

Patients' Rights in Hungary – Rules and Practice

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Introduction

July 1, 1998 is an important date in the history of the process toward the codification of the rights of patients in Hungary. When, in the phase of preparatory drafting, the issue of self-determination in health care was being discussed, the government supported the idea of codifying the patient's right to self-determination. In Chapter II. of the new Act the legislator laid down a list of rights which are to be observed during medical treatment, and provided means for their enforcement. In 1998, when the new Act took effect, the main task was to make known to every citizen the entitlements they now enjoyed during medical treatment.

The Hungarian Civil Liberties Union launched its patients' rights project in 1998, the first step in which was to provide a number of materials designed to spread information about the new regulations affecting patients' rights. The staff of HCLU have been operating a counseling hot line for giving legal aid, and giving opinions on those legal rules relating to the health service which may affect human rights. The three years which have elapsed since the promulgation of the Act seem to be a time long enough to offer the opportunity for an assessment of the effectiveness of the new patients' rights regulations. The present volume is a contribution from the HCLU staff to such an assessment.

The guiding idea in preparing these studies was to focus on the extent to which legal rules are actually translated into practice. As a first step, we focus on the making of the provisions of the Health Care Act which record patients' rights. This is followed by an examination of the legislative process which has been going on *since* the promulgation of the Act. How and why were regulations affecting patients' rights modified? What ministerial decrees have been issued to take care of matters of detail? We also assess the extent to which the existing law is in harmony with international principles and expectations.

The summary of the issues indicated above is followed by an account of some experiences we have had "in the field". Our associates have visited several hospitals to examine the ways in which health care facilities actually provide patients access to information about their rights and the ways in which these patients' rights become effective in the course of treatment. We would like to thank those physicians, nurses and patients who kindly offered our colleagues their co-operation.

The present volume is also an attempt to lay bare the shortcomings of the legal rules and the contradictions to which they may give rise in practice. Finally, as in all its publications, HCLU would like to draw attention to the importance of patients' rights and to emphasize that those who make laws and those who apply the existing law have an important responsibility entrusted to them by their fellow humans: a responsibility for the translation of basic rights into effective practice.

October 2001, Budapest

Abbreviations used

HCA – 1997:CLIV Health Care Act

CC – Act 1959:IV on the Civil Code

PC – Act 1978:IV on the Penal Code

HCLU – Hungarian Civil Liberties Union

I. Changes in the Health Care Act – the Legislative Process

Undoubtedly a paradigm change in Hungarian legislation, the new Health Care Act became effective on July 1, 1998. To arrive at an appropriate assessment of the new legal regulations, it is important to be informed about the circumstances under which the Act was composed, the modifications which it has since undergone, and generally the legislative intent which has shaped the attitude of the health ministry to the regulation of the area.

The present Health Care Act replaced the “old” Health Care Act which had been in effect since July 1, 1972¹. No change in the type of regulation is evident in it: legal instruments to regulate health care are again cast in an unified code which is designed to cover the particular branch of public administration as completely as possible. The need for new regulations had been felt in several areas. The health insurance scheme, re-organized after the political transformation of 1989, was expanding fast, property relations were becoming increasingly difficult to see through and the expectations of the public from health services were also on the increase. Professional considerations spoke equally for change: prevention was more and more emphasized, developments in science and technology were bringing to the surface new questions of an ethical kind, new forms of alternative medical care had appeared on the scene and patients’ rights had been, and were being, codified in an increasing number of countries. It was an attempt on the government’s part to meet these challenges and international expectations when in August 1996 it recorded, in a decree², a set of principles for guiding new legislation for the health sphere and set out the tasks entailed by the new legislative aims.

The government decree stated that legislation would have to start from, and take as its point of reference, the recommendations and statements published by the European Union and the World Health Organisation (WHO). The decree made special reference to one of the tasks involved, which it set out in detail in nine paragraphs: the codification of patients’ rights. The preparatory work launched in 1996 is a good example of appropriate codificatory legislation: a special codification committee was set up, the staff including almost 150 specially recruited members, renowned experts in their theoretical or practical fields of interest, and over 150 professional organizations were asked to participate in consultations. Those who were asked to give their opinion included medical institutions, professional colleges involved in health care work, scientific associations, managers of health care institutions at different levels, representatives of public servants active in health care work and a few civil associations.

The materials preparatory to legislation were also submitted to Parliaments so that members of parliament could have access to them. The materials included detailed information on a number of schemes for patients' rights effective in other countries, and the Amsterdam Declaration of WHO and the fundamental charter on bio-ethics of the Council of Europe in the appendix³. Debates in the preparatory stage centered almost exclusively on questions of codification, yet solutions were proposed to decision-makers on all issues. The extent to which Hungarian regulation has been made consonant with international principles is a subject for separate analysis.

¹ Act 1972:II on Health Care.

² Government Decree 1095/1996 (VIII. 30.) on the main principles of the HCA and the tasks involved in its preparation.

³ These two documents lay down the international principles which are to be followed by national legislatures. They will be analysed in the next chapter.

