

# Patients' rights in the Republic of Croatia – between the law and reality

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### ABSTRACT

Croatia was the first transition country to emerge after the break-up of the Former Socialist Federal Republic of Yugoslavia, where patients' rights were regulated by law. However, although the legislation on patients' rights was a significant step in drawing closer to international standards of protection of patients' rights, that is, the standards that exist in developed western democracies, legislation alone still does not have a significant effect on the actual position of patients in the Croatian health care system. After an analysis of causes of the gulf between the law and the actual position of patients, the conclusion may still be drawn that the legislation on patients' rights in Croatia was at the beginning of a process, which, by the logic of the development of democracy and civilization, is impossible to stop. This legislation is, however, only one element in the process of protecting and improving patients' rights – as human rights. The second and no less important element in that process is the development of a culture of respect for and protection of human rights in general and the human rights of vulnerable categories of people, and citizens being patients, especially when they are sick, certainly make those vulnerable categories. Alongside the political will shown through legislative and other strategic documents in the field of health and social policies, in order to achieve these goals, information and education on human rights are the key issues, that is, patients' rights at all levels – in general public and at a scientific and professional level.

**Key words:** patients' rights, legislation, information, education

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## INTRODUCTION

The concept of patients' rights, which appeared at the beginning of the 1970's in the western European States (especially Scandinavia) and the USA, has experienced impressive growth in the past three decades. The first phase of the development of this concept, which is covered by "early" research (1), was focused on the theoretical explanation of the patients' rights as part of human rights, but with emphasis on social aspects of health care, where the right to health care is dominant.

The second phase of the development of patients' concept rights was characterized by several trends: a) growth in interest in the issue of patients' rights in the general public, patients or consumers associations, health professionals and politicians and the academic community, as confirmed by numerous articles, studies and monographs (2-4); b) development of new patients' rights (e.g. the protection of personal data in medical databases, the right to a second opinion etc.); c) establishment of international legal standards in the field of the protection and improvement of patients' rights (The Declaration on Promotion of Patients' Rights in Europe, the Ljubljana Charter on Health Care Reform, the Convention on Biomedicine and Human Rights etc.); d) legislation on patients' rights in national frameworks through separate laws (Finland 1992, The Netherlands 1994, Greece, Portugal 1997, Denmark 1998, Belgium and France 2002, etc.), as part of the general laws on health care and legal regulations including special groups of patients; e) monitoring the implementation of the regulations on patients' rights with proposals for improving the position of patients (5,6).

Croatia also joined the trend of legalizing patients' rights in the early 1990's. However, patients' rights, even when they are made law, do not exist in a vacuum (7). Therefore, this study raises a question: has the new legislation over the past decade really improved and strengthened the position of patients in the Croatian health care system?

## PRESENTATION OF LEGISLATION ON PATIENTS' RIGHTS

### **The first legislation – The Health Care Act of 1993 and the Act on the Protection of Persons with Mental Disorders of 1997**

After the Republic of Croatia had become independent from the Socialist Federal Republic of Yugoslavia in 1990, work began on aligning the health care system and health insurance with a new political and economic system of the State. However, although these changes were primarily aimed at organizational and financial aspects of the system in order to rationalize and limit health care expenditure, in the Health Care Act of 1993 (Official Gazette of Republic Croatia, No. 75/93) citizens as patients were already guaranteed a set of rights: the right to accurate information and answers to all questions related to their health, the right to choose between several possible forms of medical procedures, the right to refuse examinations and treatment, including the right to change primary health care doctors in the course of treatment, the right to refuse observation, examinations and treatment by students, the right to refuse to take part in scientific research, the right to refuse surgery and other medical procedures, insofar as they are conscious and able to decide, the right to confidentiality of all data relating to their health, the right to food in line with their views of the world and the right to performance of religious rites during their stay in a health institution.

Furthermore, this Act provided for the right to seek protection of their rights to patients who consider that their rights had been violated, requesting it either directly or in writing from a head of a health institution or a private health worker and these officials were obliged to respond to a complaint without delay and to inform the patient in writing on measures taken not later than three days thereafter. Patients who were not satisfied with the measures taken to protect their rights, could seek their rights from a relevant professional chamber, the Minister of Health, or a competent court. We emphasize that in 2003 a new Health Care Act (Official Gazette of Re-

public Croatia, No. 121/03) was adopted, but its provisions relating to the rights of citizens as patients remained almost identical to the provisions of the Act of 1993 mentioned above.

