



ADVANCED HEALTH CARE DIRECTIVES – A DOCUMENT OF CLINICAL PATHWAY IN BULGARIA: IS THIS COMPATIBLE TO THE BULGARIAN LEGISLATION?

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ABSTRACT

The purpose of this paper is to initiate discussion regarding the fundamental ethical and legal issues in recognizing the Advanced Directives in Bulgaria as well as to examine the conditions in which the Directives are to be realized as a mechanism for patient's rights expanding.

The tasks we have placed are the following: 1. to present the Advanced Health Directives (AHD) concept; 2. to present facts regarding current status of the problem in Bulgaria - existing practice and its compatibility with the acting legislation; 3. to find out the reasons for the inapplicability of the AHD in the present situation of the Bulgarian health care.

We are critically disposed towards the Bulgarian model of AHD, because of its mechanical transfer or the lack of legal positions for implementation, as well as because of the contradictions with the fundamental principles of the medical ethics. The concept of AHD is part of the concept for patient's rights expansion.

Besides this contemporary medicine has made the death complicated. Every society should develop moral and medicine standards concerning most appropriate discontinuance of the supporting treatment of patients in terminal stage, considering the latest progress in the medicine area and continuously changing technologies. It is important that the patients and their families, whenever possible, should have significant role in taking such decisions, but without feeling pushed, confused or hopeless.

Key words: advance directives for health care, patients' rights, living will, respect for autonomy, principle of beneficence, and principle of non-maleficence.

INTRODUCTION

With the medicine development many lethal diseases have been overcome, but other epidemics of heavy diseases have appeared. Oncological disorders with their risk and mysteriousness, remained the main threat for the human kind through the centuries, and the Black Death and cholera have been replaced by AIDS. Diseases like tuberculosis, considered dead until recent past seem to be back..., and the communication with the seriously ill patients became more

complicated. The question about the meaning of the therapy rises again. At the beginning of 21st century with its potentials for prolonged sustaining of life by technical means, one important medico-ethical problem is brought forward. And it is about the place of the advanced decisions, preliminary will for cure and health care, declared by the patient in terminal state [1]. The above question set up the doctors and medical professionals, working the area of palliative medicine in front of many dilemmas. Emerge legal and ethical issues and the current regulations appear to be maladjusted to the new opportunities. Endorsement of the patient's rights finds its expression in the normative acknowledgement of the autonomy of the personality as a European value. The process of patient's rights

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expanding through, advance directives for health care (AHD) as a mechanism of will expression of the patient is represented worldwide, including in Europe. At present AHD are introduced to the most of the developed countries in the world. Is Bulgaria an exception from that common trend? This is a question that could not be replied with “yes” and “no”. Since 2002 in our country exists compulsory document in one of the clinical pathway “Palliative Cares for Terminal Patients”, called “Preliminary Decision and Your Long-lasting letter of attorney about health care, living will and other wishes”. In the same time this document does not possess any legal meaning and in practice is inapplicable due to the lack of corresponding legal framework.

Goal:

Discuss the fundamental moral, ethical and legal issues of the AHD acknowledgement in Bulgaria and examine the circumstances in which the AHD will try to be realized as a mechanism of patient’s rights expansion.

Aims:

1. To present the concept of AHD
2. To present consideration about the status of the problem in Bulgaria - existing practice and its compatibility with the acting legislation
3. To find out the reasons for the inapplicability of the AHD in the present situation of the Bulgarian health care

DISCUSSION

What is AHD? This is formal written document, developed in advance to represent choices of the patient related to the health care and treatments for the time when their serious illness and condition would not allow them to express their will. Except for the advance will for future medical treatment in the palliative care, AHD include also long-lasting letter of attorney for health care, by which the patient authorize somebody else who can make legal and valid choice and take decision for the necessary treatment, when the patient himself won’t be able to express his wishes. It is impossible to define every single procedure in each possible scenario. Therefore AHD discusses the choices related to the main situations in a treatment in terminal stage - cardio-pulmonalis resuscitation, pulmonary ventilation, artificial feeding and hydrating, dialysis, and antibiotic treatment [2].

