue is not considered by any law. The author was not able to identify a law text from which one could deduce the lawmaker's position with respect to the access of the family to the medical record of the deceased patient. In the absence of an explicit regulation, this issue *may be* settled in the unfavorable sense for the patient's family by *implicit* interpretation of some texts referring to the medical secret.

Here is what the law 46/2003 on patient's rights says.

Art. 10 – The relatives and friends of the patients may be informed about the evolution of the investigations, the diagnosis and the treatment, with the patient's consent.

Art. 21 – All information concerning the condition of the patient, the results of the investigations, the diagnosis, the prognosis, the treatment, the personal data, are confidential even after his demise.

Art. 22. – The information with confidential character can be disclosed only when the patient provides his consent or if the law requests that explicitly.

The law does not refer in any way to the exercise of the patient's right of access to his own record via his legal representatives, in the way we have seen in the above exemplified laws of other states. In the absence of any explicit regulation, one implicitly deduces from the quoted articles that, insomuch as a patient can no longer express any consent, the data in his record will remain secret for *anyone*. In particular, if the patient has been transported in unconscious state to a medical unit and therefore could not express any consent before leaving this world, he would take with him the medical secret for ever, the secret being revealed to his family only when they would meet again in the other world.

And another implicit deduction is that, in the absence of any opposing statement in the law 46/2003, these statements from the Deontological Code of Doctors still act on the territory of Romania (section B, The Professional Secret).

Art. 17 – The secret exists with respect to the heirs, the colleagues and the medical personnel not involved in the treatment.

Art. 18 – The secret persists after the end of the treatment or the patient's demise.

In the absence of any regulations in the sense favorable for the patient's family, some authors are hurrying to expand upon the text of the laws in the sense unfavorable to the latter. Thus, juridical counselor Dana Dicianu writes the following in [4].

As a general rule, all information concerning the state of the patients, the results of the investigations, the prognostic, the treatment, the personal data, are confidential even after the patient's demise (art. 21 from the law). Any information concerning the state of health may be provided only with the patient's explicit consent, even if those who wish to be informed are persons close to the patients (heirs, friends, etc.).

One should remark that, in order to strengthen the viewpoint according to which the family is forbidden from access to the deceased patient's record, the author resorts to terms that do not even occur in the text of law 46. Nowhere in the law the term "heir" is to be found since, as already shown, the law is not concerned with the exercise of the patient's rights via his representatives. Resorting to such a term could be an influence of the doctors' deontological code, much aged that the young law 46/2003, therefore deeper rooted in the mentality of the medical system opposed to the civilian society.

It seems strange to me how two essentially distinct concepts, *heirs* and *friends*, have been placed on the same level. A patient's son is tied to the former by a relation of divine nature, his right of knowing the truth about his parent being sacred. The friends, however, can be friends today and enemies tomorrow. Strange as well looks to me the occurrence of the term "friend" in the text of the law 46 (art. 10). How one could prove someone's friendship or lack thereof in front of the law? The law of state Arizona [2], while specifying the domain of the concept "health care decision maker", takes care to define precisely what is to be meant, in the medical context, by a "close friend" acting in the position of "health care decision maker".

36-3231. Surrogate decision makers; priorities; limitations

6. A close friend of the patient. For the purposes of this paragraph, "close friend" means an adult who has exhibited special care and concern for the patient, who is familiar with the patient's health care views and desires and who is willing and able to become involved in the patient's health care and to act in the patient's best interest.

From what was said so far one can draw the conclusion that in Romania, **the medical system considers that the family of the deceased patient is not entitled to be granted access to the medical record of the latter.**

With respect to this situation, the author of the present paper makes the following statements.

1) Concealing under "medical secret" the truth about the last moments of a patient that should be known to his family represents a profanity act towards the members of the family and a sacrilege towards the Christian morality and humanity in general.

2) Concealing under "medical secret" the scientific truth about a patient that should be known by a member of the family who is himself a scientist represents diminution of the researcher's statute, despise towards fellowship between researchers and interdisciplinary spirit, and self-positioning of the medical system above the rigorous behavior and principles entailed by science and truth.

3) If the medical care has been provided with good will, there is no reason of keeping secrets towards the members of the late patient's family. Who is not feeling guilty has no reason to hide.

