

PRESERVING THE PATIENT'S DIGNITY AND AUTONOMY IN THE CONTEXT OF ADVANCE PLANNING OF THE MEDICAL CARE

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ABSTRACT. Advance planning aims at a time, considered specific for the life ending stages, when the patient will no longer be able to express his/her desire about the medical care performed on the own person. By the history of its introduction through the medical legislation, this document is closely related with the euthanasia concept or the right to put an end to the life that is no longer worth living. From a medical approach, this may suppose the withdrawal of the futile treatments. The patient has the possibility, by elaborating an advance directive, to mention his/her refusal for certain medical treatments and procedures. The purpose of its implementation in the clinical practice is to preserve the patient's dignity and autonomy for the moment when he/she will no longer be able to express his/her will: this person can choose to end the suffering of an inhuman life. The patient will become, therefore, responsible for giving up to the futile medical care, limiting, in somehow, the actions of the medical staff. Thus, advance planning could be assimilated with the idea of medical non-compliance. The efforts of preserving the patient's dignity will inevitably bring in our attention the concept of the human being's value. Does an intrinsic value of the human being really exist or is it just built by the role played by the person in the social context? Is it fair to create moral pressure on someone to take a certain decision in that context? However, what if the advance directives were not at all associated with the idea of a *Living will* (*Life testament* – the Romanian name for this paper)? Even if the advance planning had the primary purpose to protect the healthcare professionals in their decision to withdraw the futile treatments, this document should be in favor of the patient and not against his/her deepest desires.

Keywords: *advance planning, dignity, autonomy, human being value, quality of life, life without dignity.*

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REZUMAT. *Prezervarea demnității și a autonomiei pacientului în contextul planificării în avans al îngrijirii medicale.* Planificarea în avans vizează un moment, considerat specific pentru etapele de final ale vieții, în care pacientul nu va mai putea să-și exprime dorința cu privire la îngrijirea medicală efectuată asupra propriei persoane. Datorită istoriei introducerii sale prin legislația medicală, acest document este strâns legat de conceptul de eutanasiu sau de dreptul de a pune capăt vieții care nu mai merită trăită. Din perspectivă medicală, acest lucru poate presupune retragerea tratamentelor inutile. Pacientul are posibilitatea, prin elaborarea unei directive anticipate, de a menționa refuzul său pentru anumite tratamente și proceduri medicale. Scopul implementării acestora în practica clinică este de a păstra demnitatea și autonomia pacientului pentru momentul în care acesta nu va mai putea să-și exprime voința: această persoană poate alege să pună capăt suferinței unei vieți inumane. Pacientul va deveni, prin urmare, responsabil pentru renunțarea la îngrijirea medicală inutilă, limitând, cumva, acțiunile personalului medical. Astfel, planificarea în avans ar putea fi asimilată cu ideea necompliancei medicale. Eforturile de conservare a demnității pacientului ne vor aduce inevitabil în atenție conceptul de valoare a ființei umane. Există într-adevăr o valoare intrinsecă a ființei umane sau aceasta este construită doar de rolul jucat de acea persoană în contextul social? Este corect să creezi o presiune morală asupra cuiva pentru a lua o anumită decizie în acel context? Totuși, dacă directivele anticipate nu ar fi deloc asociate cu ideea unui document de *Testament de viață* (cum este numit în limba română acest document)? Chiar dacă planificarea prealabilă avuse scopul principal de a proteja profesioniștii din domeniul sănătății în decizia lor de a retrage tratamentele inutile, acest document ar trebui să fie în favoarea pacientului și nu împotriva dorințelor sale cele mai profunde.