AHD story begins beyond the ocean. In 1967, Luis Kutner, attorney, formulates for a first time the idea about written statement for expressing the living will. Kutner aims to facilitate “the right of the dying people to control the decisions for their own medical treatment”. The first draft regulation, allowing the patients to take decisions regarding future treatment or not, is raised by Walter Sackett, a doctor, representative in the parliament in Florida in 1968. However it does not pass. Sackett tries once again in 1973 to pass the bill but is thrown on his back again. While d-r Sackett is trying to change the legislation in Florida, Barry Keene presents similar draft regulation to the California Parliament. Keene bases himself on his own experience. In 1972 member of his family is in terminal stage. Keene could not limit the sustaining treatment, despite of the fact he has gotten a written letter of attorney, signed in advanced. In 1974 Keene is elected in California parliament and starts immediately to legalize AHD, but fails. He tries to pass the bill again in 1976 and in September same year California becomes the first State in USA to legalize the advance directives. Avalanche process follows and by 1992 all States of America legitimate AHD[3].

Only 10 years after USA, in our country springs up the first such document, which lead us ahead of many European countries. The year is 2002 and the document is clinical pathway (CP) No 35 – Palliative Care of Terminal Oncologic Patients. The National Health Insurance Fund (NHIF) had started recently to pay for a tiny part of the hospital treatment and the number of the clinical pathways is only 50. In the methodic directions of CP 35, together with the clinical requirements for treatment, indications for hospitalization and dehospitalization, one can find as well the requirements for observance the rights of the patient. The consideration of the patient’s rights could be determined by the existence of written paper for Informed consent and Preliminary decision. Implementing of AHD displays the concept of expanding of patient’s rights, developed by a single national health fund.

The idea corresponds to the European Charter of the Rights of the Hospital Patient: “The patient has the right to be fully informed about everything concerning his or her state; to take independent decisions and actively participate in the decisions regarding his or her health”. It

is also in correspondence the third principle of the World Medical Association Declaration on the Rights of the Patient, adopted by the 34th World Medical Assembly, Lisbon, 1981 and amended by the 47th WMA General Assembly, Bali, 1995 saying: "The patient has the right to self-determination, to make free decisions regarding himself/ herself."

A very curious fact about legalizing of the informed consent of the patient is that the above is compulsory in the treatment of terminal patients already in 2002, and is been legalized two years later through the Law of Health. May be this is an example that the legislation reacts slower to the concept of expansion of the patient's rights, whose representative and intercessor is NHIF. In difference to the legal framework of the informed consent which is finally in force, AHD is being part of the compulsory hospital documentation, which is mandatory required to be completed by each patient, hospitalized and treated as per clinical pathway "Palliative Care" and in the same time none of the expressed wishes and decisions could be realized. In Section II of the Act of Health - Rights and obligations of the patient you can find the following statements: "Art. 95. (1) Upon incurable diseases with unfavourable prognosis the patient shall have right to palliative medical care. (2) Objective of the palliative medical care shall be maintaining of the quality of life of by reduction or removal of some immediate performances of the disease as well as the unfavourable psychological and social effects, connected with it. Art. 96. (1) The palliative medical care shall include: 1. medical observation; 2. health care, directed for care of the patient, removal of the pain and the psycho-emotional effects of the disease; 3. moral support of the patient and his relatives. (2) Palliative medical care shall be rendered by the personal physician, by medical establishments for off hospital and hospital care, by dispensaries and hospices." [4].

Where is AHD? No trace even of existence of any opportunity of advanced directives by the patient. The reasons of the above could only be guessed. May be the law-maker is not aware of the idea of patient's right, passed by the one and only compulsory for all citizens national fund of health insurance? Another assumption could be that there is a confusion of the AHD and Informed consent of the patient for starting a treatment when going to a hospital by the

