

Romania and the Rights of the Patient's Family – a not European Behavior

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By virtue of Romanian law 46/2003 of “patient’s rights”, the family’s right to access the medical record of the deceased patient is restricted being conditioned by the existence of an “explicit consent” from the patient. The families of those patients who could not express the required consent because of objective reasons such as loss of consciousness or poor mental status, are subject to the discrimination of being denied the access to the medical record. At the same time, the ambiguous and non-professional way in which the law is expressed, without any specification of the means for obtaining and validating the consent, provides the legal cover and encourages the medical units to abusively deny the family’s access to the medical record, by invoking the absence of the named consent. All these are happening simultaneously with the movement in Europe in favor of promotion of the rights of patients and of their families, while in countries such as Slovakia and Hungary, the family’s right of accessing the medical record of the deceased patient is guaranteed by law.

The author’s family is, quite probably, the first victim in Romania of the abuse introduced by law 46/2003. Under the cover of the law, the management of Emergency Hospital Floreasca denies us since eight years the access to the medical record that contains the truth about the last moments of my parent George Pavel Vuza, whose demise happened at the premises of the named medical unit in conditions not clarified up to present.

Below I list in chronological order the demarches I undertook in relation with the state institutions since the beginning of 2003 up to present and which did not improve in any way the situation, the Romanian state maintaining its unshakeable position of infringing a legitimate right of my family.

- Memoir submitted to the Ministry of Health in 10 February 2003 and recorded under number 4629.
- Memoir sent by regular mail to the President of Romania in June 2003.
- Memoir sent by regular mail to the President of Romania in September 2003.
- Memoir submitted to the Vice-president of Romanian Academy in 1 March 2004.
- Memoir submitted to the Romanian Academy in 16 March 2005 and recorded under number 977.
- Memoir submitted to the Juridical Department of the Ministry of Health in 12 June 2007 and recorded under number 36309.
- Request for access to the medical record of my deceased parent submitted to the Juridical Office of Hospital Floreasca in 6 September 2007 and recorded under number 25275.
- Memoir submitted to the President of the Romanian Academy in October 2008.
- Start of the trial with Hospital Floreasca at the Court of Sector 1 Bucharest in May 2009, presently still ongoing.
- The submission to the Constitutional Court of Romania of the exception of non-constitutionality concerning articles 21 and 22 of law 46/2003 in November 2009, solved in the negative after a one-year delay, in November 2010.

The negative answers (or the lack of any answer, as the case may be) to the above demarches proved that all possibilities of constructive dialog with the Romanian state have been exhausted, the only alternative left being the court trial. But even there the hopes are weak, considering how the Constitutional Court found as appropriate to solve the request of exception. In a strange way, both Hospital Floreasca in the documents forwarded to the court during the trial, and the Constitutional Court in the rejection decision, came with the same argument devoid of logic or reason, seemingly dictated from behind the same closed doors. The argument pretends that the family’s access to the medical record is refused in the name of the respect of the patient’s “right to private life” and of the options he made during his lifetime, being considered in an arbitrary way that the lack of an “explicit” consent is automatically equivalent to the patient’s “implicit” option that his family should not have access to his medical record.

In order to provide a pseudo-substantiation to this argument, one invokes art. 26 of the Romanian Constitution that guarantees the right to private life.

That such a substantiation is a false one is seen from the fact that the proponents of the argument are willingly distorting the content of the mentioned article from the Constitution, which states *equal respect* for private life as well as for family life. A short discussion to be now undertaken will show that the abuse under consideration represents a multiple-form violation of the peace of family life. By acknowledging this abuse, the Constitutional Court proves that it breaks itself the very Constitution that it is supposed to defend.

No one has the right to assume that, in the absence of an explicit directive from his part, the patient's implicit option would be that the members of his family should be denied the access to his medical record. To do so amounts to assuming that the natural state of the family is division and not unity, while the mutual relations between its members are based on suspicion and secret, certainly not on communion and mutual help. But then the family concept itself has no longer any sense and art. 26 of the Constitution that refers to the protection of family life has no longer a subject.