Cuvinte cheie: planificare în avans, demnitate, autonomie, valoarea ființei umane, calitatea vieții, viață nedemnă

Introduction

The patient can write, in the presence of witnesses, a document called *Advance directives for planning*² ahead the treatments to be received or not in the case of losing his/her legal decision making capacity. By talking with his/her family and with the medical doctor, he/she may decide to refuse treatments that are either unnecessary or dangerous (according to his/her own believe), or this person

² Jonsen, Albert R., Mark Siegler, și William J. Winslade. *Clinical Ethics. A practical Approach to Ethical Decisions in Clinical Medicine*. Seventh Edition. New York: McGraw Hill Medical, 2010, p. 81.

just does not want some medical procedures based on his/her personal values.³ Due to the history of this legal procedure introduction, the *Advance directives* are often associated with the idea of *Living will*. Therefore, this is merely the planning ahead of a stage associated with the life ending moments. If *Advance directives* are the most common type of advance planning, this kind of document may take different forms. In United States, for example, the standard model is used with prevalence, often mandatory, for the *Medical Directive*. The medical doctor has the duty to know the legal aspects of the state where he/she practice medicine. The second form is, indeed, the *Living will*– having a less formal aspect – which is a personal address to family, friends and medical doctor regarding the treatment options for the end of life. This type also includes the *Living wills* elaborated by some religious groups with a particular view on some medical interventions concerning that context. [That] paper may also mention lists of medical interventions preferred by the patient or to be avoided for various reasons. *The Five Wishes*, a *Living will* type of paper, has unique elaboration characteristics by mentioning the following: will be the one to make decisions⁴ for the patient, what kind of medical treatments he/she wants, how comfortable he/she wants to be, how he/she wants to be treated by people in that life' stage and – not less important – what information will be given to his/her loved ones by the medical staff. In addition to the two main types of directives in advance, some states may also consider personal notes or letters which do not follow any conventional drafting standard. Lacking any standardization, personal notes and letters will be often vague and difficult to provide a good interpretation. Therefore, the process of making medical decisions will be complicated.⁵

Although there are states where a distinction was made between the *Living Will* and the *Advance Directives* by the existence of slightly different elaboration criteria; many countries – as well as Romania – doesn't have a clear distinction between those two types. It is really important for the patient have assurance that in the final life's moments, his/her wishes will be respected. This approach will offer to the patient the assurance of maintaining his/her personal dignity⁶. However, a patient can also live for a number of years in a medical condition that would not allow him/her legally to make a decision about the treatment received. The recent medical practice and the evolution of medical

³ Aluaş, Maria. *Bioetică Medicală*. Cluj-Napoca: Medicală Universitară "Iuliu Haţeganu", 2016, pp. 65, 68.

⁴ Avery, G. "Advance decisions to refuse treatment: a prescribing dilemma". *Practice Nurse* (Business Source Complete, EBSCOhost) 39, 8 (2010): pp. 29-31.

⁵ Jonsen, Siegler & Winslade, *op. cit.*, pp. 84-85.

⁶ Van Der Graff, Reike, & Johannes JM Van Delen. "Clarifying appeals to Dignity in Medical Ethics from an historical perspective." *Bioethics* 23, nr, 3 (2009): pp. 151-160.

technologies that may prolong and greatly improve the quality of life of the patient with a serious medical condition bring us to the following question: How do we establish with certitude that there is an end-of-life condition and for what period of time this condition may last? How can we determine, on what medical conditions, life is no longer worth living? What defines the quiddity of the human being and what can be altered by some serious medical conditions with the result of an inhuman life or without dignity for the patient? Some thinkers even say that the dignity concept is improperly used in the medical context because it refers to the autonomy of the patient.⁷ What would be the connection between the concept of *human dignity* and the abandonment of an adequate medical support? Who determines this kind of correlation in a particular case? Is it a medical reality, a subjective individual perception or a social construct? The answers to those questions will generate favorable behaviors or it may even alter of the patient's perception about his/her intrinsic values. Some approaches concerning the concept of human dignity may create moral pressures on the patient to elaborate an *Advance directive* with the purpose to give up on living, based on the present impressions about the future circumstances. In some cases the patient will even feel a moral obligation to take a certain decision, which may contradict his/her own beliefs and desires.