In the early phase preparatory to legislation, the HCLU took an active part in advising, sending its opinions to members of parliament later when the bill was debated in Parliament⁴. In its "HCLU Statement on the Provisions on Patients' Rights in the Health Care Act" issued in 1977, HCLU summarized the problems which did not get into the draft during the preparatory stage or had not been formulated in conformity with human rights principles. The Statement dealt at length with the regulation of the provision of information for patients of limited or no competence and their right to self-determination, the regulation of rejecting treatment and the rights of psychiatric patients, taking in turns each provision of the Act which imposed unreasonable restrictions on patient rights, and suggested a variety of new solutions conducive to a general observance of patient rights. Some of the 53 proposals put forward in the Statement were included in modification proposals made by members of Parliament, and thus 5 of the 53 proposals came to be fully, 6 of them partly incorporated in the final text of the HCA.

Following the 1998 change of government, one of the first steps taken by the new Health Minister – who, as President of the Hungarian Chamber of Physicians, had previously spared no energy in criticizing health care legislation and the codification of patient rights – was to postpone the coming into effect of certain provisions of the new Act. The provisions concerning waiting lists, quality improvement system, the National Health Council, hospital supervisory councils and ethical committees, organ and tissue transplantation and the deceased, came into effect as late as January 1, 1999 instead of July 1, 1998, as originally planned. Similar "respite" was given to the Ministry in other areas including the launching of the patient rights advocate scheme, which was delayed by several months, and the health care mediation scheme, which was delayed by over a year, starting in the autumn of 2001 instead of January 1 2000, the time originally set by legislation.

A year after the "respite" the Health Ministry initiated another modification, which severely affected fundamental patients rights on several scores. Their proposals aimed at restricting the scope for written guarantees for limiting personal freedom, extending access to medical data by a third party, and abolishing ethical committees at certain kinds of facility. It was as a result of these proposals that the HCA came to include a new provision on the court procedure concerning the obligatory treatment of psychiatric patients. It imposed an obligation on forensic experts involved in court proceedings to decide on the application of forced treatment to psychiatric patients, under which they are to make a declaration whether the patient at the time has mental ability. If the forensic expert finds the patient's competence limited, the court is legally bound to pass on this opinion to the public guardianship authority. In 1999 the Health Ministry included this provision in the law in defense of psychiatric patients, disregarding the fact that comprehensive legislation to regulate the issues of competence and guardianship were in the making. The procedure has since proved itself pointless in practice, Expert opinion based on the patient's state at the time of transfer to the hospital may set off a legal procedure resulting in the placement of the patient under guardianship which later becomes pointless as the patient regains his/her full competence during treatment.

In connection with the modification introduced in the spring of 1999 HCLU proposed that the provisions on restraint, in order to be consonant with international principles, should include an enumeration of eligible measures of restraint, introduce the devices of periodical control and care, as well as indicate the maximum time limit for the restriction of liberty. The

⁴ Commenting on topics relevant to its activities, HCLU issues a series of Statements which contain remarks on bills coming up for parliamentary discussion.

requirement of periodical control was included in the law, but methods of restraint have never since been precisely defined.

The 1999 autumn session of Parliament again introduced a modification in health legislation. The modification which was finally made into law abrogated the institution of surrogate motherhood. Surrogate motherhood, a scheme for reproduction in special cases of medical difficulty, was to have started from January 1, 2000, but this possibility was abrogated by the government. Allowing surrogate motherhood for reasons of special health problems is required by the right to health care and the right to self-determination, the intervention does not infringe anyone's rights, and it is in harmony with the interests of society. The government justified its move by reference to the disorderly state of domestic law and its international obligations. Instead of appropriately adjusting the HCA to regulate the relatively unusual relationships which result from surrogate motherhood, the government abrogated the possibility of an intervention which to many represents the only possible solution to their health problem. The ban on surrogate motherhood could not have been based on international agreements or recommendations, since this arrangement to help couples with problems in their reproduction systems to have children is increasingly supported by the law in many countries.

In the autumn of 2000 the Constitutional Court examined the constitutionality of certain provisions of the HCA. It abrogated those provisions of the Act which imposed the same restrictions on the rights to self-determination of those of limited competence and those of no competence. (The abrogation was to be carried out by December 31, 2001.) The Court argued, that the law excluded patients with limited decision making capacity from the exercise of self-determination; this restriction is not in harmony with the requirement of proportionality. The other problem area examined and deemed unconstitutional by the Constitutional Court, was the legislator's failure to define the legally acceptable means of restricting personal freedom. The Court set Parliament the extended deadline of December 31 to change the law. In spring 2001 the government submitted a new proposal to modify the HCA, the fourth during their time in office. Described as "born under duress" the proposal was aimed at two areas: the right of persons of limited competence to self-determination, on the one hand, and the measures of restraint applicable to psychiatric patients, on the other. In its Statement HCLU criticized the proposed changes severely, arguing that neither of the proposals were in harmony with the rulings of the Constitutional Court. Under the Act as it is at present, persons of limited competence will be unduly and unreasonably limited in the exercise of their right to self-determination, and the new modification still fails to define acceptable methods of restraint.