What are doing in this situation the patients in Romania? Are they organizing in associations for the purpose of defending their rights, as are doing the patients in France or Switzerland?

No. The civilian society of Romania does not fight for the patient's rights and the medical system does tolerate such a dispute not even theoretically. The latter can be seen from a paper terrifying from one end to the other, written by the professor of forensic medicine George Cristian Curcă [3].

Outside the medical unit, the discharged patients or their representatives are free to act as they wish, but without bringing prejudice to the reputation of the hospital or of the doctor and without bringing the latter into a state of

disciplinary responsibility. The doctor is obliged to alert himself in case of such events and *to forbid the access of the mass media to information.*

Please notice carefully: a professional of the law advises deliberately in favor of restricting the free access to information.

By definition, the role of an association for the defense of patient's rights is to protect the latter by the moment when the civilian society estimates that his rights have been violated, which logically entails an opposition between patient and civilian society on one side and the medical unit on the other, an opposition following which the medical unit might face the possibility of seeing its reputation diminished.

But the author of the paper does not tolerate any situation when the reputation of a medical unit or personnel could be diminished following a confrontation with the civilian society. We are supposed to understand that patients are not permitted to express any critical position in mass media regarding the medical system, so that the associations for the defense of patient's rights are left with no other role but to cherish the medical units and their personnel.

Logically, the author of [3] is concerned only about what happens *outside* of the medical unit (where we are still free "to act as we wish", for which we should be grateful), since for what happens *inside*, the medical unit takes care itself. Medicine disposes of enough means for "re-orienting" any critical thoughts of a patient.

Is this symptomatic for a "white army" that has separated from the civilian society, considering itself above the latter and beyond any criticism?

Would we live to see patients "lifted up" from the street because they had the foolishness to express a critical viewpoint towards the white army in public, in the same way it happened with those who were criticizing the communist system?

Would we live to see journalists arrested by doctors-policemen?

Romania is the country of all possibilities.

The ethical argument

The law of the state Arizona emphasizes a principle with distinguished ethical value.

The law formally admits the existence of objective situations when the degree of involvement of the persons close to the patient, who willingly or forced by circumstances are participating to the act of care taking, might exceed the level of passive execution of instructions given by the medical personnel and reach the level of decision making (a typical example being the informed and responsible choice of a medical center or expert, a decision that in many situations is essential for the future of the patient). The law acknowledges that the persons that assumed the responsibility of such important decisions, being many times as influential for the patient as are the decisions taken by medical experts, are thereby as entitled as are the medical experts to be given the access to the patient's medical record.

One could then logically ask: those states that do not recognize the family's access right to the medical record of the deceased patient, are thereby negating the concept of "health care decision maker"? Do those states consider that there is not transfer of responsibility from the interior of the circle of medical personnel to the persons that are close to the patient but outside of the medical circle? Do they consider that the *entire* responsibility for the treatment can be exclusively assumed by the medical personnel? Do they dispose of a medical system effective to such degree that they can afford to take over the *entire* responsibility for the treatment, the patient's family being left with no responsibility of a major decision?

Maybe. I do not dispose of enough information to find the answer. What I know is that in Romania the situation is for sure not like that. In Romania, the difficulties that confront the medical system lead many times the patient's family into the situation of assuming tough responsibilities. And if the case evolves to an unhappy ending, the family is not granted the access to the patient's record from where they could understand what really happened, while the medical system is not bothered at all by the thought that the family would bear the burden of doubts and guilt forever.

This could be also seen from the record of the case in my family that I shall cover briefly in the following, so that one should understand why we are considering ourselves as entitled to continue our protest and our fight for the rights of the patient's family in Romania.

The patient has been hospitalized for the first 17 days of December 2002, during which he was almost all the time in a lethargic state, a consequence of the diminished cardiac output, for which reason he was also diagnosed with "lacunary syndrome" among many other bad things, the medical personnel letting

us understand in this way that they cannot do much for him as the nervous system seemed also affected in their opinion.

It is the right place to bring here an homage to my mother, Doctor in Medicine Valentina Vuza, who has endured heroically night after night on a chair near the patient's bed, in order to protect him from the indifference and the wickedness of the medium medical personnel, too less available for helping the patient but much more inclined to throw ugly words to the three of us, proving thus not only their lack of any elementary respect for the patient's gray hair, but also their professional incapacity of understanding the gravity of his condition.