But how did the healthcare institutions arrive at the necessity to debate these issues and what would be the key ethical aspects in drafting an *Advance directive*?

Historical and legislative framework *Advance planning* use

The framework of *Advance planning* is based on the legal introduction of the informed consent in physician-patient collaboration and the obvious progress of the resuscitation techniques. At the same time, the medical system could not overlook the limits of the resources available to be used for each patient. Thus, the development of the legislation on the *Advance directives* was influenced by the following two decisive issues:

(1) In 1969, the concept of "living will" was the first time used in the text drafted by the North American lawyer Luis Kutner, "Due process of euthanasia: the living will, a proposal".⁸ He proposed the elaboration of a document by which the patients could ask medical doctors to suspend the treatment received in the context when they would be unable anymore to express their will.

⁷ Van Der Graff & Van Delen, *op. cit.*

⁸ Kutner, Luis. "Due process of euthanasia: the living will, a proposal." *Sematic Scholar*. 1969. <https://pdfs.semanticscholar.org/8054/7a8d645a98a9cfba33ffeb463a7ee7a2f59d.pdf> (seen on 10 20, 2020).

(2) The effective introduction of the *Living wills* in the medical practice was realized due the publicity and controversy that surrounded the Quinlan (1976) case⁹ from the North American region. "After a long legal battle, a Supreme Court decision in New Jersey, in March 1976, allowed the appeal of Karen Ann Quinlan's parents (1954-1985) who was in a vegetative state, ordering the suspension of treatments likely to prolong her life".¹⁰ California was the first American state which established the use of the *Living will* in the medical practice in October 1976 by adopting the *Natural Death Act*¹¹. The European Council Meeting happened in the same year (1976) when the *Patient Charter* was elaborated. The major concern was for "a death in dignity and integrity" and for the limitation of the futile medical interventions. In 1970s it became evident, especially in United States, the necessity to have a satisfactory legal criterion for the possible non-intervention of the medical professionals, if the patient had previously expressed this desire. However, just in 1985 the *Uniform Rights of the Terminally Ill*, revised in 1989, was adopted to standardize the legal status of *Living wills*. In this context, the American movement, militant for their implementation, was initiated by hospital administrators and physicians to be armed against the proliferation of lawsuits. It was necessary to have legal protection for medical workers and to justify the cessation of the resuscitation. Some regulations were lately adopted gradually in almost all regions of the United States, but also in Canada, Australia, Europe, and others.¹²

After the Congress of the 1990, the United States passed the *Patient Self-Determination Act*¹³, implemented from December 1 of the following year. This document states that individuals receiving medical care - especially those financed from public funds - are informed from the beginning of their hospitalization about their rights to accept or refuse medical and surgical treatments. The patients are asked if they have already signed a directive in this regard. If this document doesn't exist at that moment, the patient may provide his/her signature for the withdrawal of certain medical interventions or for a complete non-intervention in some circumstances.

But how does the patient perceive the request, from the beginning of the hospitalization, concerning the elaboration of a document for *advance planning*? From the public debates about the introduction of *advance planning*

⁹ Mankus, Mary K. "Karen Ann Quinlan (1954–1985)." *Civil liberties of the United States*. 21 08 2012. <http://uscivil liberties.org/biography/4334-quinlan-karen-ann-19541985.htm> (seen on 08 05, 2020).

¹⁰ Aluaş, *op. cit.*, p. 67.

¹¹ "Natural Death Acts." *Encyclopedia of Death and Dying*. n.d. <http://www.deathreference.com/Me-Nu/Natural-Death-Acts.html> (seen on 02 24, 2021).

¹² Aluaş, *op. cit.*, p. 67.

