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The Enlargement of the Empirical Basis of Sociological Research on Human Rights in Developed Countries. The Case of the European Charter of Patients' Rights.

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DRAFT VERSION

Content

What about human rights in developed countries?

This paper does not aim at taking the floor on the theoretical debate on human rights and on the epistemological basis of a sociology of human rights. It is rather devoted to highlight a problem that, *prima facie*, such a sociology should address.

The problem is that both scientific research and policy activity on human rights in well-based democratic regimes seem to have a relatively poor empirical content. It seems, indeed, that in these countries human rights fit just with far rare and extreme situations, such as arbitrary deprivation of life, torture, arbitrary arrest and detention. To give an example, we can use the list of topics of the US State Department report on human rights in Italy: denial of fair public trial, violations of privacy, lack of freedom of speech and press, restrictions to academic freedom and freedom of association, lack of freedom of religion, obstacles to the free movement, lack of respect for political rights, governments' refusal of international and nongovernmental investigation, discrimination based on various factors, lack of workers' rights, trafficking in persons.

As everyone can see, whatever criticism can (and should) be addressed to developed countries, these phenomena are definitely (and fortunately) marginal.

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Of course, these negative phenomena, made visible thanks to human rights, in any case are very important benchmarks for the assessment of the quality of public life in these countries. They are also a warning against any possible deviation from the rule of law or any temptation to take shortcuts on governments' and other actors' side. They are, finally, a tool of crucial importance in order to deal with new kinds of problems, such as those related to biomedical research or to information technologies.

The point is that, with the relevant exception of the question of rights of immigrants as individuals and as groups, human rights discourse does not regard the everyday life of common people of rich and well-established countries. It therefore risks to be considered suitable only for developing countries or for some transnational, global issues, with, among others, a paradoxical ethnocentric effect.

Apart any political evaluation on this point, it must be stressed that this situation affects not only public policy making, but also scientific research, since it could make difficult to use the human rights discourse as a heuristic apparatus to increase knowledge on rich societies.

In order to favor the discussion on this point, this paper reports an experience of use of human rights documents and norms involving common citizens and one of the most important welfare service, that is, health care.

The European Charter of Patients' Rights

The European Charter of Patients' Rights was set up in the second half of 2002 on the initiative of Active Citizenship Network (ACN, see the website www.activecitizenship.net). ACN is the European policy program of the Italian movement Cittadinanzattiva (www.cittadinanzattiva.it), an organization well-known for its pioneering "Tribunal for Patients' Rights", established in 1980.

The Charter was drafted by an ACN working group with the involvement of experts in advocacy and patients' rights as well as representatives of 11 European citizens' and patients' organizations. It was presented and discussed during a multistakeholder conference in Brussels in November 2002 and then published in a revised version.

The Charter started by an analysis of the condition of patients in the 15 (at that time) EU countries, carried out both by the (few) available documents and by consulting national-based civic organizations and experts. A phenomenology of the most important and recurrent cases of violation of rights of citizens as patients, users, engaged families and networks, was set up. In the preamble of the Charter the meaning of this operation has been clarified:

> Despite their differences, national health systems in European Union countries place the same rights of patients, consumers, users, family members, weak populations and ordinary

> people at risk. Despite solemn declarations on the "European Social Model" (the right to universal access to health care), several constraints call the reality of this right into question. As European citizens, we do not accept that rights can be affirmed in theory, but then denied in practice, because of financial limits. Financial constraints, however justified, cannot legitimize denying or compromising patients' rights. We do not accept that these rights can be established by law, but then left not respected, asserted in electoral programs, but then forgotten after the arrival of a new government.

Cases and situations of violation of rights were grouped in 14 clusters. For each cluster a specific right of patients, violated or at risk, was identified. From this operation the following 14 rights of patients were identified:

1. *Right to preventive measures*: Every individual has the right to a proper service in order to prevent illness.

2. *Right of access*: Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.

3. *Right to information*: Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available.

4. *Right to consent*: Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.

5. *Right to free choice*: Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information.

6. *Right to privacy and confidentiality*: Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.

7. *Right to respect of patients' time*: Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.

8. *Right to the observance of quality standards*: Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards.

9. *Right to safety*: Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.