The trend of legalizing patients' rights in Croatia continued in 1997 with the adoption of the Act on the Protection of Persons with Mental Disorders (APPMD) (Official Gazette of the Republic of Croatia, No. 110/97) which came into force on 1 January 1998. This Act, as *lex specialis* for psychiatric patients, contains provisions which specifically provide for the following: procedures for voluntary and forcible hospitalization and discharge; methods and conditions of treatment and conditions for use of physical force in relation to psychiatric patients; procedures with mental patients taking part in criminal and misdemeanour proceedings and protective mechanisms to ensure the implementation of the provisions prescribed (the foundation of a commission for the protection of mental patients, penalties etc.). Furthermore, by this Act, which meets the highest international legal standards from the United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care of 1991 (8), psychiatric patients are guaranteed the following rights during their time in hospital: to be informed on admission of their rights and obligations, and to be instructed on how they may exercise their rights, as well as the purpose, consequences, benefits and risks of the proposed treatment and other treatment options; to take an active part in planning and implementing their own treatment, recovery and resocialization and be trained for work according to general programs and the program for persons with learning difficulties; to receive the appropriate monetary reward for their work in occupational therapy, if the psychiatric institution makes any income from that kind of work; to file a complaint with the head of the psychiatric institution or department regarding the form of the treatment, diagnostics, discharge from the institution or violations of rights and freedoms; to make demands and make complaints, appeals and other legal remedies to the competent judicial and state bodies without supervision or limita-

tions; to consult a doctor or a lawyer of their own choice at their own expense; to associate with other persons in the psychiatric institution and receive visitors; to send and receive letters, parcels and printed materials and to make telephone calls (at their own expense) without supervision or limitations; to listen to the radio and watch television; to possess items for personal use; to take part as they choose in religious activities within the capabilities of the psychiatric institutions; to propose transfer to another psychiatric institution and to be released from the psychiatric institution with the guarantee of support to be accepted in the community.

For purpose of control, supervision of the implementation of psychiatric treatment and care, but also to receive complaints and comments by psychiatric patients, there is a provision on obligation to establish a commission for protection of persons with mental disorders in every psychiatric institution. This Act also prescribes the obligation of founding a State Commission for Protection of Persons with Mental Disorders within the Ministry of Health, which is obliged to visit every psychiatric institution, unannounced, at least once in six months, to check on the conditions and manner of care and treatment of persons with mental disorders. Unfortunately, in November 1999 the Act on Amendments and Supplements to the APPMD (Official Gazette of the Republic of Croatia, No.128/99), abolished the commissions for protection of persons with mental disorders within psychiatric institutions (which in any case had never been founded in practice, author's note). What happened here and regarding the foundation and work of the State Commission for the Protection of Persons with Mental Disorders will be dealt with in the concluding section of this paper (9).

#### **New Legislation: The Act on the protection of patients' rights of 2004**

In November 2004 the Act on the Protection of Patients' Rights was adopted (Official Gazette of the Republic of Croatia, No. 169/04). The key

reason for its adoption was an alignment of the national health legislation with the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine of 1997 ratified by Croatia in 2003, but also a more detailed application of the provisions of the World Health Organization's Declaration on the Promotion of Patients' Rights in Europe of 1994.

Pressure from non-governmental organizations (NGOs), especially those directly dealing with health issues (10,11), accompanied by media emphasis on frequent violations of patients' rights in the Croatian health care system and society, was also one of the reasons why the adoption of the Act was initiated. This Act guarantees patients the following rights:

1. The right to information: in order to give consent or to refuse a medical procedure every patient must be previously informed about his/her medical condition, recommended examinations and procedures and their schedule, possible benefits and risks of undertaking or not undertaking the recommended examinations and procedures, and also to be informed about their right to decide on the recommended examinations or procedures. The patient is entitled to receive information about his/her condition in a manner that he/she can understand in terms of his/her age, education and mental capacity, from a health worker (doctor) directly offering the specific form of health service. A patient with reduced capacity to decide is also entitled to be informed according to his/her age, or physical, mental and emotional condition. Patients always have the right to seek a professional opinion on their condition. They also have the right to refuse by a written and signed statement to receive information on a nature of their medical condition and the expected outcome and/or medical procedures and measures undertaken, except in cases where they must be aware of the nature of their disease so as not to endanger health of other
2. The right to accept or refuse specific diagnostic and therapeutic procedures: patients have the right to accept or refuse individual diagnostic or therapeutic procedures except in cases of urgent medical intervention where failure to act would endanger the life and health of the patient or cause him/her serious harm. Patients express their acceptance or refusal of individual diagnostic or therapeutic procedures by signing consent forms, or by a statement refusing the recommended procedure. For patients who are unconscious, patients with severe mental disorders, patients who do not have disposing capacity or who are under age, the consent form is signed by patient's legal representative or guardian, except in cases of urgent medical intervention/procedures.
3. The right to protection whilst taking part in clinical trials: the express consent of the informed patient is needed for scientific research on patients and the inclusion of patients in medical teaching, which means written consent, dated and signed by the patient, given on the basis of precise and understandable documented information about the nature, importance, consequences and risks of the test.
4. The right of access to medical documentation: patients have the right to examine their medical documentation relating to diagnostics and treatment of their disease, including the right to copy that documentation at their own cost. In case of the patient's death, insofar as that patient during his/her lifetime did not prohibit this specifically by a statement made before a notary public, the marital or extramarital partner, adult children, parents, adult sister or brother and legal representative or guardian of the patient have the right to examine the medical documentation.

5. The right to confidentiality: patients have the right to confidentiality of data relating to their condition pursuant to the regulations on keeping business secrets and protection of personal data. Furthermore, they have the right to give a verbal or written statement about persons who may be informed of their condition and their admission to hospital, and they also have the right to name persons to whom this information must not be given.
6. The right to privacy: patients have the right to privacy during examinations or treatment, and especially whilst receiving personal care.
7. The right to maintenance of personal contacts: during their stay in hospital, patients have the right to receive visitors according to the House Rules of the health institution and also the right to prohibit visits by a specific person or persons.
8. The right to leave the health institution voluntarily: patients have the right to leave in-patient health institutions voluntarily except in cases prescribed by separate laws and in cases when this would endanger their health, or health and safety of other persons.
9. The right to compensation for damages: patients have the right to compensation for damages pursuant to the prescribed civil obligations laws.

In order to realize and promote patients' rights, according to the provisions of this Act, in every Croatian county a Commission for the Protection of Patients' Rights has been founded (hereinafter: the County Commission, or Commission), whilst on a national level the Commission for the Protection and Promotion of Patients' Rights has been founded within the Ministry of Health (hereinafter: the Ministry of Health Commission).

The County Commission, which has five members who are patients' representatives, NGOs and experts in the field of the protection of patients' rights, performs the following tasks: monitors violations of individual patients' rights

and proposes measures to protect and promote patients' rights in the area of the county, informs the Ministry of Health Commission of cases of serious violations of patients' rights and submits annual reports on its work to the County Assembly. The procedure to protect patients' rights begins with a complaint by a patient who considers that one of his/her rights established by this Act has been violated. Patients may express their complaint verbally or in writing through the head of the health institution offering a specific health service. If the head of the health institution does not inform the patient within eight days of the measures taken regarding the complaint, or if the patient is not satisfied with the measures taken, he/she has the right to complain to a competent county commission. This commission is obliged to inform the patient within the 15-day deadline of all the measures taken regarding the complaint. Otherwise, the county commission has the right to access premises where the health service is offered and the right to examine the way patients' rights are exercised in individual health institutions. The Commission is obliged to write a report about the inspection undertaken that must be sent within the eight-day deadline to the competent inspection service (health or sanitary), or the body responsible for supervision of the work of health workers, such as the bodies of individual professional chambers in the health service (the Croatian Medical Chamber, the Croatian Dental Chamber, the Croatian Nurses Chamber, the Croatian Chamber of Pharmacists and the Croatian Chamber of Biochemists). These bodies are obliged, within 30 days of receiving the report, and in urgent cases without delay, to inform the Commission on the action taken. If the competent body (the inspection service or chamber), on the basis of the procedure undertaken, suspects that by the violation of the patient's right a misdemeanour or criminal offence was committed, it is obliged without delay, and within 30 days from the completion of the inspection at the latest, to file a misdemeanour or criminal report and inform the Commission of the outcome of the procedure – which will inform the patient of this within eight days.