There were many cases with patients for which the care was provided for a long time by their families. It is absurd to assume that the patient would oppose "implicitly" to the access of his own family to his medical record, since without such an access the family would not have been able to provide him with the adequate care. It is immoral to assume that, as soon as he passed the doors of the medical unit, the patient would have entered a "private space", forsaking his family that supported him up to that moment. By being denied the right to access the medical record, the family members would be for the rest of their lives haunted by suspicions, uncertainties or guilt feelings, being unable to ensure themselves whether the medical unit did everything humanly possible and to get rid of the guilty thoughts that themselves might have done wrong during administration of treatments followed at home. In other words, the deceased patient's family is not given the possibility to separate in peace from the loved one who is gone forever. This represents *a psychological oppression and a moral prejudice brought in a barbarian and cruel way to the family already affected by tragedy*. The peace of family life is a right guaranteed by Constitution and no one has the right to infringe it in the name of a so-called respect of a private space which in fact does not exist and was invented for the interests of the medical system.

Such a case was found in my family. It is ourselves, the family, who undertook on our shoulders the responsibility of administration of a controversial treatment because they, the system, have discharged the patient earlier than was due after the first admission to hospital caused by worsening of the disease of which he suffered since 18 years. Therefore all evolution to the tragic final took place before our eyes and it is ourselves who witnessed the devastating side effects of that treatment. And now the system requires me to believe that the one which whom we were together for a life-time would have rejected his family during the last ten hours of his life consumed in a medical facility!

Not having access to the information in the medical record, the families of deceased patients cannot decide whether one could raise the question of treatment errors and if the case would be to request an investigation. Conversely, the unrestricted access, guaranteed by law, would represent for the family the moral guarantee that the medical unit would commit to acting with full responsibility. *To deprive the family members of such guarantee and to force on them the thought that, by the virtue of the law itself, the medical unit has the potential right to hide any possible misconduct, is again an infringement of the rights and legitimate interests of the family.*

It occurs to me as strange, unfair and disturbing the fact that for the family's access to the medical record the state requires the patient's "explicit consent", whereas for the removal of organs from deceased patients, the state intends to apply the presumed consent. Such a combination could generate not only suspicions but also macabre real facts: a requirements for organs could be satisfied by "facilitating" the leave of the world for an unconscious patient since, being unable to express any kind of consent, for organ removal the presumed consent was applied and the family could never learn what happened in the absence of the explicit consent.

The information in the medical record may contain aspects of vital interest for the close relatives of the defunct, as they might refer to a genetically transmissible condition. Let us assume that the unforeseen reaction to a treatment has also contributed to the demise. It is then logical to consider that the relatives potentially influenced by heredity would have to exercise caution if in situation to follow the same treatment. It is therefore legitimate that such relatives be fully informed. The only fair way of

fulfilling this condition is to grant the unrestricted and direct access to the medical record for the entitled persons, in order that they can estimate themselves whether the information might signal a threatening condition for their life. No one has the right to conceal information of vital interest for someone's life, but exactly such a condemnable act is legalized by law 46/2003 and approved by the Romanian state and the Constitutional Court.

The Declaration for the Promotion of Patient's Rights in Europe issued by the World Health Organization (WHO) in 1984 recognizes the patient's right to access the whole content of his own medical record, including the technical data; and, for patients unable to exercise their rights which include the deceased patient, it states the right to delegate to the entitled persons the exercise of those rights. In the spirit of the WHO Declaration, the laws of Slovakia and Hungary *guarantee the access right of the families to the whole content of the deceased patients' medical records, without imposing any restriction related to an "explicit consent"*. Slovakia and Hungary go together with Europe; Romania still goes in the opposite.

In the rejection decision, the Constitutional Court argued that the Romanian state is free from the obligation to comply with the WHO Declaration as Romania has not ratified this act. The decision also records how the state institutions which were required, according to the procedure, to communicate a point of view on the raised legal exception, have agreed to the continuation of this abuse, either explicitly in written form as the Ombudsman did, or implicitly by the lack of any expression of point of view, as was the case with the Prime Minister and the Presidents of the Chambers.

I consider that the decision of rejection of the exception of unconstitutionality to art. 21 and 22 of Law 46/2003 is a historical document, by which the elected and appointed institutions of the Romanian state, namely the Parliament, the Constitutional Court, the Government, the Ombudsman, express in unison their intention *to not apply the transparency policy on Romanian territory in the relationship between the citizen and the state medical system promoted by the WHO Declaration and to not follow the example of countries such as Slovakia and Hungary that have adopted this policy at the state level*.

