



PATIENT'S RIGHTS EXPANDING THROUGH THE ADVANCED DIRECTIVES FOR HEALTH CARE AND THE BULGARIAN REALITY

J. Marinova^{1*}, Sv. Dimitrova¹, K. Benkova², B. Parashkevova¹, G. Chamova¹,
G. Petrova¹, D. Hristova³

¹Department of Social Medicine and Healthcare Management, Medical Faculty
Thracian University, Stara Zagora

² Department of Social Activities, Medical Faculty, Thracian University, Stara Zagora

³Medical Student, Medical Faculty, Thracian University, Stara Zagora

ABSTRACT

The purpose of this paper is to discuss fundamental ethical and legal aspects of the advanced directives as a mechanism of expanding the rights of patients and their potential in the living conditions of Republic of Bulgaria. This should be done following the European trend of the Directives validation as a legal instrument to express the wish.

In the context of the development of patients' rights, advanced directives have been enforcing as necessary tool for their worldwide recognition, including Europe where the legislation reflects the complexity and contradictions of their interpretation and implementation. The questions around advanced directives are discussed in the European Commission with the clear understanding of the problem intricacy in too different circumstances, but also from the perspective of the necessity of unification in one single aggregate platform about them.

As for Bulgaria, being part of the European Union, the topic about advance directives for health care (ADCH) is on the agenda and requires serious debate, investigation and regulation initiatives. Questions and considerations about the existing practice in Bulgaria and its compatibility to the acting rules have been raised. The current practice in the country related to ADCH is more "harming" patient's rights and interests rather than supporting them.

Key words: advance directives for health care, patients' rights, previous decision, respect for autonomy.

INTRODUCTION

The development of the medicine and public health in the present days is characterized by intensive processes, direct reflection of the challenges in front of the health rules and practices of the separate countries. Those challenges are much more valid for Bulgaria and the other former communist countries as they are conditioned by the difficulties of the radical changes in the health care system.

"However, in spite of disparities in the way

***Correspondence to:** Assoc. Prof. Juliana Krumova Marinova, MD, PhD, Department of Social Medicine and Healthcare Management,, Medical Faculty, Thracian University, Stara Zagora , "Armeiska" Str, 11, Stara Zagora – 6000, BULGARIA

health systems are organized..., developments in health-related issues reveal a similar pattern in all European countries and a general and inescapable trend towards the assertion of the rights of people seeking care" is pointed out in the Opinion of the European and Social Committee on "Patients' rights" [1]. Recognition of the rights of the patient finds its expression in the normative acknowledgement of the personality as fundamental European value. The process of expansion of the patients' rights throughout advance directives for health care (ADCH) as a mechanism of patient wish expression is manifested worldwide, including Europe. At the present time ADCH are implemented in the most of the developed countries.

Purpose:

The purpose of this article is to discuss fundamental ethical and legal aspects of the advanced directives as a mechanism of expanding of patients' rights and their potential in the living conditions of Republic of Bulgaria. This should be done in the context of the European trend of the advance directives for health care validation as a legal instrument of a wish expression.

Aims:

1. To present the main discussion frame of the ADHC as a mechanism of patients' rights expanding.
2. To introduce considerations about the status of the problem in Bulgaria – current practice and its compatibility with the existing legislation.

Discussion about advance directives for health care

The problem about the normative settlement of the opportunity for preliminary expression of the patient's wish regarding arranging health cares at the end of human's life has been raised for a first time in 1967 (The first "Living will"). Luis Kutner – attorney expresses the need of such regulation in the following manner: "to facilitate the rights of dying people to control decisions about their own medical care." Almost 10 years later, in 1976 California becomes the first State in America to legally regulate this opportunity. Till 1992 all remaining states enact their own laws that regulate the advanced directives to one or another extent. The first court decision to validate advance directives was at the state level and upheld the following judicial principles:

1. "If patients are mentally unable to make treatment decisions, someone else may exercise their right for them.
2. Decisions that can lead to the death of a mentally incompetent patient are better made not by courts but by families, with the input of their doctors.
3. Decisions about end-of-life care should take into consideration both the invasiveness of the treatment involved and the patient's likelihood of recovery.
4. Patients have the right to refuse treatment even if this refusal might lead to death." [2].

