

# THE DEVELOPMENT AND PROGRESS OF PATIENTS' RIGHTS

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## I. THINKING GLOBALLY

### INTRODUCTION

The patients have both rights and responsibilities when it comes to their health and the health care services they receive. When an individual makes such a decision, she expresses her conception of the good life, of the adequate level of health, of the way she wishes to look, and of her views about bodily suffering. We cannot feel secure in our right to self-determination regarding medical treatment unless it is the case that the law provides for our rights in the context of medical treatment and for the conditions which are necessary for the exercise of these rights. The rules related to the rights of patients are meant to ensure that you should be able to exercise your human rights even during the period of your life when you are subjected to medical treatment.

### BACKGROUND

#### From the beginning to the year 1950

The point of departure is the principle which was defined fifty years ago in the *Universal Declaration of Human Rights*: „Everyone has the right to a standard of living adequate for himself and his family, including ...medical care ...” (Article 25).

#### Since the 70s,

several international declarations have been made that cover the principles of patients' rights.

Issued by

- **World Health Organization** : Declaration of the Promotion of Patients' Rights in Europe, adopted in Amsterdam, 1994
- **Council of Europe** : Convention on Human Rights and Biomedicine, adopted in Oviedo, 1997
- **World Medical Association** : Geneva Declaration, Helsinki Declaration, Sydney Declaration, etc.

### DISCUSSION

#### The categories and levels of international regulations :

**Law** : In case the rights of the patients are stipulated by law.

The rights of patients that have been included in the relevant legislation - such as the right to informed consent, the right to freedom of choice of a provider, the right to confidentiality of medical records, etc. - aim at ensuring that the choices patients make about their treatment options should become an essential part of their medical treatment, and that everybody should be able to exercise this right during the entire course of medical treatment.

**Part of the law** : The patients' rights are often declared by the general Health Care Act. Legislators in Hungary, Slovakia, Bulgaria, Poland, Croatia and Georgia have followed this way.

**Separate laws** : The specific medical intervention - as for instance, the transplantation of organs and tissues - or medical research are covered by separate laws, which in turn include provisions related to the rights of patients in that field.

**Charters** : Incorporating the rights of the patients in a charter. Federations of hospitals or a chamber of physicians may issue such a charter for instance. A document like this may have jurisdiction over specific institutions, a region or a country.

#### A list of the most important patients' rights

1. Right to health care
2. Right to freedom of choice of a provider
3. Right to be treated with dignity
4. Right to information
5. Right to informed consent
6. Right to make an advance directive
7. Right to refuse treatment
8. Right to leave the health care institution
9. Right to informational privacy
10. Right to die in dignity
11. Right to complaint
12. Right to participation in decision-making in health care

### JUDGEMENT

The most efficient way of ensuring patients' rights is for the individual countries to incorporate them into a *separate law*. A law that covers all the aspects of the rights of the patient and does not deal with any other issues than these can define unequivocal rules both for the health care provider and patient. As it forms a single legal instrument, it is readily accessible and transparent. When the rights of patients are spelled out in a separate law, that acknowledges the importance of the issue.



Right to Health Care



Right to be treated with dignity



Right to connection



Right to information



Right to refuse treatment



Right to cognition of medical record



Right to leave health care institution

## II. ACTING LOCALLY

### THE HUNGARIAN PATIENTS' RIGHTS

are discussed in 1997/CLIV. *Hungarian Health Care Act*.

Antecedents : Hungarian Constitution in harmony with

- European Social Charta (1961)
- Declaration on the Promotion of Patients' Rights, Amsterdam (1994)
- Convention on Human Rights and Biomedicine, Oviedo (1997).

Survey of patients' most important rights - which are declared in the Hungarian Health Care Act - are needfuls

### CONCLUSIONS

- Hungary ratifies those international conventions - as for instance, the Council of Europe's Convention on Human Rights and Biomedicine - which define the principles of the rights of patients
- Meaningful relations be established among the East-Central European public interest law organizations that focus their activities on patients' rights so that they could exchange information and take joint action
- Consumers of the health services should get the opportunity to play an effective role in decision-making in the health care system
- Creation of institutions that protect the rights of patients
- Whenever the rights of patients are violated, citizens should get access to legal counseling and representation
- Publications, training programs and public information services that educate the public on the rights of patients.

### ROLE OF HEALTH AND MEDICAL LIBRARIES

#### regarding knowledge of patients' rights in Hungary

Information Technology creates possibilities we could only dream of a few years ago. Health librarians, because of their knowledge and training in the identification and dissemination of information, play an important role in both health information services and patients' rights education.

**Patients' rights informations (definition)** are informations on health and medical topics provided in response to request from the general public, including patients and their families. In addition to information on the symptoms, diagnosis and treatment of disease, patients' rights information encompasses information on health promotion, preventive medicine, the determinants of health and accessing the health care system.

#### 1.) Collection management of patients' rights materials:

- public available for review and possible purchase
- selection from the organization including books, journals, pamphlets, AV and digital documents, etc.
- treatment an authentic collection in print and electronic form that meets the needs of the institution or community being served
- care about subject file collections on current topics of interest to patients, physicians, etc.

#### 2.) Organization of public information services on patients' rights:

- connecting with other organizations and agencies to facilitate resource sharing of materials
- consulting on the identification, selection and organization of patients' rights education materials in health care settings
- working with our institution and the community to develop informational and educational programs related to health issues
- sharing the results of their patients' right education experience with other professionals, both in the library field and outside, in order to improve these services

#### 3.) Construction of separated patients' rights (patients' education) web pages, links to consumer health portals

- main valued web pages, that are accessible via Internet

#### in the world :

- NLM Patients'Rights portal=  
[www.nlm.nih.gov/medlineplus/patientissues/html](http://www.nlm.nih.gov/medlineplus/patientissues/html)
- National Coalition for Patient Rights =  
[www.health.gov/nhic/NHICScripts](http://www.health.gov/nhic/NHICScripts)
- Patient R. and Responsibilities =  
[www.consumer.gov/qualityhealth/rights.htm](http://www.consumer.gov/qualityhealth/rights.htm)=
- [www.patientrights.com](http://www.patientrights.com)
- Patients' Rights education and research =  
[www.patient-rights.org](http://www.patient-rights.org)
- European Charter for the Rights of Patients=  
[www.activecitizenship.net/health](http://www.activecitizenship.net/health)

#### in Hungary:

- Foundation for Patients' Rights = [www.szozolo.hu/szozolo.html](http://www.szozolo.hu/szozolo.html)
- Hungarian Civil Liberties Union = [www.C3.hu/~hclu/](http://www.C3.hu/~hclu/)
- Patient Advocate = [www.euuzlet.hu/betegjog.html](http://www.euuzlet.hu/betegjog.html)  
[www.vitalitas.hu](http://www.vitalitas.hu)

Physicians' and Patients' Rights = [www.melania.hu/morvos/archivum](http://www.melania.hu/morvos/archivum)

- **dissemination** of Patients' Rights Information  
sending information to hospitalized patients and their families, providing a current awareness service for our health professionals about new education materials, creating hungarian consumer health information center, which provide patient information resources, reference and teaching materials, performing interlibrary loan requests for materials not available in other libraries.

### SUMMARY

The Librarians' activities are oriented towards the social and community goals of producing a healthy society as well as assisting patients' education the individual to make more informed health decisions.