¹³ Jonsen, Siegler & Winslade, *op. cit.*, p. 82.

as a *living will* until the elaboration of the *Patient Self-Determination Act*, clarifying the patient's right concerning the mentioned aspect, passed two decades without any direct or explicit connections with the *end of life*. Previously, the focus was on the futile treatments' refusal and the abandonment of resuscitation. However, the present use of the patient self-determination principle in *Advance directives* takes the appearance of a favorable argument: this approach may have a good contribution in the improvement of the medical staff – patient communication as long as the elaboration of this document may reduce of the worries of the patient and his/her family about making difficult decisions in stressful contexts. Moreover, the health professionals will also be relieved from the psychological stress concerning the decision about the medical intervention.

At the European level, the fundamental legislation on patient's right to self-determination was elaborated just in 1994: the *Declaration on the Promotion of Patients' Rights in Europe*. This text was developed by WHO and it refers to any medical act performed on the patient. The paragraph 3.3 of the present document states that if an act is required as a matter of urgency, the consent is presumed. Yet the existence of a paper on the patient's refusal of some medical interventions will be taken into account in a medical condition presupposed by the act.¹⁴ The *Oviedo Convention* of the European Council on *Human Rights and Biomedicine* states in the 9th article: "The wishes previously expressed, by a patient who at the time of the intervention is not in a state that allows him to express his will, regarding a medical intervention will be tacked into account."¹⁵ Later, the Parliamentary Assembly of the Europe Council adopted – in January 25, 2012 – the resolution R1859, which calls for the avoidance of euthanasia by generalizing the use of advance directives in all the European states.¹⁶ But the following aspect still remains in debate: how could be changed the ethical nature of an act (positive or negative) by the prior consent of the patient; or does it remain the same kind of act from the moral approach? Is it admissible to take any decision if someone obtained the patient's consent previously? Do the health professionals have an objective responsibility related to the society as a whole and conditioned by the intrinsic value of the human being?

¹⁴ European Consultation on the Rights of Patients (WHO). "A declaration on the promotion of patients' rights in Europe, European consultation on the rights of patients Amsterdam 28 - 30 march 1994." WHO. 28 June 1994. http://www.who.int/genomics/public/eu_declaration_1994.pdf (seen on 08 05, 2020).

¹⁵ Council of Europe. "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)." *Council of Europe*. 4 IV 4.04.1997. <https://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf98> (seen on 02.02, 2021).

¹⁶ Aluaș, *op. cit.*, p. 68.

In this paper, our concern is about the Romanian clinical practice where was introduced the *advance planning*, but still not well regulated by laws. The elaboration of this kind of document, in Romania, still encounters some ambiguity that will be present also in its implementation and its interpretation; even if ratified some international laws were ratified here, relying also on existing legislation at European level and some cases found in the literature. One of the European legislative texts ratified, by the *Law no. 17/2001*¹⁷, is the *Oviedo Convention of the European Council on Human rights and biomedicine*.

*Law no. 46/2003 on patients' rights*¹⁸ and *Code of Medical Ethics*¹⁹ are the only national legislative texts in Romania, still based on the international legislation, with a brief reference to the *Advance directives*. Both of them pay special attention to the presumed consent. Both of them express the importance to follow a previously elaborated document on the patient's desire to refuse certain medical interventions for the emergency cases and when the patient is unable to express his/her will. The legal framework stipulates that this kind of document can be written by an individual legally able to make a decision: having the age for legal decisions and the reacquired mental abilities. Besides, the patient must have been free from any constraint and well informed to have the ability of elaborating the document in an appropriate manner for its interpretation. That paper will be applied just in a case of a medical condition of the patient relevant for the prescription, when he/she will not be any longer able to take legally a medical decision.

Ethical principles of biomedical practice

Even if the consent is presumed for any collaboration between the medical doctor and the patient, any patient is informed on the personal duty to express the consent for the serious medical interventions. On the other hand, there are contexts and countries where the patient is informed from the beginning of his/her hospitalization about the possibility to write in that moment an *Advance directive*, refusing some disproportionate medical treatments. Thus, to

¹⁷ Parlamentul României. „Legea nr. 17/2001 privind ratificarea Convenției europene pentru protecția drepturilor omului și a demnității ființei umane față de aplicațiile biologiei și medicinei, Convenția privind drepturile omului și biomedicina, semnată la Oviedo la 4 aprilie 1997.” *Monitorul Oficial al României nr. 103 din 2001-02-28*, 02 2001.