It is to be observed that the Romanian medical system forbids not only the access of the family to the deceased patient's medical record, but also the access of the patient itself to his own medical record. In the refusal of the request made by the author as well as in the documents forwarded to the court during the trial, the management of Hospital Floreasca strongly asserted with great conviction that the patient is given only a resume of his record and certainly not copies of the whole record. In this way not only the patient's human rights are infringed, but the very text of law 46/2003 whose art. 24 states "The patient has access to his personal medical data". The tricky Romanian state may reply that no law is infringed since art. 24 does not make any reference to any medical record, but only to "personal medical data". Indeed, such an ambiguous interpretation is possible because during the parliament debates on the law, the term medical record that was present in the initial draft was eliminated and replaced with those "personal medical data" about which no one tells what they refer to. In any case they do not refer to the medical record in the conception of the management of Hospital Floreasca. The Romanian medical system fears so much the truth that could be found by families in the medical record that they took care that even the term designating the feared object does not appear anywhere in the text of the law. If by this intentional ambiguity they succeeded to render debatable the matter whether any Romanian law is infringed by denying the patient's access to his own medical record, it is however beyond doubt that *Romania infringes one of the statements of the Charter of Fundamental Rights of the European Union: "Everyone has the right of access to data which has been collected concerning him or her"*.

It is amazing to see how proud is Romania of the fact that the rights of the patients and of their families are violated on its territory.

In the last part I will show how the psychic oppression that the author has to endure since eight years illustrates not only the violation of human rights in Romania, but also the loss of any respect for the person of the scientist, banned by the society away from the center occupied by politicians, TV stars and criminals.

The author is a researcher whose results have been internationally recognized. Among those, the "Vuza canons" are used by composers, studied by music theorists, taught in universities in the U.S. and they also made the subject of an entire issue of *Journal of Mathematics and Music*. It is significant to

place the dedication of the named journal issue – “to Dan Tudor Vuza... for providing a timeless subject around which mathematics and music naturally meet” and the words of musician Tom Johnson – “Only in rare cases like Vuza, Leonhard Euler, and Hugo Riemann have theorists preceded composers”, face to face with the humiliating ways that the Romanian state consider as appropriate for responding to the requests of this researcher – either with silence or with hypocrite pretexts at the periphery of logic about a private space in which the patient would hide for protecting himself from the family’s intrusions that are of course hated by the medical system.

The author considered that in his position of researcher with an academic degree equivalent to full professor, he is entitled to have access to the truth about the last moments of the life of his parent, as were recorded in the medical record. The legitimate wish to learn the scientific truth about a deceased parent is equated in Romania to a bad deed, for which one strikes your hand according to the law. The systematic refuse by the state is emblematic for despising the status of the researcher, of which the state has no longer need. If he would be really needed, the state would not be insensitive to the fact that the activity of this researcher has been disrupted since eight years as the peace of his family has been stolen by the Romanian state via an injustice that amplifies and uselessly prolongs the an already existing suffering due to the loss of a loved one. To generate useless suffering is, as it seems, one of the talents of Romania across its history.

In his request to Hospital Floreasca, the author mentioned that the data in the medical record are needed in order to reconstitute the biography of his parent George Pavel Vuza, in view of the preparation of the volume *Notes of a Prosecutor* left by the defunct, who appeared in the end at the *Vremea Publishing House* of Bucharest, without the information looked for. In order to get it, the author invoked in his requests the article 11 of law 544/2001 concerning the access to data about a public person, but even this argument has been rejected. G.P. Vuza’s career as a magistrate was abruptly terminated by a heart attack suffered in the Christmas day of 1984, when he was obliged to work in his office at the Attorney Department of Bucharest in a temperature of three degrees. Both the immediate cause of the heart attack – the cold established in houses and offices by the dictator’s order, as well as the long term cause – the nervous pressure accumulated over years following the conflicts with the political power provoked by Vuza’s many refuses to obey the political commandments of accusing innocent people – were in fact related to circumstances created by the Romanian state itself. It would have been therefore a moral duty of the Romanian state to grant to the family all information about the evolution and the final of a disease of which the state is, in the end, responsible. By persisting in the refuse of even this minimal reparatory act, the democratic state of today proves itself to be the successor of the communist state of yesterday in the practice of concealing the truth.

George Pavel Vuza, as the first Deputy General Prosecutor of the Republic, held an important role not only in the professional organization on the modern institution of prosecution, being among others the initiator and leader of the Institute of Criminology, but also has repeatedly defended the innocent persecuted by the regime. In this respect, he put his signature on a report that disclosed the abuses in political prisons and on many clemency acts. It is unacceptable and shameful that the memory of such a personality be undermined by the barbaric treatment of the Romanian state and the medical system.

