

OBSERVING PATIENTS' RIGHTS, BETWEEN PERCEPTION AND REALITY

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Abstract

Increasingly, both at the European level and internationally, the idea has gained ground that an investment in health actually represents an investment in a country's economic prosperity. (The Council of the European Union, 2006). With all the financial and legal efforts registered in this field, not only in Romania, but at an international level as well, criticism is on the increase. As a consequence of the degradation of the population's health, of the rise in healthcare costs, of a more quality-based medical procedure, as well as a consequence of the competition brought forth by the private practices to the public healthcare services, the patient is progressively treated as a client, whose rights are and must be respected and whose satisfaction must be monitored; the numerous reports and research studies carried out within the European Commission also stand proof of this fact. (Patient Safety and Quality of Care, 2014; Patients' rights in the EU, 2014; Patient Safety in the EU: 2014, etc.)

Following the methodology of the pilot study, the purpose of the present paper is to highlight the extent to which the patients' rights are known and observed in Romania; our analysis of the specialized literature, of the reports and of the current national and European legislation has enabled us to gather information and to clarify the theoretical concepts we use.

Keywords: Patient rights, patient satisfaction, healthcare services, quality.

JEL Classification: I15, K32

Introduction

In the large framework of the services, Healthcare services play a central role, being the most important services offered to the population. As beneficiaries of these services, which are essential for a population's health status and for a country's future, and as a consequence of the ever-growing competition between the private and public sectors, we consider that patients must be treated as proper clients and consumers of the services offered by the different healthcare suppliers, whose rights must be known and observed, as in the case of consumers of any products and services on the market. Also, in this case,

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patients can contribute to the development and increase of the healthcare services quality, through correct information and proper sanitary education, which would allow them to knowingly get involved and aspire to a good health state, in accordance with their continuously increasing requirements.

1. The methodological design, by means of summarizing the most recent specialized literature on quality management and integrated management

It is not only healthcare services that raise numerous discussions, but also the notion of patient, which has evolved in time, also with the focus of medical services on total quality and excellence.

While Law 46/2003 on patient rights defines the patient only as a "*healthy or sick person who uses health services*", the World Health Organization, in Section 2 "Quality concepts and Tools" of the report called "*Quality and accreditation in health care services - a global review*" (2003) refers to patients as "consumers, users and clients" (p. 64): "*„a satisfied paying patient is a commercial asset; users increasingly assert moral and legal rights to consent and to make informed choices*" whose rights must be acknowledged and observed. While the Explanatory Dictionary of the Romanian Language (2009) defines "*healthcare assurance (protection)*" as being "*a complex of measures established by the state in order to prevent disease, to consolidate and restore health, to extend lifespan and the work capacity of the people*", additionally, healthcare assurance also represents one of the fundamental citizen rights stipulated by the Constitution of Romania (art. 34), as well as one of the fundamental consumer rights, whereas "*patient protection*" is defined as "*by laws on freedom of information and on the general protection of consumers and their data*" (World Health Organization, 2003, op. cit. Willison, D., 2000).

Although patient rights are included among the fundamental human rights, it was only in 1994, within the European Consultation on the Rights of Patients, held in Amsterdam, that the principles and strategies for promoting patient rights were defined and the *Declaration on the Promotion of Patients' Rights in Europe* was adopted, followed by *The Ljubljana Charter on Reforming Health Care*, endorsed in 1996, and by *The Jakarta Declaration on Health Promotion into the 21st Century*, endorsed in 1997.

After having studied the legislation on patient rights in the EU member states, we have selected, for exemplification, the following three cases: the law in one of the former socialist countries, a EU member state - Lithuania; a country which ranks among the smallest EU member states - Cyprus, as well as the legislation in the UK, which we have chosen due to the conciseness of the regulated rights, since the UK is well known for its focus on quality in all social and economic areas.

