

# A CHALLENGE OF THE THIRD MILLENIUM: THE PROTECTION OF PATIENTS' RIGHTS

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**[Abstract]:** The protection of human rights is a comprehensive task of all modern societies. It is the protection of human rights of those who are vulnerable by the very fact that they are patients and who have no, or very low capacity to protect themselves alone. It is an extremely challenging task. Therefore, it is necessary for all contemporary societies to undertake the task. A whole variety of names and concepts used so far have made us **consider the potential roles of patients' ombudsmen, commissioners, advisers, officers ..... or any other alternatives aimed at resolving the same problem. In some countries, ethical committees in hospitals interfere with some of the duties and the responsibilities of the representatives of patients' rights elsewhere.**

Various specific needs concerning the rights of patients when placed in hospitals, or in stationary health care units, challenge our attempts to define the role, duties, obligations, responsibilities and the authority of the representatives of their rights.

With an intention to profit from the positive and negative experiences of various countries, the Recommendations on Patients' Rights Representatives in health care units/hospitals are needed as international guidelines for addressing the problem.

The recognition of human rights is an important challenge of 20th century and it is set forth in numerous international acts<sup>1</sup> which have been issued in last century. One important segment of that recognition, the protection of human rights, is a very comprehensive task for all modern societies. The protection of human rights of those who are vulnerable by the very fact that they are patients and who have no, or very low capacity to protect themselves alone, is undoubtedly an extremely challenging and a demanding task.

Contemporary societies are becoming more and more involved in addressing this task. A whole variety of names and concepts used so far have made us consider the potential roles of patients' ombudsmen, disability commissioners, advisers, officers... or any other alternatives aimed at resolving the same problem. In some countries, for example in the Netherlands and in Croatia, Ethical Committees in hospitals had interfered with some of the duties and responsibilities of the representatives of patients' rights.

The development of scientific and practical discipline of health law, as well as the development of bioethics originates from and is closely connected with the protection of patients' rights. Bioethics, health law and sociology have become inseparable scientific disciplines concerned with the protection of these rights. The civil society inputs to the development of the legal framework concerning the protection of human rights have been increasing throughout the world. The development of a new profession dedicated to the representation of patients' rights at different levels, from health care units to government units, have become more and more obvious and needed: not only as an instrument of the protection of patients' rights, but also as an instrument of educating both patients and experts.

We have witnessed a very obvious intention by a variety of experts to establish the basis of a legal framework for the protection of patients' rights and the creation of a document entitled The

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Recommendation of the Council of Europe<sup>ii</sup>, providing for partnership relations among patients and other subjects in health care systems, even when system decisions are at issue. According to this Recommendation, the role of the representatives of patients' rights may become an instrument of establishing partnership relations in the health care system.

In order to introduce efficient patients' rights representatives, the WAML Committee on Patients' Rights Representatives was established in September 2000. During the 16th World Congress on Medical Law in Toulouse in August 2006, around table and a workshop on patients' rights were organized. Very significant were the objections given by the participants from New Zealand, Israel and Finland. For example, Ron Patterson, a Health and Disability Commissioner from NZ, in his abstract *The Education Framework for the Role of Patients' Rights Representatives: Lessons from New Zealand* wrote the following:

*The NZ law stipulates the qualification for appointment of the key patients' rights representative – the Health and Disability Commissioners – as including:.....legal qualification and expertise in health law....non-provider background..*

This indicates the recognition of specific problems connected with the establishment of credibility and an unprecedented impact of the representatives of patients' rights.

The same problem was indicated in an example from Finland stated in the following words:

*If the decision-makers in society and health care administration are not willing to accept educated, competent ombudsmen, the whole system runs the risk of losing its credibility... we have incompetent patient ombudsmen.*

While searching for a model of efficient representatives of patients' rights, we must mention a Model Act from Israel which sets forth the following: *the Israeli patient is not lacking in bodies that can represent and protect his/her interests. And yet, this large area is not sufficiently clear and the multiplicity of "addresses" may in itself cause problems.*

In the aforementioned texts, we can find some indications that the relations in health care system are closer to partnership if the role of patients' rights representatives is as independent as possible.