The article of the HCA on patient rights aims to provide each citizen fundamental liberties during medical treatment. The Act in its entirety and the rights it sets out are in harmony with international documents. Still, there are few examples of Acts in Hungary, perhaps with the only exception of tax laws, which have seen as many modifications since their promulgation as the HCA. These modifications cannot be put down as straightforward advances; indeed, in some cases they only make the conditions for the recognition of the right to self-determination in medical treatment less favorable. Institutions conducive to the observance of patient rights lag behind. Formally a few instruments of right enforcement were created but their functioning was hindered at several points by government organs and health care providers. HCLU as a civil association was excluded from the opportunity to give an opinion on all four modifications, despite the fact that civil associations have a right, laid down in the Legislation Act, to give an opinion on bills relevant to the interests they aim to protect and represent. Although several provisions of the HCA have been modified, not all articles of the chapter on

patient rights have been brought into harmony with constitutional rights and European recommendations, and the latest of the modifications have been made without a social dialogue involving many participants, which once characterized the act at the time of its conception.

II. The Hungarian Health Care Act in Light of International Expectations

General Rules on Patient Rights and International Principles

Made in 1997, The New HCA had as one of its merits the formulation of patient rights. The formulation of the law was aided and guided by the examples set by fundamental international documents and guidelines which define the unified principles of codifying patient rights on the basis of the individual's right to self-determination. It was the Amsterdam Declaration⁵ and the Bio-ethical Convention⁶ that provided the most important guidelines for legislators.

The Amsterdam Declaration was adopted as a result of a WHO meeting in 1994. The European Regional Office of WHO had been requested by the European Parliament to draw up a draft of an international document which would lay down principles for patient rights. Following a discussion of European trends and practical problems in health care legislation the document was accepted by 36 European countries, and it continues to serve as the most important set of guidelines for legislators.

The Bio-ethical Convention was the result of seven years of preparatory activity and it has become a framework agreement on the principles of bio-ethics. It was accepted and signed in 1997 by the member states of the European Council, other states invited to the meeting and representatives of the European Union. The signing countries, including Hungary, undertook an obligation to incorporate the requirements enunciated in the convention into their legal systems. The Hungarian Parliament is expected to accept the parliamentary resolution on the confirmation of the Convention in November 2001⁷. Once the law takes effect, the provisions of the convention will become part of the national legal system.

Act CLIV of 1997 on Health Care has been modified several times since its introduction and ministerial decrees have been issued to regulate specific details. International principles had served as guidelines for the making of the Act, and it has to be continually assessed in terms of those principles. In what follows, therefore, we will try to find answers to the following questions: how did Hungarian legislation realize the guarantees for patient rights, and how far does the Hungarian legislative environment live up to international expectation and recommendations?

Both the general aim and the individual rights contained in the Act are in harmony with the principles of the Amsterdam Declaration and the Convention. The Act aims to secure equality of opportunity, the right to non-discriminatory treatment, and the dignity and self-determination of the patient. According to the main rule the patient's consent is necessary for every medical intervention, and consent is to be based on full information previously given to the patient. as required by both international documents. The enactment of fundamental rights creates the possibility of referring to these rights directly. (Prior to the declaration of patient rights there was no legal rule in health care which could be resorted to directly in cases of infringements of patient rights. Only indirect reference could be made to the Constitution and legal rules from other branches of the law in protection of patient rights.) In what follows we

⁵ WHO (the World Health Organisation, a branch of United Nations) – A Declaration on the Promotion of Patients Rights, Amsterdam, March 1994.

⁶ Council of Europe, Convention on the Protection of Human Rights and Human Dignity with Respect to Their Application in Biology and Medicine. Convention on Human Rights and Bio-medicine, Oviedo, April 4, 1997.

⁷ Legislative activity was still going on at the time of the completion of the present volume.

will take the points enunciated in the Amsterdam Declaration and the Convention as our guide in examining whether the detailed rules for regulating patient rights in our existing law comply with human rights principles, and which issues are in need of further regulation.

Information

The problems raised by the patient's right to information are addressed in the first passages of the Amsterdam Declaration, and the first item to be dealt with is access to health care institutions. Health services and the procedure through which citizens can avail themselves of them are to be made public⁸. In Hungary, as in most European countries, there is no legal rule specifically prescribing or regulating this. According to written information from the Ministry, which was prepared for an international comparative study⁹, citizens are informed of health services in several ways. First of all, the Ministry runs a central homepage on Internet which features a nation-wide list of all health care institutions as well as civil associations involved in health care-related activities. The latter associations are grouped according to types of health problem. Secondly, patient rights advocates active in hospitals as well as civil associations and local health care providers help members of the public to get information. In addition to information on the freedom to choose one's physician, information assisting citizens in finding the physician or hospital dealing with a specific health problem has been increasingly sought for. Obviously, there is a growing need for a legal rule which would prescribe the establishment of a central information service, in conformity with the Declaration.