In the Republic of Lithuania, the "Law on patients' rights and the compensation for the damage done to their health" was adopted in 1996, amended in 2009, and it stipulates the following ten rights of patients: *Right to High Quality Health Care Services; Right to Choose a Health Care Institution and a Health Care Professional; Right to Information; Right not to Know; Right of Access to Entries in One's Medical Records; Right to Privacy; Specifics of the Right to Privacy; Patient's Right to Anonymous Health Care; Patient's Participation in Biomedical Research and Teaching Process; Right to Compensation for the Damage.*

The Safeguarding and Protection of the Patients' Rights Law, 2004, of the Republic of Cyprus stipulates the following 15 patients' rights: *Right to health care and treatment* (according to the patient's needs, within a reasonable period of time, unconditionally in case

of medical emergencies; high quality services, through the cooperation of all service suppliers and medical institutions involved in diagnosing and treating the disease etc); *Dignified treatment* (according to the patient's own religious and cultural values, ensuring the access of the family and friends, psychological support etc); *Access to health care services* (available and affordable services, in harmony with the possibilities of the health care system and of the available financial, human and material resources); *Prohibition of unfavourable discrimination* (in case there is a need to choose which of the patients will benefit from a certain health care service, this shall be done without discrimination of any kind, in a fair manner, based on the objective scientific / professional criteria); *Health care in a medical emergency or in a life threatening situation* (in case there is a medical emergency, the medical institution or the physician shall examine and treat the patient as soon as possible and in the best conditions possible; if this cannot be done, the patient shall be transferred to a different institution); *Medical examination in an Emergency Department*; *Right to information*; *Health care with the consent of the patient* (the patient has to express consent to the treatment after having received in-depth information they can understand - innovative treatment, transplants etc; exceptional cases when the medical information is not given to the patient but to their family etc); *Medical information*; *Health care without the consent of the patient* (when the patient is in a mental or psychological state preventing them from expressing consent; if that is the case, the consent is considered to be implied; in the case of minors, consent must be expressed by the parents or by other authorized persons, etc); *Participation of the patient in scientific research or experimental treatment*; *Confidentiality*; *Protection of the patient's privacy*; *Rights of the patient regarding medical records access*; *Right of representation* (in patient groups or associations, with a view to expressing their opinions on health policies and their implementation).

The National Health Service Constitution - NHS in the UK looks completely different. Published in 2012 and amended in 2015, it only stipulates six generic rights of patients. The Constitution is legally binding for all the bodies of the National Health System, for the private sector and for all suppliers in the field; it includes the patients' rights, the rights of patients' families and of their next of kin, of the employees, and their responsibilities as well. The Constitution lays down the following rights of patients: *Access to health services*; *High quality services and environment*; *Nationally approved treatments, programmes and medication*; *Respect, consensus and confidentiality*; *Informed choice*; *Involvement in the patient's own health care and in the NHS activity*; *Complaints and damages*.

Starting from the remark that, in spite of existing differences, the national health care systems in the EU member states all focus on the same fundamental patients' rights, in 2002, the *Active Citizenship Network* along with other civil organisations elaborated a document called "*European Charter of Patients' Rights*", which stipulates 14 fundamental rights: *the right to preventive measures, access, information, consent, free choice, privacy and confidentiality, respect for patients' time, observance of quality standards, safety, innovation, avoidance of unnecessary suffering and pain, personalised treatment, and the right to complain and to receive compensation*.

In 2003, Romania adopted *Law no. 46 on Patient Rights*, which includes the fundamental patient rights as well as penalties for the medical staff in case these rights are infringed; however, it does not include any provisions with respect to the patients' responsibilities, as is the case with other European laws. Under this law, the fundamental patient rights in Romania are the following: *Patients have the right to the highest quality of medical care*;

Patients have the right to be respected as human beings, with no discrimination; Patients have the right to access medical information; Patient consent regarding the medical procedure; The right to confidentiality regarding the patient's information and private life; Rights of the patient in the field of reproduction; Patient rights to treatment and medical care.

Thus, we can see that there exists neither a common vision nor a unitary definition of patients' rights at the European level; still, the regulation process is under way. Hence, on October 25, 2013, the EU introduced the *Directive on cross-border healthcare* that includes *three major changes focusing on patients' rights*: the right to choose and to have the expenses for the received treatment reimbursed, either in the public or in the private health care system, anywhere in the EU.

The law in Cyprus – *The Safeguarding and Protection of the Patients' Rights Law*, adopted in 2004, stipulates, in Part III - Control Mechanisms -, the duty of every state hospital to appoint a person named “Patients’ Rights Officer” to safeguard the patients' rights. This officer has specific duties; according to art. 22 (2).