We were told that the patient's discharging is mandatory following some regulation that limited the hospitalization period for some categories of people. The patient has been sent home with the recommendation to follow a complex and controversial treatment (Digoxin, Spironolactone, an ACE inhibitor).

Both the proponents and the opponents of this treatment agree on one point, that it must be followed under strict monitoring.

H. Schepkens et al., [12]

A combination of ACE inhibitors and spironolactone should be considered with caution and *monitored closely* in patients with renal insufficiency, diabetes, *older age*, worsening heart failure, a risk for dehydration, and in combination with other medications that may cause hyperkalemia.

We, the patient's family, have seen ourselves at once invested with the quality of "health care decision maker" and with a huge responsibility on our shoulders, without even realizing that and without having someone to make it clear to us at the right moment. It is ourselves who administered the treatment during 6 weeks, instead of the medical personnel who would normally had to do that, and this during a difficult period, when we were completely alone, people around us being concerned with how to spend the holidays, not how to care about the suffering of a family. If a drug intoxication that I have reasons to suspect, until truth is found, had indeed occurred, it means that we have ourselves contributed to it without being aware.

Just a little before discharging, I was told that a new medicine was tried on the patient. Obviously without telling what medicine. Medical secret.

The lethargic state continued at home, without signs of visible improvement.

But in the third day a miracle happened. The patient waked up in the morning with a clear state of mind, in the same way as we used to know him. There was no trace left of the doctors' "lacunary syndrome". Strangely, the patient did not remember he went through difficult moments and he was hospitalized. He would not believe he suffered a serious disease; we had to persuade him. "This means that I resurrected" were his words.

The process of improvement continued slowly, the patient even reaching the point where he was willing and able to make a short walk on the street. Until the day when, disturbed by the endless arrhythmia caused by the atrial fibrillation of which he never suffered so far, he expressed his wish to resume the previous treatment with beta-blockers that he followed during 18 years after he had an infarction, this treatment having been suspended on the occasion of the recent hospitalization. Myself I have opposed this wish as strong as I could. The doctor in charge has been informed and she advised a minimum dose, mostly with the purpose of not upsetting the patient. One should understand that we are talking not about any patient, but about one with an uncommon personality. Attorney George Pavel Vuza did not hesitate to oppose himself to the abuses of the communist system, saving the life and the liberty of many unjustly accused people. One needs a strong will and courage for this, and such a will cannot be easily contradicted.

Therefore the patient made the attempt he wished; we have ensured ourselves that he took a minimal dose, as we have been advised. However, the consequences were unexpectedly serious: a bradycardia occurred followed by the lost of the strength that he had so hardly recovered. This is quite mysterious insomuch as many recent papers recommend the association of beta-blockers to the treatment of heart failure.

Hard weeks have followed, the patient loosing more and more his strengths and us loosing the hopes.

I insisted that the patient is seen by a doctor but he refused and it was not wise to contradict him. In our position of "health care decision maker", we were feeling the hardship of weighing the odds of keeping

the patient home, where he disposed of our care but he lacked medical care, against of submitting him to a new hospitalization, however exposing him to the harshness of the medium medical personnel and to the wickedness of those who are not willing to help.

In the end, as his condition became more serious with the addition of nervous symptoms with dramatic manifestations, I have assumed the responsibility of preparing a new hospitalization in a unit that disposed of the means of tomographic neurological examination.

But in the last but one evening of January 2003, some additional respiratory symptoms occurring and ourselves arriving at the bottom of strengths after countless night watch, we had the bad inspiration to call a private ambulance service, only with the purpose to help the patient with an oxygen recipient. Not a single moment it crossed through our minds that the end could be not far.

It is the right place to express here criticisms to the medical system of Romania, by whose “care” it proved to be not possible to dispose of an oxygen recipient permanently at home (according to the information that we were offered, such a device was available at a certain price per hour and with the mandatory presence of an assistant, for ourselves being possible to support neither the prohibitive price nor the presence of the stranger in our house); whereas in France, for instance, I had the opportunity to see myself the existence of centers that rent such devices for home usage.