¹⁸ Parlamentul României. „Legea nr. 46/2003 drepturilor pacientului.” *Monitorul Oficial al României nr 51 din 2003-01-29*, 01 2003.

¹⁹ Colegiul Medicilor din România. „Codul de dontologie medicală.” *Colegiul Medicilor din România*. 06 01 2017. <https://www.cmr.ro/new/wp-content/uploads/2017/01/COD-DEONTOLOGIC.pdf> (seen on 09 20, 2020).

what extent is this person indeed guided by the health professionals in the elaboration of the *Advance directives* without pushing him/her toward an undesirable decision? Another serious objection to the elaboration of the *Advance directives* concerns the interpretation of this kind of document. With the advance of the medicine, it will be possible that some medical paradigms will be changed in a few years.

As we mentioned before, the fundamental condition of advance planning is a patient having his/her fully legal capacity to write this document. However, we may think about a person with innate disabilities: it will not be allowed legally for him/her to make any medical decision. Moreover, this person may be unable to bring practical benefits to his/her community. How this kind of context will be regarded? How to use a certain amount of resources to sustain his/her life by some costly medical procedures? The use of the community's resources for a person with an innate disability could be regarded as being futile? How is it possible to find justifiable ethical arguments to consider the life of that human being as an existence without dignity? It is true that this patient never had the chance to write an *Advance directives* paper. Any medical decision will be made by his/her family in accord with the laws. As an analogy, in the case when a similar medical condition will occur later in life, the patient still has the right to enjoy and live his/her own life without any given label from the society – from those who never went through the same experiences. What kind of criteria can be used to determine whether or not a life has dignity? Does it have something to do with the happiness that may be acquired having that medical condition? Are the people without awareness of their own identity and lacking legal decision-making capacity deprived of happiness?

The *advance planning* papers are valid just for a period of several years, depending on the country's legislation. The shortness of this period is based, firstly, on the alert progress of the medical knowledge and biotechnologies. Secondly, the life circumstances of an individual could be changed dramatically in a few years, the priorities and values can also be very different. The criticism for the *Advance directives* use is based on the following issues:

“The limits of its application, terminological inaccuracy, the previous existence of the right to refuse the treatments, implemented in most countries of the world, danger of slipping to claim euthanasia or medical assisted suicide, the alteration of the relationships between medical field professionals and patients as a consequence of the legalization of the death moment”.²⁰

²⁰ Aluaș, *op. cit.*, pp. 71-73.

It is not possible an absolute freedom for any act or decision, neither the existence of a right to die. But the focus of the debates can be on the ethical principle of freedom that is based on receiving correct information for being able to make well papers for a future interpretation. Otherwise, the existence of this kind of document will lead to more problems and concerns. The periodical updates are also important because on their absence, this document may be an incomplete one and an inadequate one in rapport with the real desires of the patient. Even if someone decides to write his/her *Advance directives* to plan for a certain medical condition, it still exist a huge risk of misunderstandings. A poor written paper will lead to more work for the medical professionals and the obligation update their knowledge about all the legal changes on the topic.

As a hypothetical case, we may think about a woman who elaborated an *Advance directives* paper asking to not be resuscitated²¹, but she has a heart attack at the age of 30 when she is mother of 2-3 small children, also employed and having many other social responsibilities. The physician may think that the document was written for completely different circumstances and he may not follow the recommendation to not resuscitate her. But this physician still may consider as being the most important to follow the paper's instruction, with all the costs. From a legal point of view, this health professional has all the rights and justifications to act in this way. Is this decision, in the same time, the right one from a deontological or moral approach? What will give a real assurance to this physician about good ethical standards and moral value of the medical decision taken? There are cases when not the lack of medical means puts the end to the life of the incurable patient or in a vegetative state, but the medical staff – the society as a whole are those who label a treatment as being futile based on the costs / benefits balance. Therefore, for the same context, physicians from a different geographical area would arrive even at an opposing decision based on other principles that are important in their own community. The medical progress also brings different approaches on the same medical condition: nowadays we have solutions for many cases that in the past where doomed to a life of torment. Is it ethical to consider as a priority to avoid any resources consumption for futile treatments or rather to invest more resources on research with the purpose of providing a meaningful life to those patients? The society is confronted with a conflict generated by the irreversible intrusion of biotechnologies, with a growing perfectionism, in the management of human life and health. The rapid progress of medical biotechnologies puts the man in the