10. *Right to innovation*: Each individual has the right of access to innovative procedures, including diagnostic procedures, according to international standards and independently of economic or financial considerations.

11. *Right to avoid unnecessary suffering and pain*: Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.

12. *Right to personalized treatment*: Each individual has the right to diagnostic or therapeutic programs tailored as much as possible to his or her personal needs.

13. *Right to complain*: Each individual has the right to complain whenever he or she has suffered a harm and the right to receive a response or other feedback.

14. *Right to compensation*: Each individual has the right to receive sufficient compensation within a reasonably short time whenever he or she has suffered physical or moral and psychological harm caused by a health service treatment.

For each of these rights, besides a general definition, a list of concrete circumstances and policy directions were set up. Let's take a couple of examples:

3 - Right to Information

Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available.

Health care services, providers and professionals have to provide patient-tailored information, particularly taking into account the religious, ethnic or linguistic specificities of the patient.

The health services have the duty to make all information easily accessible, removing bureaucratic obstacles, educating health care providers, preparing and distributing informational materials.

A patient has the right of direct access to his or her clinical file and medical records, to photocopy them, to ask questions about their contents and to obtain the correction of any errors they might contain.

A hospital patient has the right to information which is continuous and thorough; this might be guaranteed by a "tutor".

Every individual has the right of direct access to information on scientific research, pharmaceutical care and technological innovations. This information can come from either public or private sources, provided that it meets the criteria of accuracy, reliability and transparency.

7 - Right to Respect of Patients' Time

> *Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.*
> The health services have the duty to fix waiting times within which certain services must be provided, on the basis of specific standards and depending on the degree of urgency of the case. The health services must guarantee each individual access to services, ensuring immediate sign-up in the case of waiting lists. Every individual that so requests has the right to consult the waiting lists, within the bounds of respect for privacy norms.
> Whenever the health services are unable to provide services within the predetermined maximum times, the possibility to seek alternative services of comparable quality must be guaranteed, and any costs borne by the patient must be reimbursed within a reasonable time. Doctors must devote adequate time to their patients, including the time dedicated to providing information.

The final part of the Charter contains the definition of three "political rights" of citizens' organizations engaged in protection of patients' rights. They are:

- the right to perform general interest activities;
- the right to perform advocacy activities;
- the right to participate in policy making.

The link with Human Rights

In order to give strength to the patients' rights set up in the ACN Charter, a close link with the Charter of Fundamental Rights, contained in the EU Nice Treaty of December 2000, was established. It was indeed considered as the basis of the 14 patients' rights. The link between patients' rights and fundamental human rights set up in the Nice Charter was explained as follows:

> The Charter of Fundamental Rights, which will represent the first "brick" in the European constitution, is the main reference point of the present Charter. It affirms a series of inalienable, universal rights, which EU organs and Member States cannot limit, and individuals cannot waive. These rights transcend citizenship, attaching to a person as such. They exist even when national laws do not provide for their protection; the general articulation of these rights is enough to empower persons to claim that they be translated into concrete procedures and guarantees. According to Article 51, national laws will have to conform to the Nice Charter, but this shall not override national constitutions, which will be applied when they guarantee a higher level of protection (Article 53). In conclusion, the particular rights set forth in the Nice Charter are to be interpreted extensively, so that an appeal to the related general principles may cover any gaps in the individual provisions.

The main point of reference for patients' rights in the Nice Charter was, of course, identified in the Article 35 of the Charter, which provides a right to health protection:

> *The right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.*

As for the relation between Article 35 and national legislations and institutions, the ACN Charter maintains that

> Article 35 specifies that the Union must guarantee "*a high level of protection of human health*", meaning health as both an individual and social good, as well as health care. This formula sets a guiding standard for the national governments: do not stop at the floor of the "minimum guaranteed standards" but aim for the highest level, notwithstanding differences in the capacity of the various systems to provide services.