Regrettably, the employee who took the call did not understand that we ask for an oxygen recipient, hence the ambulance arrived without this equipment. Because of this and of other considerations that were not clarified to us, the doctor decided as mandatory the hospitalization in an emergency unit that he chose. I opposed to this choice, suggesting the alternatives of the medical unit where I had already prepared the hospitalization and that of the unit where the patient was previously hospitalized and where his case was known. The doctor rejected both alternatives. He offered us the possibility of signing a paper by which we were declaring that the hospitalization was refused by the family. My mother, already exhausted, could not even understand what means such a declaration and refused to sign. Myself I have also refused, sincerely thinking that maybe the doctors from the unit where the patient was to be taken against our will could help him to get well over the night, and not in the least imagining they would push him into the eternal night. In fact, when my parent and myself we arrived at the medical unit, I stated precisely that we wish the patient to be helped to get over the night so that we can take him the next day to the unit where I have prepared his hospitalization.

And, after that, the story continues as in the “paradigm”. Screams were heard and frightening scenes were seen across the “doors” of the maximal emergency department that did not even have doors, so that we can see, hear and remember without having the right to ask. At only half an hour from hospitalization one could hear the patient’s distressed vocalizations, after which I have seen how he was transported in a state of unconsciousness, which never happened to him as long as he was with us at home. Ten hours later he passed away. Apparently in heavy torments, being “extremely agitated” as it was written with microscopic characters in the medical record that I was allowed to look at for a short time.

Until truth would be discovered, our minds will bear the burden of these obsessive questions.

Had the mysterious medicine whose name lies locked under the medical secret played any role in the patient’s miraculous recovery in the third day after his return at home?

If so, would have it been benefic for the patient to take another dose?

Was indeed the patient’s attempt to resume a previous treatment determinant for stopping and reverting the recovery process?

Had indeed a drug intoxication with hyperkalemia occurred, a fact suggested by the abnormally high potassium level inscribed in the patient’s last 10 hours medical record?

Was it malefic our hesitation to sign the paper by which we were refusing the hospitalization?

What had determined the state of unconsciousness shortly after the hospitalization?

Would the patient have had a better fate in another medical unit or maybe even at home? Would him have ended his days in higher gentleness, peace and dignity in another place?

And, again until truth would be discovered, the family keeps the doubt that, in the whirling torrent of events of the patient’s last night, still left unclarified up present, his life was shortened because one had applied a typical treatment to an atypical situation, his case not being known in advance for being thoroughly analyzed. As I was writing in the Introduction, medicine bases its methods largely on statistics. Unfortunately for them, not all patients are enough “reasonable” to match the typical case revealed by statistics.

The record of the case ends here. But here starts another record, that of the author's confrontations with the medical secret and system. After the tragic event, whose details are still kept secret for the members of the family, I had to go together with a relative at the establishment of the state medical unit for transportation of the patient's lifeless body. It is there that an employee allowed myself to have a short look into the patient's record, after which he asserted in front of witnesses that I could get a copy of the record by registering a written demand. The assertion has been contradicted one month later by the employees of the registration service, who rejected my demand under the motivation that only the juridical institutions are entitled to require the access to the mentioned document. It is true that by the moment when this happened, the law 46/2003 did not exist yet, but nevertheless I have shown that even this law did not bring any clarification in the problem considered here. Besides, the memoirs sent to the state institutions after the publication of this law remained unanswered.

And here is the circumstance that started my endeavor of looking behind the medical secret.

While at the state medical unit, I have remarked two ecchymoses on the patient's lifeless face. The first thought raised by this finding was related to a refined and efficient "calming" method, a doubt also supported by the mention "extremely agitated patient" in the record. After all, it would have been neither the first nor the last manifestation of violence of the medical system; such a sample can be found even in the first issue of *Medica* that records a patient's testimony at page 10.

I have tried to get up from the examination table and he hit me.

But my memory also remembered the image of a page from the medical record that retained my attention because of the cryptic inscription "BiPAP". After long searches I found documents about the devices for respiration support "Bilevel Positive Airway Pressure"; from a picture with such a device I deduced that the ecchymoses on the patient's face *might have been* caused by the elastic straps of the mask. The truth, obviously, has been buried together with the patient.

