

The Reflection of Human Rights in the Health System from the Angle of Patients' Rights

Cristina-Luiza Erimia

Ovidius University of Constanta, Faculty of Pharmacy, Constanta, Romania

Rodica Sîrbu

Ovidius University of Constanta, Faculty of Pharmacy, Constanta, Romania

Emin Cadar

Umf Carol Davila Bucharest, Faculty of Pharmacy, Bucharest, Romania

Aneta Tomescu

Ovidius University of Constanta, Faculty of Medicine, Constanta, Romania

Stelian Paris

Ovidius University of Constanta, Faculty of Pharmacy, Constanta, Romania

Abstract

Ever since the drafting of the principles for the promotion and implementation of patients' rights in European states member of the W.H.O., human values expressed in several intergovernmental instruments were reflected in health care systems. Given that patient rights are part of human rights and are intended to promote long-term patient autonomy, this article examines how human rights are respected from the angle of patient interaction with the health system. In the contemporary era, when the right to health is a human right and is based on its natural rights, European countries and the European Community have addressed the question of the rights of people who use health services. This article aims to present the reconsideration of the position of the patient in its interaction with the health system, which involves the statement and application of new rights and obligations. However, when exceptional limits are imposed on patients' rights, they must be consistent with human rights instruments and have a legal basis in national laws. The limitations that may be imposed on patients' rights, seen as individuals, may be subject to limitations or restrictions only when they are justified by a major interest, such as, for example, public health.

Keywords: fundamental rights, the right to health, patients' rights, European legislation, public health, public policies, the European Union

1. Introduction

Throughout historical evolution, the patient has had many obligations, but no rights in the modern sense. For authorities, much more important than individual wellbeing was epidemic control, which is the underlying reason for public health care.

The findings of political democracy, along with economic and scientific progress, have changed the game of power.

In the decades that followed World War I, the progress of citizens' rights became the foundation for modern patients' rights. The introduction of the popular vote and the clear definition of citizens' rights created the foundation for articulating a desire for various social services, including healthcare. In our opinion, scientific progress between the two world wars has highlighted the potential to treat a growing number of diseases, not only increasing the number of patients but also their expectations.

The idea of modern citizenship should not be limited to voting rights and participation in formal political decisions. In our view it must also offer rights in other spheres such as the right to work, to life, education, housing and healthcare.

In the contemporary era, when the right to health is a human right and is based on its natural rights, European countries and the European Community have addressed the question of the rights of people who use health services.

Patients' rights are part of human rights and are intended to promote long-term patient autonomy. These rights are often intertwined.

Although political statements, for example on human rights, are too general and imprecise to serve as a manual of patients' rights, their value as a source of ideological inspiration and ethics was significant.

2. Theory

Before the explicit advent of patients' rights, several generations were needed. The 1945 Charter of the United Nations and the Universal Declaration of Human Rights of 1948, followed in 1950 by the European Convention on Human Rights [1] have not addressed the problems of the patient, but several universal human rights.

These documents, together with the International Covenant on Civil and Political Rights (1966), International Covenant on Economic, Social and Cultural Rights (1966) [2] and the European Social Charter (1961) [3] offered together a framework and a set of basic concepts that have been applied to patients' rights.

The legal regulation of patients' rights started with the European Consultation on the Rights of Patients of the W.H.O. (Amsterdam, 28 to 30 March 1994), which authorized the document "Principles of patients' rights in Europe: a common framework", which consists in a set of principles for the promotion and implementation of patients' rights in European states members of the World Health Organization. Subsequently, the Oviedo Convention [4] gave the patient a catalogue of rights and proclaimed his fundamental rights.

A result of these signals has been an increase in the national regulations on patients' rights in almost every European country, even though in some countries patients' rights had formal laws, applied relative to the political culture, such as the right of an individual to take legal action if a right is denied to a certain function or in cases of discrimination based on ethnic criteria or sexual behaviour.

In some systems, patients' rights are brought together in a general framework, in others there are numerous specialized legal documents.

In the context of the European Union, the affirmation of patients' rights had to take into account in particular the right to mobility of the citizens between EU states and the principle of equal opportunities, in the sense of the patient benefitting from quality services in both the countries of origin and the receiving countries and, particularly, to promote the implementation of these rights in all Member States.