Another aspect of the right to information is access to the information which is necessary for exercising the right to self-determination. Both international documents define the right to information and informed consent as a fundamental right which can be departed from only in truly exceptional cases. Accordingly, Hungarian legislation allows a very narrow range for deviations from the right to information. In harmony with the international documents, the HCA upholds the patient's right to waive his/her right to information, except when s/he has to be aware of the nature of his/her illness in order that s/he should not endanger the health of others.

Self-Determination

In harmony with both patients rights documents Hungarian regulations incorporate as a general rule the requirement that the patient's informed consent is to be obtained for all medical intervention, and that it is to be obtained without any deception, threat or duress. There are two areas in which Hungarian legislation does not come up completely to fundamental human rights principles.

Incompetent Patients and Self-Determination

The HCA incorporates several guarantees which promote the involvement of incompetent patients in decisions on health care. The most important requirement is that incompetent patients are also to be informed and their opinion is to be taken into consideration "to the extent to which it is professionally possible" in decision-making. The rules make it possible

⁸ Amsterdam Declaration 2.1.

⁹ Supporting Patients' Rights and Empowering Citizens: Emerging Systems in Europe. WHO European Partnership on Patients' Rights and Citizens' Empowerment (EPPRCE), Biennial Report, Draft for Consultation, 2001

for a competent person to issue an advance directive, i.e. designate a person who will represent his/her interests in case s/he loses his/her competence. In absence of a surrogate decision-maker designated in this way, the Act provides a list of those persons who are authorized to decide for the incompetent patient.

According to the Amsterdam Declaration, an incompetent patient is also to be involved in the process of decision-making, depending on his/her physical and mental state¹⁰. All relevant facts known at the time are to be taken into consideration and so is the presumable wish of the patient¹¹. The Hungarian rule deviates from this in prescribing only that the opinion of the patient is to be taken into consideration to the extent to which it is professionally possible. We would need a stronger rule, a formulation which results in the patient's actual involvement, an interrogation concerning his/her opinions and reasons, a consideration of the facts and his/her earlier wishes, as is expressly stated in the Declaration. The Hungarian HCA also fails to meet this fundamental requirement when it does not specify the considerations which are to be weighed by the surrogate decision-maker. Whether specified in an advance directive, or designated via the law, the surrogate decision-maker is to keep in mind primarily the patient's wish and set of values rather than his or her own.

Under the HCA a person affected in his/her competence – whether incompetent or of limited competence – may not exercise his/her right to self-determination. A person of limited competence is not allowed to give or withhold assent in questions concerning his/her treatment, either on his/her own or with his/her legal representative. This arrangement is completely at variance with the spirit of both the Declaration and the Convention. The most important point made in the Amsterdam Declaration is that, the legal representative's entitlement to decide notwithstanding, the patient is to be involved in the decision to the extent that his/her state allows¹². The Convention makes exercise of self-determination dependent on the patient's ability to consent, i.e. a condition to be weighed in a given specific situation¹³.

Some change to the above unacceptable state of Hungarian legislation was made by the 2001 modification in the Civil Code adopted in 2001. From November 1, 2001, courts have been empowered to interpret and weigh competence in terms of specified decision-making areas, and thus they are now allowed to desist from limiting the patient's right to self-determination when they find no reason to limit it. Under such an arrangement the ward may count as competent with respect to his/her medical treatment. With this provision the legislator has made it possible to maintain general limitations on competence. In the general limitation of competence the ability to assent to treatment is not weighed on its own merits, thus in such cases the ward is not allowed to exercise his/her right to self-determination.

Self-Determination and the Child

Age is also relevant to competence. Under the Hungarian Civil Code those below 14 years of age count as incompetent, and those between 14 and 18 as of limited competence. Under the rule of the HCA outlined above thus no children below 18 have a right to self-determination in questions relating to health care since they are all subject to the same limitations. According to the Amsterdam Declaration minor patients are to be involved in the decision-

¹⁰ Amsterdam Declaration 3.5.

¹¹ Amsterdam Declaration 3.7.

¹² Amsterdam Declaration 3.5.

¹³ Bio-ethical convention 2 Article 6.

making process as much as their understanding allows¹⁴. Similarly, the Convention prescribes that, the opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity in decision-making on treatment¹⁵.

The HCA makes one single allowance in favor of the self-determination of minors: their opinion as that of incompetent persons is to be taken into consideration “to the extent which is professionally possible” in decisions on health care which affect them. This provision is out of harmony with the special points made in recommendations put forward in international documents. The modifications made to the HCA in 2001 include a few legal rules which confer a set of additional entitlements on children above 16, but this allowance does nothing to alleviate the solid fact that the regulations as a whole are contrary to the spirit of the international documents. The additional entitlements are restricted to the freedom of the child above 16 to resign his/her right to information and decide to designate a person who is to be informed instead of him/her (both functions may be carried out only by competent persons), and to designate a surrogate decision maker in a deed, or to exclude certain persons from making decisions on health care questions that affect him/her. Beyond these entitlements, s/he is still excluded from participation in decisions, and no one will inform him/her that s/he is entitled to designate a surrogate decision maker who subscribes to the set of values which are closest to his/hers. Narrow as the range of entitlements conferred by the new rules taking effect from January 2002 is, they may become important enough to serve as a starting point for extending the self-determination of those above 16. It is one of the most urgent legislative tasks to regulate the right of children to self-determination in the special terms in which they deserve to be treated.