As another significant fact, one mentions here that in the response to the memoir submitted in 2003 to the President of Romania, the presidential counselor Octavian Știreanu has ensured the petitioner that President Iliescu ordered that the memoir be forwarded for solution to presidential counselor on juridical matters Mihai Constantinescu and to the ministry of health Mircea Beuran. Not only that no solution was subsequently received, but in 2009 the very same Mircea Beuran, now as manager of Hospital Floreasca, was the one who signed the documents forwarded to the court by which the medical unit reasserted its unshakeable will to not allow the family’s access to the medical record. This speaks for itself about how the state understands to address the citizens’ demands. The Constitutional Court is one of the most important institutions of the state. The argument concerning the life-threatening danger of not being informed about the hereditary conditions that might be enclosed in the medical record of a deceased relative had found no echo in front of the Constitutional Court. This argument together with other arguments on the line of those above presented was exposed in a memoir submitted to the court. Although it took one year until the court took the case and one month was needed for deciding on the matter, there was no single evidence in the rejection decision that the court discussed at least one single argument of

the memoir! This is how much the quietness and safety of family life matters in Romania, where citizens matter in front of the state more like dispensable items in a herd rather than respectable humans.

A Romanian version of the present document has been sent in June 2011 to member of European Parliament Cristian Preda, substitute member of the Committee of Petitions and of the Subcommittee on Human Rights, and had in copy two others members of the Parliament, namely Monica Macovei, member of Committee on Civil Liberties, Justice and Home Affairs, and Norica Nicolai, substitute member of Committee on Civil Liberties, Justice and Home Affairs. The document has been sent at the official email addresses of the named Parliament members. One request I have addressed to Mr. Preda was that, in case he does not dispose of the means of taking any specific action, to at least inform the European Parliament about the situation of human rights infringement of which I am the subject since eight years. In less than two hours Mr. Preda responded that although impressed by the injustice, he cannot do anything as the case is not of the competence of the European Parliament. Mrs. Macovei did not respond in any way while Mrs. Nicolai deleted the message without reading it. In this situation I have resent the document to Mrs. Nicolai, this time with a special introduction in which I was recalling that the Committee on Civil Liberties, Justice and Home Affairs of which she is a member has among its responsibilities “the protection within the territory of the Union of citizens' rights, human rights and fundamental rights (...), as laid down in the Treaties and in the Charter of Fundamental Rights of the European Union” and I was pointing out to the fact that Romania infringes the Charter of Fundamental Rights of the European Union, as shown previously. There was no answer to that message. I would then ask myself and (rhetorically) ask the above named members of the European Parliament: what for they have been elected by us, the citizens of Romania, if instead of fulfilling their minimal duty of at least informing the committees of which they are members about the citizen’s problems, their understanding of their duty towards the electors is to delete the messages coming from them?

The document has also been sent to Gheorghe Funar, former member of the Romanian Parliament. Also from him there was no answer. In a document that he distributed over the net, Mr. Funar called for the modification of the Romanian Constitution in the sense of mandatory participation of citizens to elections. I would then ask Mr. Funar: why does he consider himself as entitled to oblige ourselves to participate to elections, when after elections the members of the parliament, including himself, do not consider themselves as obliged to listen to the elector’s problems and there is no law to oblige them to do so if they have not the moral sense to do it willingly?

Who are those who have today in Romania an interest to hide the truth that the family has a legitimate right to know? The answer can only be one: they are those who want to carve the pattern of a new man, according to these hardened times. A man with a soul of stone not caring if his ancestors are living today and tomorrow they disappear behind the doors of the medical system, or if his childhood village exists today and tomorrow disappears under the wheels of bulldozers, or if his country exists today and tomorrow becomes the subject of transaction between global business leaders. A man supposed to accept the loss without remorse and especially without questions and supposed to be able to wash with the sponge all memories in order to return as soon as possible to the role of tiny wheel that was attributed to him in the social mechanism. They are those who want to cut the links between generations, destroying the family unit and thereby putting in danger the nation. They are those who would kill even the little spirituality left in the exhausted man, namely the care for parents and ancestors. There are those who want to *replace the truth with oblivion*.

Against such people we have the right and the duty to fight.

The present document is intended as a manifest addressed to all progress forces anywhere in the world and as call to support the author’s fight against the tyrannical law that makes possible such abuses (Thomas Jefferson - *Law is often but the tyrant's will, and always so when it violates the rights of the individual*), with the hope that international pressure would determine in the end Romania to follow the example of the European states who adopted the transparency policy in the relation between the medical system and the civil society.

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