Health Fund. But let us abandon this purely legal side of the problem AHD and examine the ethical aspects. Going from the assumption that the medical professionals should respect the written in advance directives for future care as part of the patient's rights. This corresponds to the signed by World Medical Association - Statement on the Care of Patients in Terminal illness, revised by the General Assembly of WMA, South Africa, 2006 where the following principle is formulated: "Physicians should recognise the right of patients to develop written advance directives that describe their wishes regarding care in the event that they are unable to communicate and that designate a substitute decision-maker to make decisions that are not expressed in the advance directive. In particular, physicians should discuss the patient's wishes regarding the approach to life-sustaining interventions as well as palliative measures that might have the additional effect of accelerating death". The declaration says "recognize the right of patients to develop written advance directives". No one even thinks of the idea to oblige the patient to think of such rationalization and written declaration of advanced palliative care. Unfortunately this is the case in Bulgaria. This is absolutely unethical because no one can bind a patient to think of these so difficult questions about end of one's life. Physician cannot also compulsory present to the patient information concerning his or her treatment. As it is described in the 7th principle of the World Medical Association Declaration on the Rights of the Patient, adopted by the 34th World Medical Assembly, Lisbon, 1981 and amended by the 47th WMA General Assembly, Bali, 1995, the patient can refuse such information. And what do our physicians do? They "pursue" the patients given palliative care with statements like: *Terminal stage is far gone in the way, irreversible state, caused by injury or disease, which is not curable and due to which the physicians expect the person to die even after optimal medical treatment; life supporting treatment will not even improve the status of the person but will only prolong his dying*, which the patients are obliged to read in our compulsory template of AHD. Medicine professionals are facing a difficult task. To be able to fully complete the clinical pathway, they risk harming the patient asking him/ her to obligatory declare wishes like whether he wants or not autopsy. Before that they, "humanely considering" patient's rights, explain [5]. that *Autopsy is examination of*

corpse (patient's one) *aiming to discover the reason for the death*. Many more examples similar to the above one could be found in this template. This specific one, besides everything else, illustrates one of the many contradictions in the normative database. According to the existing regulations of the medical institutions – oncological dispensary and palliative care wards (the only ones in our country working with compulsory AHD as we have mentioned many times already) autopsy could not be executed only after explicit order by the director. Or as the physicians working in such institutions share – one exerts so much psychological energy to make the patient to fill in the AHD template, risking to harm their emotional welfare in case the patient would have not wish thinking about this and afterwards it appears you cannot fulfill this most often met will about autopsy denial???

Is this the way to recognize the fundamental principle of the medical ethics – the principle about respect to the autonomy of the patient and the right to determine their own life and death? And what about the other fundamental principles of the medical ethics – the principle of beneficence and the principle of non-maleficence?

We can criticize a lot the Bulgarian model of AHD. Even only for the mechanical transferring across the ocean and automatically translation of an American template/ form, in which are listed options impossible to be executed in Bulgaria. But we better stop here, because we aim not to reject the idea but only the method of its implementation in Bulgaria, method incompatible to the fundamental principles of the medical ethics.

Deduction:

The process of advance directives should be initiated by the patient. Free express of will should be the fundamental right. If the process is initiated by the Fund, respectively medical institution, it should not be compulsory. Otherwise it becomes immoral act, contradicting patient's rights, considering the NHIF is their intercessor.

CONCLUSION:

Contemporary contemporary medicine has made the death complicated. Every society should develop moral and medicine standards concerning most appropriate discontinuance of the supporting treatment of patients in terminal stage, considering the latest progress in the medicine area and continuously changing technologies. It is important that the patients and their families, whenever possible, should have significant role in taking such decisions, but without feeling pushed, confused or hopeless. [6].

Based on the strong authority the physician possesses in such circumstances, the requirements towards them are big. To balance patient's needs and medicine's integrity and assures peaceful death of the patient. And also to balance between the fundamental principles in the medical ethics – principle of non-maleficence, principle of respect for autonomy, and principle of beneficence.

REFERENCES

1. Medical ethics, textbook, Plovdiv, 1996
2. Sample Advance Directives Form – February 1, 1999 – American Academy of Family Physicians; <http://www.aafp.org/afp/990201ap/617.html>
3. History of Advance Directives, available on: http://www.medicinenet.com/advance_medical_directives/index.htm
4. Health Act, Promulgated SG № 70/10.08.2004, last amended and supplemented, SG № 101/18.12.2009
5. Clinical pathway № 297 National Framework Contract -2010 National Health Insurance Fund ;<http://www.en.nhif.bg/web/guest/functions>,
6. Kalahan Daniel, The Goals of Medicine: Setting New Priorities, An International Project of The Hastings Center, first published in The Hastings Center Report, 1996, Sofia, Tempo, 1998