3. Results and Discussions

One of the most important rights of patients is that of being informed. Patients' right to information is proclaimed in both international (the WHO Declaration, the Helsinki Declaration of the World Medical Association [5], the European Charter of Patients' Rights [6]) and in national documents, which represent the implementation of international legislation and in the field and of the European acquis.

The doctor can take the best therapeutic measures for the patient, but they must explain them to the understanding of the patient. Information about healthcare services and about the best way to use them should be publicly available, for the benefit of all those concerned.

It may be noted that at present, citizens, especially those from vulnerable groups, do not have basic information on their rights and obligations as patients. The lack of this information is due, on the one hand, to the lack of activity in the healthcare system in terms of communicating the minimum information on these rights and obligations, but also to a certain social inertia which has not hitherto led the interest of the Romanian patient in this matter [7]. Basically, citizens find out his rights and obligations in relation to the health system only when they have a problem in this area and get to use one or several services of the health system.

According to this principle, patients have the right to be fully informed about their health, including on the medical factors of their condition, about the proposed medical procedures, the potential risks and the benefits of each procedure, about alternatives to the proposed procedures, including the effect of non-treatment. Patients have the right to be fully informed about the diagnosis, prognosis and the progress of treatment.

Governments are obliged to provide information on health issues, information from both the state and private health service providers [8].

Transparency is an essential feature of an effective healthcare system, access to information also empowering citizens to participate effectively in political decisions taken at European, national and international levels.

For civil society it is necessary to monitor whether the state develops appropriate policies to promote access to health, so that individuals have access to information about the development and implementation of public health policies [9], without their fundamental rights being violated.

Information may be refused to patients, exceptionally, when there is good reason to believe that this information would cause them great harm, without any exception of possible positive effects. Such situation may be, for example, when a diagnosis with very grim prognosis must be communicated. Several issues ensue, both legal and ethical.

If the patient has the right to be informed about his health and has not explicitly requested not to be informed, can the doctor conceal the diagnosis on the grounds that it would cause greater harm? Medical practice in the field has shown that it is essential, both for the patient and for the health system, to have psychological support [10] for those patients who will be communicated unpleasant news regarding the diagnosis or treatment. Thus, a 2001 study [11] conducted on a group of 89 Canadian women with cancer, showed a 24% reduction in direct healthcare costs for those who received cognitive behavioural therapy. During the study the estimated savings amount to \$ 6,199. This saving would have been significantly greater if treatment had been provided by social psychologists rather than psychiatrists.

The main responsibility in the healthcare field lies with the states, in the obligation to ensure a proper promotion and protection of public health, for the improvement of the quality of life.

Pursuant to that principle, everyone is entitled to respect for his person as a human being, to self-determination, to physical and mental integrity and to the security of his/her own person.

Thus, a person cannot be treated medically without consent. Informed consent arose from the need for vulnerable people not to be exploited [12].

By free and informed consent is understood the patients' right to participate in decisions affecting them [13]. Before signing, patients must receive information, to understand and to remember them, to analyse the situation and make decisions. The patient will have to be able to explain to others, in simple terms, the procedure which he/she is subject to.

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This can be expressed earlier occurrence of such situations in the patient's medical condition or when this occurs and the patient is still conscious.

In terms of self-determination, we consider relevant to bring into question the patients' right to decide whether they wish to be kept alive artificially.

This option can be expressed prior to the occurrence of such situations in the patient's medical condition or when this occurs and the patient is still conscious.

If the patient is braindead, the decision rests with carers who have to decide taking into account the previously expressed wishes of the patient.

Eloquent in this respect is the case of Terri Schiavo, a legal battle in the United States relating to artificially maintaining vital functions, which lasted from 1990 to 2005 [14]. In this case the issue was whether to apply the decision of Maria Theresa "Terri" Schiavo's husband and legal representative to remove the feeding tube that maintained Terri's vital functions. Terri was diagnosed as being in a persistent vegetative state, although this diagnosis was disputed by her parents and the doctors employed by them. The highly publicized and prolonged series of legal challenges raised by her parents

and the state and the lack of federal legislative intervention caused a delay of seven years before her supply tube was finally removed [15].