We can make a point on the global tendencies in the market economy and democratization of all social behaviors and in the health care system, as well.

However, a clash of interests goes *hand in hand* with the market economy and corruption. We therefore think that more should be said about corruption.

Every year, a very well-known organization - *The Transparency International*, develops a Corruption Perceptions Index<sup>iii</sup>, providing information on different countries regarding the corruption issues. We can say that a broader *image of the country* depends on the level of corruption existing in that particular country. In addition, according to most researchers, the perception of corruption is highly dependent on the situation in the health-care sector.

The reasons for corruption in the health sector are connected with various financing problems *but a growing body of evidence show that scale of corruption is vast in both rich and poor countries*<sup>iv</sup>.

There is insufficient literature on political corruption, which result in the corruption in health sector, as well. Since the health sector market is dependent on the legislative framework of that country, it is very obvious that corruption at the political level opens up the market for any product used in the health sector, especially the market for medicaments. Patients are the final consumers in the health sector: the less they know about medicine and the health-care market, the fewer questions they can raise about money spent ON and IN health care system. That is the reason why the patients' rights representatives are not only there to help in the prevention of the violation of human rights, but also to prevent political corruption from happening. It is clear why the development of such institution dedicated to the protection of patients' rights always been obstructed. In other words, such independent representatives of patients' rights would be a *danger* because they would enable partnership relations in the health care system and they would immediately address any issues arising within the sector, even those concerning the market and the money involved. Such an institution would protect not only human rights but would also prevent corruption. This is why the patients' rights protection has become a real CHALLENGE OF THE THIRD MILLENIUM.

Without developing partnership relations aimed at the protection of the human rights, we cannot

solve these problems and the only possible partnership relations for patients can be established by introducing independent representatives of patients' rights.

With an intention to profit from both positive and negative experiences of various countries, the WAML Recommendations on Patients' Rights Representatives in health care units/hospitals are intended to become international guidelines for addressing the problem.

#### RECOMMENDATIONS ON PATIENTS' RIGHTS REPRESENTATIVES (PRR) IN HEALTH CARE UNITS/HOSPITALS:

- 1) The role of PRR in health care units/hospitals is to advise, assist, inform and offer consultation to patients and health care workers regarding patients' rights.
- 2) Free access to medical documentation and a legal obligation to observe the professional secret are the essential prerequisites.
- 3) The patients' rights representatives in health care units/hospitals are preferred to be professionals with multidisciplinary qualifications in health, law, ethics, sociology and psychology.
- 4) The national legal framework should be a precondition for the work of these professionals to ensure their independence from health care institutions, health insurance companies, drug and medical equipment producers and various political entities.
- 5) Members of the civil society sector dealing with human rights must be engaged in the supervision of the work of these professionals.

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i Convention for the Protection of Human Rights and Fundamental Freedoms, UN, 1950

International Covenant on Economics, Social and Cultural Rights, UN, 1966

Convention for the Protection of individuals with regard to Automatic Processing of Personal Data, 1981

Convention of the Rights of the Child, 1989

Declaration on the Promotion of Patients' Rights in Europe, WHO Regional Office for Europe, Amsterdam, 1994

Convention for the Protection of Human Rights and Dignity of the Human being with regard to the Application of Biology and Medicine: Convention on Human Rights and Medicine, Concil of Europe, Oviedo, 1997

ii Recommendation No 5 of the Concil of Europe from February 2000

iii [http://www.transparency.org/policy\\_research/surveys\\_indices/cpi](http://www.transparency.org/policy_research/surveys_indices/cpi)

iv [http://www.transparency.org/index.php/global\\_priorities/other\\_thematic\\_issues/health/](http://www.transparency.org/index.php/global_priorities/other_thematic_issues/health/)