A question for the supporters of the "secret": what memories would I have kept of this if I had not been allowed to see the medical record for a minute and the mention "BiPAP", written with almost illegible characters according to the doctors' good habits, did not strike my attention?

Distinguished medical experts, if you raise the barrier of medical secret between us and the truth, then: do not throw on our shoulders the burden of a complex and risky treatment because you have limited the hospitalization period in a state medical unit; do not oblige my mother to watch during nights on a chair near the patient's bed for compensating for what the medium medical personnel was supposed but not willing to do and for protecting him of the harshness of the latter; do not deprive ourselves of the right to dispose of an oxygen recipient at home; do not require myself to do detective work for clarifying the origin of the suspect traces on the patient's face; do not put on my consciousness the burden of the doubt whether I did well when I agreed with the transportation to that medical unit.

But, if for various reasons, some of them objective for which we have understanding, you cannot accomplish all of the above, then, distinguished medical experts, **it is moral and ethical that, in the same way as we have shared with you the responsibility and the worries of the treatment, in your turn you share with us the right of access to the patient's medical record!** It is neither moral, nor ethical that you sleep in peace, being reassured from the medical record that you had done all what could be done, while ourselves we have the sleep troubled by the questions that find no answer because it is you who have decided they should not have an answer.

From an ethical viewpoint, I consider as highly worthwhile the fact that, in the French law, "défendre la mémoire du défunt" is inscribed in the first ranks among the reasons that justify the family's access to the medical record of the deceased patient. I have not remarked in the Romanian laws, in the comments upon laws or in the expressions of attitude, such a connection between a matter of honor and a document of medical character. Instead, I have remarked, by the sad experience of my family, the tendency of some medical personnel to act hasty and irresponsibly, with negative impact on the defunct patient's memory. I cannot overlook the carelessness with which some medical personnel applied the label (that cannot be called "diagnostic") of *senile dementia* exactly where not appropriate and to the person that did not deserve it. Attorney George Pavel Vuza exposed his career and his liberty to the danger by taking the defense of political prisoners and of the victims of the abuses of the communist system. Many have recovered, with his aid, their threatened liberty, but he paid with his health for the uninterrupted state of stress caused by these

actions obviously in opposition with the intentions of the “party”. Being obliged to interrupt his career because of an infarct, he continued, **until his last days**, to help with expert advice and with good deeds. Which does hardly correspond to the description of the mentioned degenerative disease. Instead of benefiting of the honor due to a hero of the nation, he ended his life treated as a “senile dement”.

It is a shame for a nation to not respect its heroes.

The bioethical argument

The medical record of the deceased patient may contain data that are significant for those family members that are tied to the patient via heredity. The solution that this record is analyzed by an expert that would communicate only his conclusions to the interested relatives is not always safe enough. After all, the expert does not have a personal interest in this matter, it is not his person that could be affected by the hereditary heritage, hence it is not unexpected that his analysis could overlook something. The proponents of the medical secret could argue, “let the son request the analysis of the parent’s medical record by the family doctor who will decide whether a hereditary influence is possible”. Some people would comply and do so, on their own risk. But can someone convince me that a doctor, especially an overloaded one, has the patience and availability to do a thorough analysis on something as volatile as an hypothesis, that concerns someone who is not even in the position of a patient? Would not he overlook a detail that could manifest itself after years? Who would then assume the responsibility? (Obviously not the medical system). The patient’s relative, if genuinely interested and informed, knowing the whole family and his own history, would be able to establish a connection between personal events and facts from the medical record that could very well be skipped by a doctor’s analysis which after all is not too much interested in a problem that does not affect him personally.

An additional argument is that, after a number of years, the scientific progress could allow the extraction of additional meanings from the data in the medical record, having significant value for the people directly interested, in a qualitatively new way that was not available by the time that immediately followed the patient’s demise. But, in the situation when the interested relatives continue to be deprived of the right of access to the patient’s medical record and that record continues to be stored by the medical unit where the patient was hospitalized, it is very possible that exactly at the moment when the data from the record would be again needed, that record had been considered old document and destroyed. Unlike other countries where this matter is explicitly considered by the laws that regulate the access to the medical record (in favor or not to the civilian society), I could not find from the laws of the Romanian state if there is a minimal period for keeping the medical records or if maybe this issue is left at the will of every particular medical unit.