Refusal of Treatment

As a general rule, Hungarian law allows patients to refuse medical treatment. However, the more specific rules relating to this general provision in the HCA fall short of needs in one respect.

Whenever an incompetent patient or a patient of limited competence wishes to reject life-sustaining or life-saving intervention, the health care provider automatically initiates proceedings with the competent court to substitute for the declaration of assent. According to the Amsterdam Declaration, if a legal representative refuse to give consent and the physician or other provider is of the opinion that the intervention is in the interest of the patient, then the decision must be referred to a court or some form of arbitration¹⁶. This may seem always to be the case since e.g. a life-saving treatment can hardly fail to serve the patient’s interests. When, on the other hand, the rejection of a life-saving intervention has been the result of a fully considered decision, i.e. the patient has declared his/her will concerning it in an official deed while still in the state of competence, automatic substitution of a declaration cannot be accepted and the treatment is to be stopped. In any case, this provision of the HCA is in need of being made more precise.

The Moral and Cultural Values of the Patient – On Freedom of Conscience

¹⁴ Amsterdam Declaration 3.5.

¹⁵ Bio-ethical Convention 2 Article 6.

¹⁶ Amsterdam Declaration 3.6.

The first Chapter of the Amsterdam Declaration states as one of the human rights due every human being the fundamental right to have his/her moral and cultural values respected by others¹⁷. According to another paragraph, the patient has the right to have his/her culture and set of values respected during treatment¹⁸. The HCA does not deal with the question of the patient's set of values anywhere, which is out of harmony with the Declaration. It is also open to criticism, considering the fact that respect for different moral codes is acknowledged as a right among the rights of physicians. In Article 131. the Act entitles the physician to deny treatment of a patient if the treatment in question is at variance with the physician's moral code, conscience or religious conviction. Nowhere in the Act is the deeper consideration underlying this provision carried over onto the plane of the patient's rights. The absence of any application of this principle to patients in the Act raises questions in other cases as well when e.g. a patient withdraws his/her consent. This is important because if the patient has dissented from treatment for a well-considered reason, he or she will not have to refund the expenses incurred until withdrawal. In other words, the state respects his/her decision. Since, however, a "well-considered reason" remains poorly defined, the question arises how far the health care provider will be prepared to respect decisions based on moral codes and deep-felt convictions.

Informational Self-Determination

In addition to the HCA there is a legal rule which specifically affects the regulation of health care data. The HCA contains the general rule that all patients have the right to be given information about their health care records, to inspect them and have copies of them made at their own cost. If certain data are missing from a patient's health care records or if some data are imprecise, the patient has the right to ask for the data to be completed or corrected. In addition, the Amsterdam Declaration also prescribes that arrangements are to be made under which the patient has the right to ask for correction, deletion, disambiguation or updating of data which are dubious, out of date or irrelevant to the treatment¹⁹. By contrast, Hungarian legal rules do not allow for the deletion of data: erroneous data are to be deleted in such a way as to keep the original recoverable later on. Erroneous data put on record by mistake, however, are a possible source of injury to the patient's dignity, and there is no acceptable reason against their deletion.

The Representation of Patients

Collective Rights

The Amsterdam Declaration states that patients have the collective right to take part via their representative in the planning and assessment of health care services at every level. Collective representation, which is a fundamental element of the protection of patients' interests, is effective in a very narrow area in Hungary today. On the one hand, there is a National Health Council, which was formed with a considerable delay despite a legally prescribed, obligatory deadline. The Council is empowered to express opinions and make proposals concerning the government's health care policies. Its members include 10 representatives of patient organizations, with one representative for each type of disease. On the other hand, most health care providers are to set up a supervisory council which also count representatives of civil associations among their members. Half – in some cases one third – of the members of the

¹⁷ Amsterdam Declaration 1.5.

¹⁸ Amsterdam Declaration 5.8.

¹⁹ Amsterdam Declaration 4.5.

council are delegated by health care-related civil associations active in the given area of health provision. The council's tasks involve monitoring the activities of the institution as well as giving opinions and making proposals concerning the functioning, running and development of the facility. The supervisory board may play an important role in the representation of patients' interests as it liaises between the management of the health care facility and the population as well as in representing the interests of the citizens of the given territory. Over and above the mandate for the establishment of supervisory boards the HCA does not give any guarantees concerning the attention and weight to be given to the council's decisions. Legal institutions that would guarantee patients' collective rights at other levels of decision – such as the local government level – are also lacking. To meet the expectations enunciated in the Amsterdam Declaration, full-range guarantees for patients' representation at all levels of planning and evaluation relevant to health care matters would be necessary.