In addition, a set of other pertinent rights of the Nice Charter were cut out. They refer either directly or indirectly to patients' rights:

- the inviolability of human dignity (article 1);
- the right to life (article 2);
- the right to the integrity of the person (article 3);
- the right to security (article 6);
- the right to the protection of personal data (article 8);
- the right to non-discrimination (article 21);
- the right to cultural, religious and linguistic diversity (article 22);
- the rights of the child (article 24);
- the rights of the elderly (article 25);
- the right to fair and just working conditions (article 31);
- the right to social security and social assistance (article 34);
- the right to environmental protection (article 37);
- the right to consumer protection (article 38);
- the freedom of movement and of residence (article 45)

Then, other international documents and declarations were recalled as the basis of the patients' rights:

- the WHO Declaration on the Promotion of Patients' Rights in Europe, endorsed in Amsterdam in 1994;
- the WHO Ljubljana Charter on Reforming Health Care, endorsed in 1996;
- the WHO Jakarta Declaration on Health Promotion into the 21st Century, endorsed in 1997;
- the Council of Europe 1997 Convention on Human Rights and Biomedicine;
- the Council of Europe Recommendation Rec(2000)5 for the development of institutions for citizen and patient participation in the decision-making process affecting health care.

The rationale for these quotations is that "all these documents consider citizens' health care rights to derive from fundamental rights and they form, therefore, part of the same process as the present Charter".

The implementation of the Charter/1: the Civic Audit

As an implementation of the right of citizens' organizations, stated in the Charter, to act in health systems for the protection of patients' rights, a monitoring of the situation of the 14 patients' rights was carried out in 2003-2004. Because time and resource constraints, it was implemented in the 15 "old" EU countries only using the technology of *Civic Audit*. It is the production by citizens of their own information with the possibility to contribute in assessing public policies. This type of activity has been successfully experimented in Italy by Cittadinanzattiva on several issues and services, including health care at national and local levels for some time now.

In practice, ACN and partner organizations carried out a survey which main features were the following.

First of all, there were identified four sources of information:

- Key persons operating in the health care at national level (KP);
- Partner organizations as qualified informers on the state of patients' rights in each country (PO);
- Hospital authorities responsible for hospital management (HA);
- Concrete situations able to be directly observed inside hospitals by partner organizations' monitoring groups (DOH).

The survey was conducted in each country focusing on the three main hospitals of the capital and identifying a sample of key persons.

Secondly, a set of *174 indicators* regarding the 14 patients' rights and forming a *Patients' Rights Matrix* were defined. For example, with regard to right to time the following indicators were defined.

Right to safety	**DOH**	**HA**	**PO**	**KP**
Protocols for the sterilization of medical instruments used in hospitals *(Y/N)*			*X*	*X*
Protocols for the prevention of hospital infections used in hospitals *(Y/N)*			*X*	*X*
Risk management techniques used in hospitals *(Y/N)*			*X*	*X*
Epidemiological investigations of hospital infections carried out *(Y/N)*			*X*	*X*
Cases when the right was not respected			*X*	*X*
Opinion on the extent the right is respected			*X*	*X*
Procedures for reporting the following *(Y/N)* ▪ Hospital acquired infections ▪ Burns from fires ▪ Falls ▪ Pressure ulcers ▪ Phlebitis associated with intravenous lines ▪ Restraint-related strangulation ▪ Preventable suicides ▪ Failure to diagnosis or incorrect diagnosis ▪ Failure to utilize or act on diagnostic tests ▪ Use of inappropriate or outmoded diagnostic tests or treatment ▪ Medication errors/adverse drug effects ▪ Wrong-site errors; surgical errors ▪ Transfusion mistakes		*X*		
Reporting of near misses *(Y/N)*		*X*		
Office or person in the hospital charged with coordinating activities for reducing the risk of infection *(Y/N)*		*X*		
Written procedures (protocols) for checking and reducing risks control of hospital infections *(Y/N)*		*X*		
Priority codes in triage procedure in Emergency Room *(Y/N)*	*X*	*X*		
Emergency exit signs *(Y/N)*	*X*			
Evacuation route for wheelchair users *(Y/N)*	*X*			

Fire extinguisher *(Y/N)*	*X*			
Evacuation maps *(Y/N)*	*X*			
Special evacuation procedures for wheelchair users on map *(Y/N)*	*X*			

Let us give another example, regarding the right to personalized treatment. In this case some indicators are quantitative (#).