Who would then be found responsible in the situation that the record data, interpreted in the light of new scientific facts, would have helped the deceased patient’s descendants by counteracting some negative influences of heredity, but this was not possible since the record has been destroyed meanwhile?

I consider therefore that, from a bioethical viewpoint, it is fair that the deceased patient’s record should be handed to the relatives that are directly tied to him via heredity, so that the record could be analyzed and re-analyzed at any time, either directly by the interested people if they are competent to do it, or with the help of an expert chosen by the interested people.

The viewpoint expressed here is not just a personal opinion of the author. In other countries such as Hungary, this is not merely a “viewpoint” but a legal reinforcement, as one can see in [1].

[1], Section 24 – *The Right to Become Acquainted With the Medical Record*

(9) During a patient’s lifetime, or following his death, the spouse, a lineal kin, a sibling or common law spouse shall have the right to become acquainted with the health care data, upon written request, if

a) such health data is required in order to

aa) identify a reason that might influence the life or health of the spouse, a lineal kin, a sibling or common law spouse (...).

The philosophical argument

The medical secret, with its meaning of a barrier between truth and the patient’s family, appears to be not only against the right of free access to information, but also against a fundamental cognitive ideal of humanity.

Christoph Schiller writes in *Motion Mountain* [13], ch. *The Brain, Language And The Human Condition*, p. 693:

The choice of moving away from the tremendum towards the fascinans stems from an innate desire, most obvious in children, to reduce uncertainty and fear. This drive is the father of all adventures. It has a well-known parallel in ancient Greece, where the first men studying observations, such as Epicurus, stated explicitly that their aim was *to free people from unnecessary fear by deepening knowledge and transforming people from frightened passive victims into fascinated, active and responsible beings.*

The family who has suffered a human loss is a victim. The sole rational comfort, in the spirit of human dignity that the family can find is trying to understand the deep and hidden reasons of the unhappy event. If there was a disease, then trying to understand the disease itself. If some element adverse to us defeated ourselves in the realm of facts, human dignity requires us not to let us be defeated in the realm of reason.

The medical secret opposes itself to this aspiration in a fundamental way. It assumes the implicit premise that the members of the deceased patient's family are some kind of retarded people that are supposed to leave at least a part of their subsequent lives in darkness and fear, in the position of "passive victims".

Where the light of knowledge does not penetrate, there superstition and fear are at their ease.

Thus, the lost suffered by the family should be felt as total and devastating, enhanced and approved in some sense by the medical system and his secret who "took over" the life of the patient, generating in the family members' souls the terrifying feeling that the masters over our lives and bodies are not ourselves, but those ones. The perspective that sometime they could be treated under the seal of the same secret as the patient that has just deceased fills the souls of the still alive people with the fright of the moment and the uncertainty of the future.

The medical systems load thus the members of the civilian society with a fear generating psychological pressure.

„And fear is the basis of all unjust authorities”, concludes Christoph Schiller.

One knows how much evil social Darwinism brought to the world – two conflagrations and the establishment of totalitarian systems.

Gertrude Himmelfarb – Darwin and the Darwinian Revolution [7]

... it was a short step to the preservation of favored individuals, classes, a nations – and from their preservation to their glorification. Social Darwinism has often been understood in this sense: as a philosophy exalting competition, power, and violence over convention, ethics, and religion. Thus it has become a portmanteau of nationalism, imperialism, militarism, and dictatorship, or the cults of the hero, the superman, and the master race.

Starting from the mechanical and exalted application of the concepts "the struggle for existence", "the natural selection" and "the survival of the fittest", social Darwinism has spread the domination of the few over the many, maintained via the elaboration and application of the model of an individual deprived of personality, equalized and educated in order that he obediently integrate himself into the social group that was indicated to him and he fulfills without opposition the tasks he was assigned.

The medical systems of the totalitarian states were conceived in such a way to actively contribute to the application of "natural selection", especially by eliminating the individuals politically undesirable.

Obviously in such circumstances, the medical secret was held in great honor. The truth was always hated by totalitarian states.