The Individual Representation of Patients

Besides setting out the collective rights of patients, the Amsterdam Declaration also expresses, at several points, the need for the representation of individual patients in certain cases. This is also secured by the Hungarian HCA. According to the Act, the patient rights advocate is empowered, by a written proxy warrant, to represent the patient in matters relating to his/her health care and s/he is also empowered to act on behalf of psychiatric patients – also with a proxy warrant – in civil commitment hearings. These regulations are completely in conformity with the aims of the Amsterdam Declaration.

In one issue, however, the regulations adopted recently have made a step backwards. On August 22, 2001, the health minister modified²⁰ the ministerial decree on the procedure to be followed by the patient rights advocate²¹, completely prohibiting the patient rights advocate from acting by proxy warrant. Under the modified decree, the patient rights advocate is not empowered to represent the patient before an authority or other organization or in mediation, or to render legal services to patients, or to accept a commission to act as their solicitor. This rule conflicts not only with the HCA as a higher order legal rule but is also at variance with the principles of the Amsterdam Declaration.

The Rules of the Waiting List

“In situations of the limited availability of some medical treatment in which the health care provider has to choose between possible patients, every patient has the right to a decision made as a result of an unbiased procedure based purely on medical criteria and free of discrimination.” This is what 5.5. of the Amsterdam Declaration says about the procedure popularly known in Hungary as the “waiting list”. The Hungarian legal instruments have called this institution into being, identifying professional criteria for choosing the patients and their order of treatment and of course prohibiting discrimination. Outdoing the Amsterdam Declaration, the relevant provisions of the HCA also demand publicity, so this piece of health care regulation could be regarded as perfectly satisfactory, were it not for the decree of the health minister²² on the services available on a waiting list basis, which stipulates the further

²⁰ Health Ministry Decree 27/2001 (VIII. 22.) on the modification of Health Ministry Decree 77/1999 (XII. 29.) on the rules of the legal standing of the patient rights advocate and the procedure to be followed by patient rights advocates.

²¹ Health Ministry Decree 77/1999 (XII. 27.) on the legal standing of the patient rights advocate and the rules of the procedure to be followed by patient rights advocates.

²² Health Ministry Decree 22/1998 (XII. 27.) on the health services available on the basis of a waiting list.

condition on the launching of the waiting list that the foreseeable waiting time for the patient has to exceed 2 months. (The HCA itself was slightly modified so that this decree could be incorporated.) This additional criterion introduces an unacceptable limitation. The inclusion of such a vague temporal condition is at variance both with the principle of security in the law and the international principles. The decree narrows down the range of occasions giving rise to the launching of waiting lists and thus leads to failure to open a transparent list even when the situation otherwise conforms to the original intent behind the Amsterdam Declaration and the Hungarian HCA.

After this review of general rules on patient rights we turn to an assessment of legislation relating to the rights of psychiatric patients, more specifically we will be seeking to answer the question: how far do our legal instruments conform to fundamental international principles.

The Treatment of the Mentally Ill: International Norms and the Hungarian Regulation

Containing a subsection on the rules of “the treatment of the mentally ill” the old Health Care Act in Hungary took effect in 1972. The regulations contained in that Act were substantially modified on February 15, 1995, introducing the following changes in rules concerning psychiatric patients: in cases of emergency treatment the physician has to initiate supervision by a court within 24 hours after admission, decisions for involuntary treatment are to be made by a court within 8 days, the patient is to be heard in the proceedings, and, if the patient has no representative, the court is to secure a representative for him/her *ex officio*, and, finally, the court is to review its own decision every 30 or 60 days. These were the first steps toward bringing Hungarian regulations into harmony with international legal principles.

Due to the special situation of psychiatric patients, their rights and the rules relating to their situation are addressed in a separate chapter. According to the present law, the personality rights of psychiatric patients are to be given increased protection during medical treatment. The rights of psychiatric patients are to be accorded special protection because they are unable to assert and protect their own interests, due to their mental condition, so others are to do this for them, or they are to be given help in asserting their rights with the help of others.

In December 1999 the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment²³ (CPT) conducted a survey in Hungary. They visited psychiatric wards in hospitals and social care homes providing care for mentally ill persons. Their reports shed light on several shortcomings and articulated recommendations for improved care for psychiatric patients. If the member state continues his practice against the recommendations of the Committee the Committee may decide to make a public statement on the matter.

During their visit in hospitals the Committee found several serious professional shortcomings: patients were not given written information on admission and applications of restraining measures were not recorded in writing. With those admitted for emergency treatment the Committee found it to be an established practice that attempts were made within the time between admission and court review to persuade patients to undergo treatment voluntarily. During their visits in social care homes the Committee recorded the wide-spread use of cage

²³ A committee established by the international Convention for the Prevention of Inhuman or Degrading Punishment or Treatment. The Convention was declared by Act 1995:III.

beds, a practice which is widely considered professionally objectionable, and urged the government in its report to put an end to the use of cage beds.