As another consequence of this principle, everyone is entitled to respect for their own confidentiality, to the respect of their private life.

There are certain areas in the health sector in which privacy acquires other dimensions, such as, for example, the medical services related to the sexual and reproductive health [16], particularly that of sexually active adolescents or of homosexuals [17]. These vulnerable groups often avoid to ask for professional help, on the one hand for fear their secret being disclosed and, on the other hand, for fear of being seen in a certain institution providing health services [18].

Although the obligation of medical confidentiality is guaranteed by all normative acts (international, European, national), there are situations where it can be surpassed by another obligation of public or general interest. This is the case of patients that could pose a danger to themselves, to the family and to others, where the legislation allows the information of "third parties" about certain aspects of the medical act. In the event that a patient would be a threat in terms of spreading sexually transmitted infections or HIV / AIDS due to unprotected intercourse, the doctors have the duty to ensure they protect third parties through adequate information or counselling [19]. Most of the times it is enough for the doctor to ensure that the patient has the real representation of the risk he/she poses and would take the right steps to protect their sexual partners or family from possible infection.

On the other hand, patients cannot claim the right to privacy in order not to alert medical staff on a number of risks that they themselves would have been required to prevent, such as, for example, if an HIV-positive patient who does not inform his/her dentist about his/her health. [20]

The patients' right for their privacy to be respected has great applicability in healthcare especially when it comes to terminating a pregnancy, sexual and gynaecological diseases etc. In this respect are relevant the decisions of the European Court of Human Rights - ECHR.

Thus in the case *R.R. v. Poland* [21] the Court was again asked to rule on the highly sensitive issue of abortion, only a few months after a resounding rulings in the field [22].

Poland was convicted of breach of *Articles 3 (prohibition of inhuman and degrading treatment) and 8 (right to respect the private and family life)*, the Court expressing a paradoxical jurisprudence position. Although the Court expressed its position on granting the freedom of Member States to recognize or not the right to abortion, it also showed its growing will to ensure this right when it is protected internally. The laudable desire to protect pregnant women who want an abortion, resulting from the solution ruled in 2011, contrasts sharply with the refusal crystallized at the end of 2010 to grant a conventional autonomous right to abortion.

On art. 3 of the Convention, the Court held that it cannot be excluded that the acts and omissions of the authorities in the field of healthcare policy may engage, in certain circumstances, their liability under art. 3 because of their failure to provide appropriate medical treatment [23].

In this case, the Court found that, although the applicant should have had access to the genetic testing recommended by doctors, the whole period was marked by procrastination, confusion and lack of counselling, the applicant not being properly informed. She was admitted to a hospital by a subterfuge, as emergency.

National law imposed a duty on the State to ensure free access to prenatal information and tests, especially in cases of suspected genetic disease or developmental problems. However, there is no indication that the legal obligations of the state and medical staff about the patient's rights were taken into account.

The Court noted that the applicant was in a state of great vulnerability. Like any pregnant woman in such a situation, she was deeply disturbed by the information that the foetus could be affected by some malformation. It was therefore natural for her to want to get as much information as possible to determine if the initial diagnosis was correct, and if so, what the nature of the disease was. Due to the delay on the part of health professionals, she had to endure weeks of painful uncertainty regarding the health of the foetus, her health and the future of her family in the perspective of raising a child suffering from an incurable disease, suffering which reached the minimum threshold in accordance with art. 3 of the Convention, on which the violation was found.

Regarding art. 8 of the Convention, firstly, the European Court confirmed the applicability of that article to the facts of the

case, recalling that “*the decision of a pregnant woman to continue the pregnancy or not falls within the scope of private life and personal autonomy*”.

Undoubtedly, the legislation regulating abortion affects private life [24], and the state has a wide discretion to define the circumstances under which permits abortion, but once this decision is made, the legal framework designed for this purpose must be coherent and able to take account of the various legitimate interests at stake at an adequate level and in line with obligations under the Convention.

Analysing the procedural dimension of this Article, the Court held that prenatal genetic testing targets different purposes and cannot be regarded as an incentive for pregnant women to seek abortions, and that States are required to organize the health system to ensure the effective exercise of freedom of conscience of doctors, without being able to deny patients access to health services, in accordance with the applicable law, and the courts must provide an effective appeal to remedy situations such as that in which was the applicant.