2. Research on the extent to which Romanian patients are aware of their rights

Starting from the assumptions presented above and from the priority that is given in the EU to the quality of health care services, to the patients' safety and satisfaction and to involving them in the health care services they receive, we have considered it useful to carry out a research study aiming to establish the extent to which Romanian patients are aware of their rights. The current research starts from one of the conclusions put forward by the European Commission Report - “*Patient involvement*” (2012), which highlights the fact that „*very rarely the interviewed patients knew their right to be involved in the decision-making about their healthcare*”, the importance of patient involvement even in health-related policy-making being recognized by The European Commission (EC) in its White Paper “*Together for Health: A Strategic Approach for the EU 2008-2013*”.

2.1 Research methodology

The study was conducted as a pilot study; it was carried out in December 2015, through a statistical survey, by distributing questionnaires (100) to patients that were hospitalized in one emergency university hospital in Bucharest. This hospital was chosen so as to provide a good representation of patients suffering from various diseases, as a consequence of the great number of patients, including the emergencies, and also to make sure that the patients came from different social backgrounds, since university hospitals treat sick people from both the urban and the rural areas. No selection criteria were formulated for the persons included in the study. The patients were made aware of the importance of the study and, consequently, the questionnaires were accurately filled in, with no invalidations necessary. No discriminations were made in applying the questionnaire, with respect to health status, age, gender or residence, in order to ensure a high degree of representativeness.

The questionnaire comprised eleven questions. The main objective of the study consisted in identifying the extent to which patient rights are known and observed in the case of patients hospitalized in the emergency hospitals in Bucharest. Consequently, the following five working hypotheses have been formulated:

- *H1. The degree of awareness regarding the legal framework for patient rights is over 50%;*
- *H2. The level of awareness with respect to patient rights is directly influenced by the level of education;*
- *H3. The main source of information regarding patient rights is the written press and radio stations;*
- *H4. Patients consider that they know their rights;*
- *H5. Patients consider that their rights are observed in a proportion of over 50%*

2.2. Analysing and interpreting the research results

Pursuant to the data processing we have found that 69.5% of the respondents reside in the urban area and 30.5% in the rural area (the gender distribution indicates equality between women and men (31-31)).

Regarding the age distribution of patients – Figure no. 1 – we find an equal number of patients in the 26-35 and 36-45 age groups (14 patients each), together representing 45.16% of the total number of respondents, which is a worrisome fact from the point of view of the population’s health (patients aged up to 55 years representing 77.42% of the total number of patients questioned).

From the perspective of the level of education, the highest percentage is represented by high school graduates – 36.36%, followed by higher education graduates – 31.82% - Figure no. 2. It is worth emphasizing that the patients with a high level of education – university and doctoral studies – represent together 38.63% of the total number of respondents.

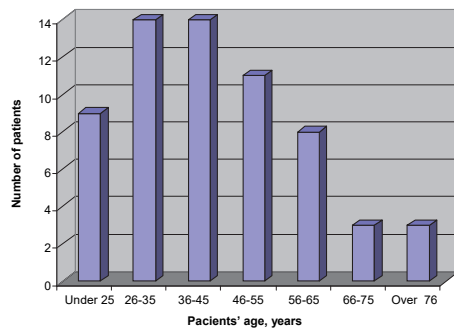


Figure no. 1: Age distribution of respondents

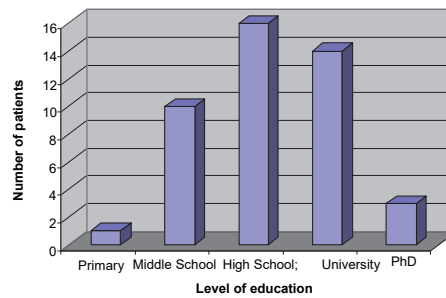


Figure no. 2: Distribution based on the respondents' level of education

66.13% of respondents have heard of the existence of some rights they have as patients, which has led to the validation of the first working hypothesis - *H1*.