In light of ruling 36/2000 (X. 27.) of the Constitutional Court a modification to the HCA is very much requisite. Act 2001:XXXIV., adopted in early 2001, substantially modified rules on health provision including ones relating to psychiatric patients. The new section applying to psychiatric patients came into effect on July 12, 2001.

In what follows we will make an attempt to present how far regulations presently in effect comply with international principles.

Civil Commitment Procedure

Psychiatric patients may be treated on a voluntary basis or involuntarily by the order of a competent authority.

In the latter case the patient is deprived of the possibility of exercising his right to self-determination. No attempt is made to obtain his/her assent to the treatment, s/he has no right to make a statement. Persons other than himself/herself make decisions affecting his/her life. There is no guarantee that s/he will be treated by the physician of his/her choice, or by the one s/he trusts. S/he is not always allowed to inspect his/her medical records. S/he finds him/herself in a situation in which s/he is at the mercy of others. Therefore, procedural guarantees are needed which will secure the protection of his/her rights.

Under present Hungarian law medical treatment against the patient's will is allowed in two cases. We speak of involuntary treatment when the court has previously made a decision on the necessity of treatment for the patient. In this case the hospitalization is preceded by a court order. We speak of emergency treatment when the patient has come to be in a condition which necessitates instant treatment in a psychiatric facility, and the physician accordingly takes steps to commence treatment. In such cases the court decides on the necessity and legality of the physician's decision after treatment has already begun.

In Hungarian practice most patients are admitted into psychiatric wards by an emergency order. Admission of patients in Germany reveals a picture similar to the Hungarian one. In the majority of cases the court decides on the necessity of treatment afterwards. The type of compulsory treatment when the court decides on the necessity of treatment prior to admission is unknown in Austria, where court decision always follows treatment already begun.

Both recommendation R (83) 2²⁴ (henceforward: Recommendation) and resolution Nr. 119²⁵ of the General Assembly of the UN (henceforward: UN Principles) allow for court decision on the treatment of psychiatric patients both before and after the beginning of treatment. (This model of regulation is followed by Hungarian law.)

²⁴ Recommendation R (83) 2. On the Protection of Persons Suffering from Mental Illness or Subjected to forced Treatment, Article 4. The Recommendation proposes rules and guidelines on the involuntary treatment of psychiatric patients for the member states of the Council of Europe.

²⁵ Principles for the Protection of Psychiatric Patients and the Development of Psychiatric Treatment, 1991, Principle 16.

Hungarian regulations are in harmony also with the gist of the European Convention of Human Rights²⁶ (henceforward Convention) the regulations of which are binding on Hungary. Section 4 Article 5 of the Convention states that “Everyone who is deprived of his liberty” – i.e. psychiatric patients included – “...shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court.” This is in conformity with the legal principles declared in the Hungarian Constitution and the provisions of the HCA.

The Convention defines no specific period of time for the obligation “to make a speedy decision”, leaving this to be decided by national legal systems. The WHO Principles on the rights of the mentally ill²⁷ (henceforward: WHO Principles) summarize in 10 paragraphs the expectations which have to be met by all legal regulations of psychiatric care. Paragraph 7 rules – with reference to the UN principles – that court review is to take place within 3 days after the physician’s decision that treatment must begin.

In Hungary since 1998 courts decide within 72 hours after receipt of the notice on the necessity of emergency treatment. The time specified for the same in Germany is 24 hours. Austria has a more complicated court procedure. With the court proceeding in two stages (personal hearing, then trial), it may take several weeks before a court decision is made.

The provisions of the HCA relating to court review can be said to be in conformity with European legal principles and practice.

The Right to Medical Treatment

Freedom from Discrimination

In order for the patient’s right to medical treatment to become practically real, it is necessary not only that hospitalization should begin as a result of a properly conducted, lawful procedure, but also that the health care provider should not discriminate against the patient for the sole reason that s/he is being treated as a psychiatric patient.

According to UN principles “there shall be no discrimination on the grounds of mental illness”²⁸. “The special measures which are taken in the protection of the rights of psychiatric patients and in the interest of their development do not qualify as discrimination”²⁹. The Recommendation makes similar statements on non-discriminatory professional provision.

The provisions of the HCA conform to international legal principles in so far as the Act declares the right to health care provision without discrimination. Under Article 7 of the HCA “every patient has the right to the health care treatment which is required by his/her state of health and which is free of discrimination.” This means that every patient has to receive treatment of the same quality as other patients suffering from the same disease. E.g. a psychiatric patient in need of surgical treatment has to receive surgical treatment of the same quality as other, non-psychiatric patients in need of surgical treatment.

Quality of Care

²⁶ The European Convention on Human Rights was promulgated by Act 1993:XXXI.

²⁷ Principles elaborated by the World Health Organisation of United Nations in 1996.

²⁸ UN Principle 1, Paragraph 4.

²⁹ UN Principle 1, Paragraph 4.

International documents also lay down the principles of professional provision. According to the UN principles “every patient shall have the right to be treated ... with the least restrictive or intrusive treatment³⁰”. The WHO principles also declare that the patient is to be secured the least restraining form of institutional provision. Hungarian regulations are in tune with these international principles when they state that “psychiatric treatment is to be conducted by applying the least disadvantageous and unpleasant methods³¹”.