As a most common definition "advance directive is a written document in which people clearly specify how medical decisions

affecting them are to be made if they are unable to make them, or to authorize a special person to make such decisions for them" [2]. Generally advance directives are described as "Living wills" and "Durable power of attorney for health care".

In the United States, by the law, all competent adults have the right to complete an advance directive. The goal of this legislation is "to empower all health care consumers to make their own judgments regarding medical decision-making, to approve of potential treatment they believe they would want, and to refuse care they do not perceive as being in their best interest." [2].

Currently many countries in the European Union and Europe have legally endorsed opportunities for the patients to preliminary express their wish related to the health care and possible conduct of specific conditions, mainly incurable diseases. They have also the opportunity to assign representative, who has the right to take informed decision on their behalf; in the cases the patient cannot exert this right. We should emphasize that the legal framework is very diverse in the different countries. An answer to the Parliamentary question to the European Parliament (26.01.2006r.), given by Mr. Kyprianou on behalf of the Commission was: "... there are no existing EU rules regulating issues of advance directives or advance statements. ...The Commission is not aware of any issues regarding patient orders or precaution orders which would be directly related to the cross-border mobility of patients." [3].

"1.1.4.... particularly in the light of EU citizens' right of free movement between the 27 Member States and their equal opportunities to enjoy high-quality service in their country of origin or host country, and above all to encourage their practical application in all of the Member States" was pointed out in the Opinion of the European Economic and Social Committee (EESC) "Patients' rights", 2007 [1]. The newest trends with regard to patients' rights and proper ways for implementing them are visible in this document. The tendency with the appointed context is to seek to give the individual an increasing say in health-related matters. The rising incidence of chronic illnesses and ageing population are considered as factors connected to the patients' dilemmas and expectations about the treatment and long-

term care into account “living with an illness or disability” needs and requirements.

EESC welcomes and acknowledges the 14 rights proclaimed in the European Charter of Patients’ Rights and especially considers that three rights are linked horizontally or are preconditions for other rights. These rights are: right to information, right to free and informed consent and right to dignity. These rights are directly connected to the possibilities of their affirmation and application, including through advance directives for health care. „3.3.1.5 The patient must have the possibility of choosing a person to represent him if he is subsequently unable to make his preferences known.”; “3.4.1.5 In terminal cases or where patient is undergoing particularly difficult treatment, staff needs to be even more vigilant. Respect for a person and his right to die in a dignified manner is achieved by providing universal access to palliative care designed to reduce pain and maintain a certain quality of life by guaranteeing the right of a patient to have his choices respected until the end of his life. Among other things, this means putting in place a procedure such the designation of a proxy to ensure that the patient’s wishes are made known.” [1].

„Europe seeks consensus over “living wills””[4]. Issues of the such consensus were discussed at the European Science Foundation (ESF) workshop, Advance Directives: Towards a Coordinated European Perspective?, Zurich, Switzerland, June 2008 . Whether a common European position on advance directives is possible to be achieved and to be morally acceptable with clear judgment about advance directives as a tool or proper way of extension of the basic human right across all the Europe that the people can consent to or refuse medical treatment at any time? [4, 5] Such position maintains their informed choices of medical interventions related to their own values and wishes. In the means of the present situation it is difficult to achieve agreement even over the degree of consensus that could be achieved. Serious challenges are legislative, ethical and clinical issues regarding to advance directives. Some European countries have not national legislation for advance directives. The existing legislative framework concerning advance directives differs widely across Europe. Issues of the advance directives are opened for different interpretations. This is concerning not only to the very complicated issues of euthanasia and assisted suicide, but also for the attitude to emergency treatments such as artificial

ventilation and intravenous hydration. The skepticism about the European consensus over advance directives is reasonable in wide and unclear meanings concerning the Article 9 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4.IV.1997. “Article 9 – Previously expressed wishes. The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.” [6]. “This group argued that the convention needs greater clarity on the significance and respect for autonomy, as well as clarification on the approach to decision-making for patients without a surrogate” outlined Susanne Bauer the workshop convenor [4]. The complexity and diversity of approaches to advance directives across Europe limited the degree of consensus that could be achieved. It is obvious that the existence of very wide legislative diversities across European countries and presence of the “tourism for euthanasia and assisted suicide” predestinate consensus very difficult to be achieved. However it makes all the more important to establish common ground and understanding on this matter. A ground for this is also the necessity to find a mechanism solving the conflicts between the expressed wishes of the patients and existing practices in case of disease while being abroad.