Out of the total number of patients who had a high school diploma, 81.25% declared that they knew of the existence of some specific patient rights, while only 64.71% of the respondents who had higher education diplomas (university and doctorate) had heard of the existence of these rights (taking into account their percentage in the sample, 29.54% of respondents with high school diplomas gave positive answers compared to 25% of the ones who completed higher education) – Figure no. 3 – which has led to the invalidation of the second hypothesis, according to which the level of education influences the patients’ awareness regarding the existence of specific patient rights - *H2*.

When asked about the source of information on the existence of patient rights, 69,1% of respondents indicated a single source of information, the rest gathering information from multiple sources. The first position among the sources of information is occupied by the written press and television– 37.04%, followed by the explanations given by the specialty medical staff– 33.33%, and the internet – 18.52%; the last position, (11.11%), is occupied by the mandatory notices regarding these rights, which must be displayed in all health care centres in Romania – Figure no. 4; the facts above have led to the validation of the third working hypothesis - *H3*.

The conclusion is also supported by the Eurostat data, according to which 42% of Romanians have never used the internet, compared to 21%, which is the E.U. level (Business24, 2013), and also by the European Commission Report (Special Eurobarometer Patient Safety and Quality of Care, 2014), which shows that in Romania, the main source of information regarding the quality of ealth care services is television - 35%, compared to 19%, the European average.

Out of the total number of respondents, 55.74% consider that they know their rights as patients, which has led to the validation of the second-to-last hypothesis - *H4*. As there is a difference of -10.39% between the respondents who declared they had heard of the existence of such rights and the ones who consider that they know these rights.

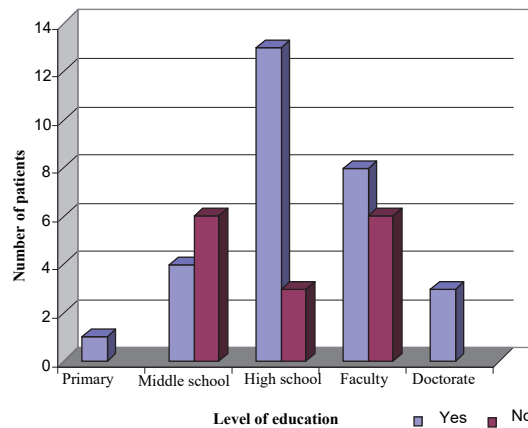


Figure no. 3: Distribution of awareness regarding patient rights based on level of education

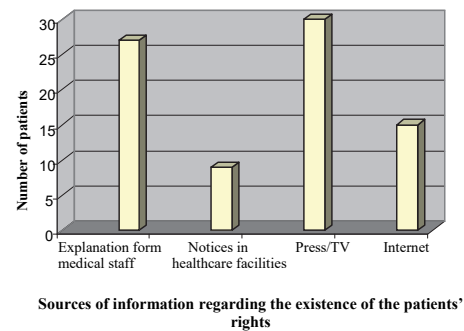


Figure no. 4: Distribution of the sources of information for patient rights

- Prior to testing the last hypothesis - *H5*. We have considered it important to identify the extent to which respondents are truly aware of their rights as patients; consequently, they were asked to name some of these. When asked this open question, 38.71% of the respondents were unable to mention any rights, and out of the ones who filled in the questionnaire, only 18.42% knew their rights (11.29% of the total number of respondents), most of them confusing patient rights with the rights of insured patients (the most frequent answers were related to the free or covered drugs or treatment cards). As a consequence of this low percentage of respondents who have a correct understanding of patient rights, we consider that the answers to the last question are not relevant and, therefore, the last working hypothesis has been cancelled. In spite of all this, we found that, although 44.26% of respondents stated that they did not know their

rights as patients, only 37.10% answered that they could not say whether their rights were respected or not; most respondents (33.87%) consider that their rights are respected to an extent of less than 50% - Figure no. 5.

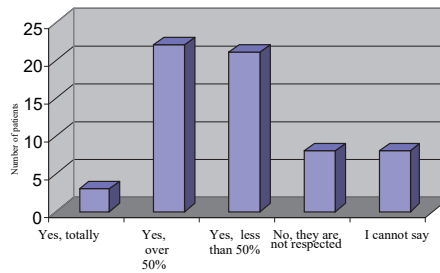


Figure no. 5: The perception of the extent to which patient rights are respected

Conclusions

Pursuant to the revision of the specialized literature in the legislation of EU member states, as well as to the study performed, we can state that there is no unitary approach either to the concept of patient or to their rights. Furthermore, in Romania, there is confusion between the patient and the insured, as well as regarding their rights.