For the sake of the most effective protection possible and the promotion of patients' rights on a national level, the seven-member Ministry of Health Commission was founded (three representatives of associations working to protect patients' rights, one representative of the media, three representatives of the Ministry of Health) to perform the following tasks: to monitor the implementation of the realization of patients' rights pursuant to this Act, discuss the reports by the County Commissions, give opinions, recommendations and proposals to the competent bodies on the situation established within the scope of work of the County Commissions, propose measures to build a comprehensive system of protection and promotion of patients' rights in Croatia, and cooperate with Croatian and international bodies and organizations in the field of protection and promotion of patients' rights.

## **IN THE CONCLUSION**

Croatia is the first transition country to emerge after the break-up of the Former Socialist Federal Republic of Yugoslavia, where patients' rights are regulated by law. However, although the legislation on patients' rights was a significant step in drawing closer to international standards of protection of patients' rights, that is, standards that exist in the developed western democracies, we are of the opinion that the legislation alone still has not had a significant effect on the actual position of patients in the Croatian health care system. There are many reasons for this situation, but methodologically we can break them down in two groups: the political and legal reasons, and the cultural and social reasons.

As for the first group of reasons, we emphasize first of all the practice of taking over (frequently simply copying) international documents and solutions/mechanisms from foreign legislations in order to meet the criteria set by certain international bodies (the CE, EU etc.) without taking into account the objective capacity of the Croatian community for their implementation. An obvious example confirming this claim is

the Act on the Protection of Persons with Mental Disorders of 1997, adopted as part of the reform of criminal legislation, which was a condition for Croatia to be received into the Council of Europe, and by whose amendments of 1999, the commissions for protection of persons with mental disorders in psychiatric institutions were abolished – since due to staffing, organizational and financial reasons it was not possible to establish them.

Secondly, the lack of political will to adopt subordinate implementation regulations to apply the existing legislation in practice. For example: the State Commission for the Protection of Persons with Mental Disorders, which should have been founded way back in 1998, has not been founded yet as far as we know (sic!).

And finally, there is a lack of transparency in the work of the competent bodies who should ensure the implementation of the existing legislation. For example: reports on the work of County Commissions for Patients' Rights are unavailable to the public, and the same is true of the National Commission, and it is therefore impossible to establish whether and in which situations, how often and in which health institutions patients' rights are violated.

From the second group of reasons we have mentioned the cultural and social reasons, we emphasize that citizens are insufficiently informed and educated about the concept of patients' rights and the existing legislation (12), very rarely seek protection of their rights as patients when they believe them to have been violated, since the prescribed legal procedures are long and complicated, and citizens are accustomed to the pattern of the doctor's omnipotence and their own incompetence regarding treatment. Also, health workers are insufficiently informed and educated about the concept of patients' rights and the existing legislation; they resist the concept of patients' rights as they believe that they are aimed against their professional autonomy. Additionally, health workers still do not see patients as partners in the health care process, but have a paternalistic attitude towards them, that is, the traditional

medical paternalistic relationship dominates between doctors and patients, where the doctor is dominant and implicitly or explicitly questions the patient's autonomy.

In the light of the above, it is clear that there is a serious discrepancy between the legislation and the actual position of patients, which, despite the proclaimed rights, has still not been placed in the centre of the health system. However, we can make the following conclusion: it is indisputable that with the legislation on patients' rights in Croatia the process has begun which, by the logic of the development of democracy and civilization, will not be halted. However, legislation is only one, albeit important, element in the process of protection and improvement of patients' rights as human rights. The second, no less important element in that process is the development of a culture of respect and protection of human rights overall, and the human rights of vulnerable categories of people, which citizens as patients, especially when in need of a treatment, certainly are. It is the opinion of the authors of this paper that,

with political will shown through legislation and other strategic documents in the field of health and social politics, the keys to achievement of this goal are information and education on human rights, that is, patients' rights, at all levels: in the public and on professional and scientific level. Inclusion of the subject of patients' rights in courses at some Croatian medical and law schools and colleges of higher education over the past few academic years and support to projects in this field provided by the Ministry of Science, Education and Sport have made a major contribution to this issue.

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