Besides from the great legal differences concerning ADCH – from lack of such directives to the implementation of AHD in some countries with explicit regulations about the euthanasia (Belgium, Netherlands, and Luxemburg – 2008), there are also too diverse approaches in ADCH implementation in the clinical medicine. In most of the European countries, performance of activities corresponding to patient’s ADCH and determined as a kind of euthanasia, despite of the existing regulations, is being forbidden [4, 5].

Status of the problem in Republic of Bulgaria: existing practice and its compatibility with the operative legislation.

Current situation in Bulgaria in relation to ADCH is represented by a document called “Preliminary Decision”, part of documentation of the clinical pathway “Palliative care for patients with oncological diseases” (CP No 297) [7]. This document represents at the same time both declaration of informed consent and long term power of attorney for health care and wish expression.

- The analysis of the above mentioned document raises serious questions about its compliance to the acting legally regulated rights and responsibilities in the contemporary medical practice in Bulgaria [8].

- Another problem is the compliance of the document to the ethical norms of conduct. There are many critical remarks regarding the “usefulness” of the above document for the patient as well as for the doctor directly involved in the process of obtaining of informed consent.

What is the role of this paper from the patient’s rights perspective?

It is an integral part of the documentation of the above mentioned clinical pathway and from that aspect it is mandatory for the patients hospitalized under this pathway with “20 days total hospital stay within the timeframes of the terminal stage, within 6 months of the oncological disease”. In what way the compulsory character of the document contributes for the recognition of the rights of the oncological patients in terminal stage of disease? Is this “obligatory” consideration of the autonomy does not confront the right of choice of the terminal sick person to express or not certain wishes concerning health cares at the end of the life?

How to consider the compulsory completion of this paper from the right of dignity point of view? In this sense which of the person’s wishes could surely be fulfilled and executed by the medicine personnel involved in the palliative cares? Which “choices of treatment” could really be respected? Wouldn’t they be interpreted as kind of euthanasia in the reality of Bulgarian regulations which unconditionally bans it without giving a legal definition of this complex conception [8]? Could not starting or stopping the life-sustaining treatment, artificial feeding and hydration be really put into Bulgarian practice according to the declared in the paper patient’s wish? Isn’t this “Preliminary Decision” causing harm rather than help to the terminal patient? Isn’t this “Preliminary Decision” a case of imaginary consideration of the autonomy, which is rather more harmed through the infringement upon the right of choice for expression of the preferences and desires of the patient? Why a document that could be described as disgraceful should be completed for a hospital stay of 20 days only? What legal validity such document has considering it remains in the Oncological dossier of the patient and is kept there without other copies being archived elsewhere and without knowing who is taking the responsibility for its execution? Isn’t this just a mechanical approach

which has not got anything rational in it which worths being defended?

This raises questions about balance of patient’s rights and professional responsibilities in the process of rendering complex palliative cares to the patient. It’s often done in a therapeutic alliance, where the relatives of the patient, the patient himself and the entire medical team, ensuring adequate quality care play a relevant role. Even the law arranges clearly the issue with the ADCH, if the professional perceives a certain action, requested by the patient in ADCH, as unacceptable from a moral point of view, would he execute it? If the professional respects the preliminary expressed will of the patient but the corresponding as a result actions as euthanasia and contradicting to his moral position and conscious, what ethical conduct he would prefer? Are the ADCH one-way unburdening the relatives from the responsibility in a certain moment or they could be taken in a different way? Could ADCH really be sufficient legal mechanism revealing the participants of the therapeutic alliance from responsibility? What is the way to leverage the best balance of rights and responsibilities, of personal and public interest? Where are the borders and could they be defined considering there are no unlimited “absolute” rights, unified “values” and categories like “quality of life” for instance.