Right to personalized treatment	**DOH**	**HA**	**PO**	**KP**
Personalized support given in hospitals - Choice of meals *(Y/N)*		*X*	*X*	*X*
Personalized support given in hospitals - Psychological support for terminal patients and their families *(Y/N)*			*X*	*X*
Personalized support given in hospitals - Spiritual support based on personal *(Y/N)*			*X*	*X*
Personalized support given in hospitals - Cultural mediation and/or foreign language interpretation *(Y/N)*			*X*	*X*
Personalized support given in hospitals - Educational support for children hospitalized *(Y/N)*			*X*	*X*
Cases where this right has not been respected *(Y/N)*			*X*	*X*
Distribution of patients meal *(#)*		*X*		
Religious assistance available *(Y/N)* ▪ Protestants ▪ Anglican ▪ Catholic ▪ Orthodox ▪ Jewish ▪ Muslim		*X*		
Psychological support *(Y/N)* ▪ terminal patients and their family ▪ transplant patients and their family ▪ women who have suffered violence ▪ patients in other conditions		*X*		
Written procedures for second opinion *(Y/N)*		*X*		
Number of hours for visiting the patients *(#)* ▪ Sundays and holidays ▪ weekdays		*X*		
Interpreters *(Y/N)*		*X*		
Cultural mediators *(Y/N)*	*X*			
Play areas inside paediatric wards *(Y/N)*	*X*	*X*		
appropriate furnishing inside paediatric wards *(Y/N)*	*X*	*X*		
parents be present 24 hrs. day *(Y/N)*		*X*		
a place for relatives to sleep in the room that is appropriate *(Y/N)*	*X*	*X*		
Use of cafeteria for parents *(Y/N)*		*X*		
Educational support for children *(Y/N)*		*X*		

Thirdly, citizens' organizations were involved in the collection of information through the direct observation of hospital facilities and interview hospital authorities. This gave them the opportunity to put into practice their right to participate in evaluating services and policies. However, as well as being the most innovative part of this research, it also proved to be the most difficult, due to the fact the that this type of citizens' activity does not seem to be a ordinary practice in most countries. For many organizations it took a long time and required many attempts before they were actually able to have an interview with the hospital administration. Often, they were given the so-called "run around", as hospitals seemed to adopt a passive resistance approach, not recognizing the legitimate role of citizens to seek information regarding health care services. In the end, four countries (Portugal, Ireland, Germany and the UK) were not able to get an interview with hospital authorities.

Fourthly, an overview of official data on the 14 patients' rights existing at European level was done by people from the Faculty of Statistics of La Sapienza University of Rome.

The research gave information on the state of patients' rights by identifying phenomena that can be considered *indicators of attention* towards those rights; and it reflected an approach to health care issues based on the point of view and the condition of citizens, patients or users of health facilities.

The main results regarded two aspects. On one side, information on the existing phenomena affecting each of 14 rights on a European basis were gathered. On the other side, it was possible to rank the 14 rights with reference to the registered level of attention.

As for the first point, it can be given the example of two rights.

> *2. Right to Access*
> *Access to care: A limited universalism - What essential levels of care?*
> In all the countries the existence of groups of people not covered by national health services or confronting obstacles limiting their access to adequate care was reported. These obstacles are the lack of coverage by public insurance for health services considered essential to the public, the existence of administrative and/or economic obstacles to access services, and the access to drugs which have been approved in other countries, but not yet in their own.
> *Physical access: Accessibility, but not for all*
> A satisfactory widespread availability of facilities for public access to hospitals emerged in 11 countries out of 13. However, accessibility for persons with disabilities that are clearly marked was reported only in 8 countries out of 13.
>
> *14. Right to Compensation: Insurance policies, not ever existing - A good practice not much followed*
> In almost all of the countries there are insurances covering the compensation for possible damages to patients. Nevertheless, they do not always cover both provider and doctor but usually just one of the two. In two countries hospitals and doctors do not have any insurance.
> In five countries, committees or structures to assist patients in reaching final agreements on compensation and/or on its amount, do exist and in almost all cases are independent from hospitals.

As for the second point, it can be reported the table ranking the level of attention to rights.