²¹ Sherynn, Perry J. "Legal Implications for Failure to Comply with Advance Directives: An Examination of the Incompetent Individual's Right to Refuse Life-Sustaining Medical Treatment." *Behavioral Sciences and the Law* 20 (2002): 253-269.

impossibility of managing all the consequences of this invasion²² and to make a decision without real doubts or questions from a moral approach. A decision that today may appear as the best one from the ethical approach tomorrow could be blamed as an act of rushing in the decisional process with significant negative consequences: the evolution of the medical ethics is adapted to the fast development of the medical biotechnologies and of the knowledge in the medical area.

On the other hand, the criteria for the moral value of a medical act in this context are difficult to be established because of the plurality of the variables involved in the ethical issue concerning the *advance planning*. For the simplification of the decisional process, in the last decades, the field's literature mentions the *quality of life* concept which is, in the same measure, difficult to define and controversial²³. With all the confusion concerning this new concept, it is used by many medical professionals with the hope to find some standards to define when a life could be or not worth living. Having the guidelines provided by the *quality of life* concept, the health professionals may determine when is desirable (from a practical approach) withdrawing the medical support for a suffering life.

Nowadays, the tendencies in medical practice are favorable to the interruption of the futile treatment, but in the past decades this kind of decision made by a medical doctor or the family was regarded, at the community level, as a type of euthanasia (passive euthanasia in most of the cases) and incriminated: "Passive euthanasia consists therefore in the lack of application or the interruption of a treatment which may prolong life."²⁴ That early approach on *advance planning* rise the following question: how did we come to consider the withdrawal of medical treatments morally acceptable?

The *slippery slope* argument, which may also lead to a logical failure of the argumentation, promote the idea that a first case that won a process concerning a particular bioethical issue, seen as unacceptable before, will become a reference case for the following similar requests in the Court. This behavior will lead to the proliferation of the type of medical decisions and acts, pushing the legally accepted limits further. Once accepted a thing, this will entail later consequences seen as unacceptable at the present moment. The use of *slippery slope* argument is still not always relevant or morally justifiable; it can hide many decisional errors.

²² Anders, Günther. *L'obsolescence de l'homme : Sur l'âme à l'époque de la deuxième révolution industrielle (1956)*. Edition de l'Encyclopédie des nuisances. Paris: Ivrea, 2002.

²³ Aluș, *op. cit.*, p. 31.

²⁴ Oprea, Liviu, și Cristina Gavrilovici. *Bazele comportamentului individual în sănătate*. București: Pro universitaria, 2015, p. 224.

The fundamentals of the medical doctor – patient relationship²⁵ are the principle of life inviolability²⁶ and the necessity to maintain and to strengthen the trust through their collaboration²⁷. *Beauchamp* and *Childress*²⁸ proposed four ethical principles for the medical practice: autonomy, non-maleficence, beneficence and justice. Considering the *slippery slope* argument, the use of *advance planning* may lead to social pressures in favor of the proliferation of euthanasia and medically assisted suicide and, later, to acts that take place without the consent of the patient / relatives; or the agreement may be obtained by the use of force²⁹. In this kind of context, the consulting session on the *Advance Directives* or the *Living Will*, from the beginning of the hospitalization, would implicitly put a pressure on the patient to give the consent for morally unacceptable acts, performed with the legal protection. The patient will be convinced concerning the unwritten rules of the society concerning the avoidance of the irrational consumption of the medical means. This attitude is based on the stigma of the terminal stage sickness and of the people lacking the self-determination capacity, without awareness of their own identity. When the legal framework exists on patients' right to self-determination, the society may push the citizen's decision toward an action that will end the unnecessary sufferings. Finally, some voices will support with arguments the medically indicated euthanasia.³⁰ However, different groups and communities don't have the same views on the ending period of life, even in the context of the suffering. From a Christian theological approach, the last period of the individual's life is considered to bring him/her closer to God. Those moments may also provide relieve for the family to accept the irreversible came in the life of the loved one: a grieving period when they detach their feelings and emotions from the presence of the loved one in their life.³¹