We could also comment the utility of the actions, determined as type of euthanasia towards the individual and public interest, including “justified” or “unjustified” economical expenses for the intervention at the end of man’s life. Their role in reliving or improving of the quality of life of a person, who has declared in advance their wishes regarding the interventions, is questionable. Generally speaking what should be the conditions in which those wishes have been declared? Having in mind there are cases in which the diagnosis itself is not certain, as well as what exactly are the consequences of applying or not of different interventions at the end of human’s life. Isn’t the medical staff transformed to a group of people acting only according to the instructions of the patient in acting as a “supplier of services as ordered by the client, the result of which could be the death of the applicant”? Where is the cross point of the expressed rights, responsibilities and interests? May be in case of terminal state the right of dignity, addressed to the death of the person as a natural end of their life is put on the foreground?

In 2008 the Bulgarian Centre of Bioethics organized a national conference: “Expanding the Rights of the Patient throughout Advanced

Health Directives – towards Unified European Platform”. This points the attention to this so important problem. Now when Bulgaria is a member of the European Union, this issue is raised for discussion in all ethical, legal and social aspects. A fundamental consideration in this perspective could be the following: the implementation of ADCH is under discussion in the Council of Europe, which means that it is feasible to be developed a unified European platform, part of which of course is our country. Besides this, the ability of the patients to travel throughout united Europe places serious questions about the respect of their rights.

The attendees of the conference, including the authors of this article, created a Declaration, which underlines unconditionally that “Advance directives for health care are a mechanism for expansion of patient’s rights and their potential in the living conditions in Bulgaria should be investigated”. This document represents the main directions to coordinate the efforts to supporting the opportunities of advance directives for health care in Bulgaria.

CONCLUSIONS

1. In the context of the patients rights development, advance directives for health care are set and ratified as a necessary instrument for strengthening their position worldwide, incl. Europe, despite of the different legal framework, reflecting the complexity and contradictions in ADCH interpretation and execution.
2. The questions around advance directives for health care are discussed in the European Commission with the clear understanding of the problem intricacy in too different circumstances, but also from the perspective of the necessity of unification in one single aggregate platform about them.
3. The topic advance directives for health care is on the agenda in Bulgaria, being part of the European Union, and requires serious debate, investigation and regulation initiatives.
4. Current practice in the country related to advance directives for health care is more “harming” patients’ rights and interests rather than supportive to them. (Preliminary decision as per CP “Palliative care for patients with oncological diseases). We stay unified about the statement this is a “malpractice”, poor instrument for wish expression under the conditions of the Bulgarian health law. This practice is not of help neither to the patients nor to the medical providers or patient’s relatives.

„Life is above everything” and it’s natural end is death. The right of a death with dignity, as it is perceived by the person, is relevant to each of us. All of us are affected directly by this problem and its multilayer dimensions and related to them ethical dilemmas. The idea of the “good death” as “quick, painless, at home and surrounded by family” is amazingly identical for a big number of the people. And may be the most important thing in the contemporary medicine and health care systems is to find and implement really “best practices” so that they could support in best possible and most humane way this right.

REFERENCES

1. Opinion of the European Economic and Social Committee on “Patients’ rights’, (2008/C 10/18), Official Journal of the European Union, 15.1.2008, C 10/67, available on <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2008:010:0067:0071:EN:PDF>
2. History of Advance Directives, available on: http://www.medicinenet.com/advance_medical_directives/index.htm
3. Answer given by Mr. Kyprianou on behalf of the Commission, 26 January 2006, Parliamentary questions, European Parliament, available on: <http://www.europarl.europa.eu/activities/archives/>
4. Europe seeks consensus over “living wills”, European Science Foundation, News, 31 October 2008, available on: <http://www.esf.org/research-areas/medical-science/news/ext-news-sinleview/article/europe-seeks-consensus-over-living-wills-514.html>
5. Advance Directives: Towards a Coordinated European Perspective? ESF Exploratory Workshop, available on: http://www.ethics.uzh.ch/ibme/newsarchiv/advance-directives/ESF_Workshop.pdf
6. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4.IV.1997, available on: <http://conventions.coe.int/Treaty/EN/Treaties/html/164.htm>
7. Clinical pathway (CPN^o 297) “Palliative care for patients with oncological diseases”, available on: <http://www.nhf.bg/web.guest/39>
8. Health Act, Promulgated SG N^o 70/10.08.2004, last amended and supplemented, SG N^o 101/18.12.2009.