General classification of Patients' Rights according to the Degree of Attention

DEGREE OF ATTENTION	RIGHT	SCORE
HIGH	Access – Physical	26
	Complain	26
	Privacy	25
	Information	24
	Safety	24
MEDIUM	Personalized Treatment	22
	Quality	21
	Innovation	20
	Avoid pain	20
LOW	Free choice	19
	Compensation	19
	Prevention	18
	Consent	18
	Access – Care	17
	Time	16

Score: min 9, max 27; average: 21
Active Citizenship Network, 2005

The implementation of the Charter/2: agreements with health authorities

A second kind of implementation activity has been the opening of roundtables with health authorities at national and at European levels, in order to define policy programs able to take into account the content of the Charter. At the moment, the most relevant result of this activity is the agreement between Cittadinanzattiva (including the two initiatives of the Tribunal for Patients' Rights and the National Alliance of Associations for the Protection of Chronically Ill Patients-CNAMC) and the Italian Lazio Region. It must indeed be taken into account that in Italy the management of health service in decentralized.

The agreement was signed on June 2004. One of the three points of the agreement regarded precisely the European Charter of Patients' Rights. Cittadinanzattiva and Lazio Region decided

1. to institute a **permanent roundtable for discussion and review**, with periodic work sessions every three months, in which the General Directors of health clinics and hospitals and the representatives of Cittadinanzattiva present in these health services, through the Patients' Rights Tribunal and the associations of chronically ill patients belonging to CNAMC, will participate, in order to determine the most important questions regarding access to services and their quality, and to discuss the possible solutions that may be carried out in a reasonable time period;
2. to set forth, by common accord, **directions and standards for the annual review of the General Directors' activity** from the public's perspective, on the basis of the 14 rights of the European Charter of Patients' Rights, avoiding that the evaluation be based primarily on economic and financial criteria. The results of this public evaluation

contribute to the review and thus the reconfirmation and economic incentivization of the general directors of the local health agencies and hospitals. Cittadinanzattiva, acting through the Patients' Rights Tribunal and the organizations of the chronically ill belonging to CnAMC, undertakes to provide the Region with the data emerging from the periodic monitoring and civic audits carried out in cooperation with the health agencies and the Region;

3. to undertake to decrease the **waiting periods** for a number of particularly critical diagnostic and specialist services. In the first year of implementation of this protocol, the services taken into consideration will be **ultrasound in the first trimester of pregnancy, mammography, CAT, NMR**. The specific activities will be based on the convocation of health service roundtables, the determination of the actions to consider for the reduction of waiting periods, their implementation and review of their results.

Apart the establishment of the permanent roundtable which is dealing with the whole contents of the agreement, among the results already achieved, it can be noticed that related to the right to time. In particular, a unique system of phone reservation enabling general practitioners to ask priority for urgent cases allowed to deliver services within 72 hours to thousands of people at risk. Moreover, new rules on waiting times were established by the regional administration, enabling citizens to have access to alternative services in case of inability of the administration to respect the predetermined maximum time.

Conclusive remarks

Of course, the process of implementation of the Charter is only at the beginning. Moreover, it was not yet promoted any legal action asking the respect of the rights of the Charter at national level. But this is a consideration more relevant on the policy side rather than on research side.

On the side of research, what presented above suggests that human rights framework could be used as a heuristic tool to gather information and enrich the knowledge on situations affecting common citizens in countries where serious crisis in human rights do not exist. In particular, the Charter of Patients' Rights has allowed citizens' organizations and health stakeholders to grasp as critical and negative a number of phenomena that otherwise could have been considered as normal. For example, it enabled to consider the lack of administrating painkillers or morphine to alleviate suffering not only a medical matter, but also a matter of human rights. On the other hand, this approach allowed to consider a number of citizens' organizations as actors of the implementation of human rights in their countries, definitely enlarging the number of people involved in this discourse.

The use of human rights as a point of reference for situations and problems as the one of patients' rights could, in my opinion, enlarge the field of research of a sociology of human rights in developed countries, avoiding its limitation – apart immigration-related issues – to extreme situations.

From the knowledge point of view, the 14 patients' rights established in the Active Citizenship Network Charter could be considered as human rights indicators, enabling human rights to be observed on the field. The fact that such indicators come from the activity of citizens' organizations involved in policy making activities could be considered an added value of this process.

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