Although 88,71% of Romanian patients are not aware of their rights, 46,77% believe they are not at all complied with or that the extent to which they are complied with is lower than 50%. Starting from the premise that the extent to which patients' rights are complied with is also reflected in the view they have of the quality of the health care services they benefit from, the results of our survey are also supported by the Patient Safety and Quality of Care Report (Special Eurobarometer, 2014). The conclusions of this research, conducted between November and December 2013 under the form of interviews taken on behalf of the European Commission, on a sample of 27,919 respondents with different social and demographic backgrounds (out of which 1,013 were Romanian) show that 73% of Romanians believe that, overall, the quality of health care services is poor, in contrast to the 25% European average, although only 17% of these patients or their families have suffered from side effects (hospital - acquired infections, wrong or delayed diagnoses, surgical errors etc), as against the 27% European average. Still, 78% of Romanians consider the quality of health care services provided in Romania to be poorer than in other EU countries. In this respect, we believe it is necessary to organise an intense national campaign to inform the public, following the example of the one carried out in the past by the National Authority for Consumer Protection, which registered very good results, a campaign that would explain the difference between patient and insured, as well as their rights.

Moreover, starting from the example of other countries and of best practices, Law 46/2003 ought to be amended, in that it should include not only patients' rights but also their responsibilities, as well as the administrative means of taking legal action through a Patients' Rights Officer, who is to provide assistance to patients and medical staff and also to ensure their rights are observed.

References

- Active Citizenship Network, 2002. *European Charter of Patients' Rights*. Rome. Available at: http://ec.europa.eu/health/ph_overview/co_operation/mobility/docs/health_services_co108_en.pdf [Accessed: 14.01.2016].
- Business24, 2013. *Eurostat: România, pe ultimul loc din UE la accesarea internetului în 2013*. Available at: <http://www.business24.ro/internet/utilizatori-internet/eurostat-romania-pe-ultimul-loc-din-ue-la-accesarea-internetului-in-2013-1539508> [Accessed: 16.01.2016].
- DEX,2009[online].Available at:<http://dexonline.ro/definitie/ocrotire>. [Accessed: 09.01.2016].
- European Patients Forum. *Patients' Rights in the European Union*. Available at: http://www.eu-patient.eu/Documents/Projects/Valueplus/Patients_Rights.pdf [Accessed: 14.01.2016].
- European Commission, Directorate-General for health and Consumers, 2012. *Eurobarometer Qualitative study. Patient involvement. Aggregate Report*. Available at: http://ec.europa.eu/public_opinion/archives/quali/ql_5937_patient_en.pdf [Accessed: 14.01.2016].
- Romanian Parliament, 2003. Law no. 46 regarding patient's rights. M. O., Partea I nr. 51. România, Camera Deputaților. *Constituția României* [online] Available at: http://www.cdep.ro/pls/dic/site.page?den=act2_1&par1=2#t2c2s0a34, [Accessed: 9.01.2016].
- Seimas of the Republic of Lithuania, 2009. *Law On The Rights Of Patients And Compensation Of The Damage To Their Health*. Available at: http://www3.lrs.lt/pls/inter3/dokpaieska.showdoc_e?p_id=384290 [Accessed: 09.01.2016].
- Special Eurobarometer, 2014. *Patient Safety and Quality of Care*. European Union. Available at: https://open-data.europa.eu/en/data/dataset/S1100_80_2_411 [Accessed: 08.02.2016].
- The National Health Service. *The NHS Constitution* [pdf.] Available at: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england> [Accessed: 02.02.2016].
- The Council of the European Union, 2006. *Council Conclusions on Common Values and Principles in European Union Health Systems*, OJ 2006/C 146/01, 22.6.2006.
- World Health Organization, 2003. *Quality and accreditation in health care services - a global review*. Geneva: Switzerland.
- World Health Organization, 2016. Genomic resource centre. *Patients' rights*. Available at: <http://www.who.int/genomics/public/patientrights/en/> [Accessed: 02.02.2016].