Hungarian practice, however, falls short of international principles in terms of the right to treatment. Both the UN and the WHO Principles prescribe that psychiatric patients must be secured community-based treatment³². According to Hungarian regulations psychiatric patients may be treated against their will in health care facilities only if they are in a condition which poses danger, or immediate danger, and they have to be released from hospital as soon as treatment has been completed. Treatment may then be continued on an outpatient basis. Patients who have just been released from hospital but express a wish for in-patient treatment, or their lawful representative, may apply for admission to a social care home. This is no longer the area of health care but that of social services, with a different set of conditions and rules. Regrettably enough, there is a sore lack in Hungary at present of forms of treatment for psychiatric patients other than medical treatment in hospitals, which live up to the requirements of modern psychiatric practice and international legal principles.

In 2001 modifications to the Act on Social Services got under way. The modifications envisage a greater role for the development of communal provision, day-time and temporary psychiatric homes, social services rendered in the patient’s own home including home assistance and provision of meals. All of these are designed to be managed by local authorities.

Competence and the Right to Self-Determination

We have seen that the HCA excludes both incompetent persons and persons of limited competence from the opportunity to exercise their right to self-determination. This was what lead to the Constitutional Court’s ruling 36/2000 (X.27) according to which these provisions were unconstitutional. This was followed by Act 2001:XXXIV. The modification prescribed by the Constitutional Court ruling was to have regulated the right of persons of limited competence in matters of health care in a way different from the right of those who are incompetent. In our view, the situation in terms of the right of incompetent persons and persons of limited competence to consent and rejection is the same after the modification as it was before it. This is important also because this state of regulations severely affects the right of psychiatric patients to self-determination.

Judgement on competence plays a key role in the treatment of psychiatric patients. If the person is competent, s/he and no one else decides – within the bounds of the law – on matters relating to his/her treatment. This is in harmony with international legal principles. Consent is an ineluctable condition of all interventions which can be performed on human beings³³.

If the patient is under guardianship with respect to his/her right to self-determination in matters of health care, his/her guardian is to decide for him/her on consent to the treatment.

³⁰ UN Principle 9. Paragraph 1.

³¹ HCA Article 190. Paragraph b.

³² UN Principles 3 and 7; WHO Principles Paragraph 4.

³³ WHO Principles Paragraph 5 on self-determination.

The UN principles contain similar guidelines on this issue: a psychiatric patient may be treated without his/her consent as long as the patient's personal representative empowered by law consents to it on the patient's behalf³⁴. The –WHO principles go beyond the legal principles enunciated in the HCA. According to Principle 5 if the mental patient is incapable of making a decision, surrogate decision-maker proceeds on his/her behalf. No one may be put down as incapable of exercising his/her right to self-determination just because on one occasion s/he was incapable of exercising his/her right to decide. Psychiatric patients are to be given the benefit of not being put down as generally incapable of exercising their right to self-determination but having it always examined in specific cases whether they are capable of making a decision in line with their interests.

If the psychiatric patient is not under guardianship but s/he is in fact in a condition of incapacity to exercise his/her right to decide, the right to consent is exercised by the persons who are listed in the HCA. If the limitation of competence is only transitory and does not require the patient to be placed under guardianship, the patient's right to self-determination is not to be restricted on the long term. Such a case is in harmony with the above-mentioned WHO Principles.

The Recommendation puts the matter in general terms: “the placement, by itself, cannot constitute, by operation of law, a reason for the restriction of the legal capacity of the patient³⁵”. Hungarian regulations live up to this general legal principle: no person may automatically lose his/her competence only because s/he has once been treated for some psychiatric ailment.

General rules on patient rights are to be applied to the more specific right of psychiatric patients to self-determination. With respect to the right to self-determination, however, there is a rule applicable only to psychiatric patients, according to which psychiatric treatment of incompetent psychiatric patients and psychiatric patients of limited competence requires only the consent of their lawful representative. To prevent abuses of this right in the protection of the rights of psychiatric patients, legal regulations presently in force incorporate a procedure under which the validity of the consent of the lawful representative and the necessity of treatment are to be reviewed by a court *ex officio*. In our view, this rule goes beyond international legal principles because it prescribes a decision to be made by an independent judicial body on every case of psychiatric treatment in which the patient's lawful representative is entitled to decide for the patient.

General rules on patient rights are authoritative also for the right of psychiatric patients to consent and information. According to these rules the patient's consent to treatment is to be based on appropriate information. This applies to the provision of information for psychiatric patients as well, with the difference that if the patient is in a dangerous or immediately dangerous condition, an attempt to provide information must be made in every case, but the need for consent may be disregarded. In addition to the general rules, the HCA also prescribes that psychiatric patients are to be informed in the hospital about their rights, especially about those relating to civil commitment procedure, either orally or in writing.

Informing patients involves letting them know their medical records. Under the HCA the