The totalitarian state does not approve of that unique communion between the one who departed and those who stayed, which would occur if the people who stayed would be granted the truth about the last moments of the one who departed. That state cannot tolerate anything that could suggest to the individual the idea that his true origins are of divine and not animal nature, as the system would want to convince him. The members of the family should not spend time with meditations about the eternal land. The ties between the one who passed away and his family should be severed without delay, the patient must be buried the soonest possible under the medical secret, so that the family would forget him and quickly resume their assigned places and duties as tiny wheels with no rights or souls in the gear of the social mechanism.

From this point of view, the barrier between the patient and his family raised by the medical secret appears as an anachronistic remnant of the practices of totalitarian kind, incompatible with the Human Rights and with democratic ideals.

Unfortunately, such a mentality still persists in the conception of both the medical system of Romania as well as of "good willing people" who recommend to me "Forget all what has happened".

Nicolae Iorga
That who forgets, does not deserve.

“But the other states of the Western Europe, where the barrier of the medical secret is still interposing itself between the deceased patient and his family? Were they too under the influence of social Darwinism?” would ask me my opponents.

Maybe. It is certain that there are large differences between the culture and the conceptions of countries, therefore without being myself there I cannot give any answer. The expert with whom I have discussed the problem of the claim of the access at the medical record of my parent, at the WHO headquarters in Geneva, has told me in conclusion: “The doctors in Romania of course admire your endeavors of understanding the case of your parent from a scientific viewpoint”. It is in this way that matters are seen from the cultural perspective of an inhabitant of a Western country. In Romania, however, the medical system respond with an offended silence to these endeavors which, from his viewpoint, are equated to a bad deed, contrary to the law.

I only know this, I had the double infortune to be born in Romania. Double, since first of all, many years of my existence have been wasted under the bestially domination of the communist system. Some people had a good time during those years and have an even better time in the present; I definitely was not among those. The communist heritage is still weighing heavy in Romania, the hierarchy of merits is upside down, the scientists, more exactly that part of them who did not leave the country, are neither encouraged nor respected by the society. Myself I was pushed into developing my activity exclusively in the benefit of foreigners, as in my country no one is interested into what I am working. Not even when I have asserted my voluntary willingness for initiating a humanitarian action in the favor of the patients deprived of continuous monitoring facility, my parent being one of them.

And second, because, even liberated from the domination of communism, Romania continues to lie under the domination of the medical secret. If I had been born in a Western country, I would have waged there the fight against the medical secret. But I would maybe had the satisfaction that my professional activity is better appreciated and supported.

Instead of conclusions

I do not expect that all of you agree with the opinions I have exposed here.

Likewise I realize that the right of free access to information would triumph over the medical secret in Romania not because of me, if this would ever happen.

The already mentioned WHO expert suggested me to organize an association that would fight for the defense of the patient’s rights. But I have neither the talent of a leader, nor that of an organizer. I am just a scientist who only wants to see in peace about his activities. The medical secret does not bring the peace. “Opposer un secret médical ne fait que générer des souffrances inutiles”, says the lawyer from Switzerland.

And moreover, I would not find those to join me in the mentioned association. A poll quoted by professor V. Astarastoae shows that the Romanian patient is fully satisfied with the medical system, so that he has no reason to fight.

Would some of you consider that these opinions are too “strong”? I am not alone, there are other people who share my convictions. A professor from Germany, known in Europe not only as a computer science expert but also as a militant for the patient’s rights, has written in the answer to the letter that I have sent to him: “Obviously I have very strong views in support of access to information both public documents but also private information, e. g. patient files. A patient must have (while alive) the possibility to give relatives permission to access and **relatives must have access after his/her death without permission of the patient**”.

Distinguished readers, in case that some of you and the medical system of Romania would still disagree with my opinions and would continue to be against the access right of the family to the deceased patient’s medical record, it means that you implicitly disagree not only with me, but also with the professor from Germany, with the lawyer from Switzerland and with all forces of the progress that in this moment fight all over the world for the defense of this human right.

George Bernard Shaw

The reasonable man adapts himself to the world; the unreasonable one persists to adapt the world to himself. Therefore all progress depends on the unreasonable man.

Completed today, 29 June 2006, on the holiday of Saints Peter and Paul.

Dedicated to the memory of my parent, George Pavel Vuza.

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