From the human rights perspective, the patient has the right to have its own moral and cultural values and the right to be respected their philosophical and religious beliefs. Regarding the patient's refusal to give their consent to a medical intervention on religious grounds [25], we can take the example of Jehovah's Witnesses cult members. Witnesses are very categorical in this regard. They would rather die than receive a transfusion in case of an accident or an operation. This refusal also applies, of course, to underage children. Most witnesses carry a document signed both by themselves and by two witnesses establishing the refusal of transfusion and prohibiting medical personnel to perform it if unconscious. Jehovah's Witnesses organization shows that blood transfusion is the equivalent of eating blood because it resembles an intravenous feeding. A witness who accepts transfusion will be called before the committee of judges, behind closed doors, and will be excluded from cult [26].

In our view, we consider it necessary to make some remarks concerning the protection of religious freedom. As a universal human right, the right to freedom of thought, conscience, religion or belief, guarantees the respect for diversity. Its free exercise directly contributes to democracy, the rule of law and stability. The violation of this universal right may exacerbate intolerance and often is an early indicator of potential violence and conflict.

Everyone has the right to manifest religion or belief (individually or together with others, in public and in private), in worship, observance, practice and teaching, without fear of intimidation, discrimination, violence or attacks. People who change their religion, those who renounce religion and those adherents of non-theistic or atheistic beliefs must be protected equally. Violations or abuses against the freedom of religion or belief, committed both by state and non-state actors, are widespread and complex and affect people from all over the world, including in Europe.

In line with global and European standards on human rights, the EU and its Member States undertook to respect, protect and promote the freedom of religion within their borders. In Europe, the freedom of religion or belief is protected in particular by Article 9 of the European Convention on Human Rights [27] and Article 10 of the EU Charter of Fundamental Rights [20].

In contrast with the freedom to have a religion, to have a belief or disbelief, the freedom to manifest one's religion or belief may be subject to strictly regulated limitations, necessary to protect public safety, order, health or the morals or the fundamental rights and freedoms of others. These limitations shall be in accordance with international standards and must be interpreted strictly. Limitations on other grounds, such as national security, are not allowed. Any limitations on the freedom to manifest religion or belief must meet the following criteria: must be stipulated by law, are not applied in a manner which vitiate the rights guaranteed in Article 18, to be applied only for purposes for which they were intended, to be directly related and proportionate to the specific need for which they were created and may not be imposed for discriminatory purposes or applied in a discriminatory manner.

Reaffirming its determination to promote, in its foreign policy on human rights, the freedom of religion or belief as a right that is exercised by any person anywhere, based on principles of equality, non-discrimination and universality, the European Union adopted the EU Guidelines on the promotion and protection of freedom of religion or belief [29]. By this document and in its foreign policy instruments, the EU intends to contribute to preventing and addressing in a timely, systematic and consistent manner, the violation of this right.

Conclusions

Ever since 1948, various international bodies have presented various declarations and agreements on patient rights, of which some refer exclusively to health, such as Article 35 of the Charter of Nice, which guarantees a high standard for the protection of health, the right to security preventive health, or the right to benefit from medical treatment under conditions established by national laws and practices.

As regards the Council of Europe should be recalled, in particular, Recommendation Rec (2000) 5 on the development of structures for citizen and patient participation in the decision-making process affecting health care [30]. The recommendation reaffirms the universality, indivisibility and interdependence of all human rights and fundamental freedoms and the need for people with disabilities to enjoy fully without any discrimination, these rights and freedoms.

The document took note of the failure to promote the rights of disabled citizens, for which inequality of opportunity is a violation of human dignity.

The Council of Europe, convinced that human rights must be addressed to ensure the integrative participation of persons with disabilities in society, recommends their incorporation into all relevant policy areas at international, national, regional and local level as ensuring equal opportunities for members of all groups in society contributes to strengthening democracy and social cohesion.

Patients' rights are part of human rights and are intended to promote long-term patient autonomy. These rights are often intertwined. From the same principle on human rights and values in healthcare, each citizen has the right to health protection, to the extent available, through adequate disease prevention and healthcare, and to the opportunity to pursue reaching the highest possible level of health.

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