Regarding the euthanasia, in general, three different actions are on debate: not starting a treatment that is considered futile, interrupting it or actually taking someone's life.³² The nowadays international agreement on the

²⁵ Oprea, Liviu, Cristina Gavrilovici, Mihaela-Cristina Vicol, & Vasile Astărăstoae., *Relația medic-pacient*. Iași: Polirom, 2013.

²⁶ The Danish Council of Ethics. *End of life. Ethical challenges and problems*. Traducere de Tim Davies. London, 2006, p. 122.

²⁷ Ibidem, pp. 128-129.

²⁸ Beauchamp, Tom L., & James F. Childress. *Principles of Biomedical Ethics*. seventh edition. Oxford: Oxford University Press, 2013.

²⁹ Beauchamp & Childress, *op. cit.* pp. 131-132.

³⁰ Ibidem, p. 160.

³¹ Croitoru, Ioan Marian. "Abordarea suferinței prin dimensiunea spirituală a credinței în Dumnezeu." În *Influența valorilor creștine asupra bioeticii europene*, de Mircea Gelu Buta, 291-302. Cluj-Napoca: Editura Renașterea, 2015.

³² The Danish Council of Ethics, *op. cit.*, p. 150.

topic of euthanasia proposed the use of this term just for the active actions of the physician with the goal to end someone's life. Critics of euthanasia warn that this practice may become as common as today is the withdrawal of life ending treatments. The history of *advance planning* is a proof of the slippery slope model: since the first case that won in the Court, the internationally unwritten principle concerning the topic was drastic changed with the introduction of new laws. In some cases, the health professionals had the tendency to withdraw the futile treatments in some cases even before having the any legal framework in support of this action.³³

Even if many debates are made around the life ending decisions, the context demanding a written paper may be very different from one case to another one. It can be, indeed, a case of a terminal illness or an irreversible stable medical condition as an advanced dementia or a persistent vegetative state, the individual being kept alive by machines. The approach for each case is completely different due to the patient's distinct condition and because of the specific type of medical care required. By consequence, when the patient elaborates the *Advance directives* paper, he/she must be aware about all of these distinctions and their different medical implications. Moreover, the individual may choose between the complete refusal of medical care and refusing few specific ones like the following: the palliative care, the artificial life maintenance and others. The patient may refuse the medical interventions which are in contradiction with the personal values and preferences – demanding instead an alternative medical care. A good example would be, in this case, the individuals who, based on religious views, will refuse blood transfusions, but they still require medical procedures with the use of blood substitutes.³⁴

Although the international documents highlight the need for talks with the patient on *advance planning*, some studies mention that the medical doctors are still reluctant and avoidant on talking with their patients on the topic.³⁵ By consequence, the preferences of the terminally ill patients are poorly meet: the medical care for the end of life is still very aggressive. The issue about the *Living Will* thus remains one of the most expressive images of the existing gap, in Günther Anders' view, between the fragile human being and the medical biotechnology with increasing possibilities that comes with the risks to govern our life. The intrusion of these new technologies on the human life and body request deep reflections on the personal identity, the personal values: on the personal views

³³ Ubel, Peter A. *Critical decisions : how you and your doctor can make the right medical choices together*. 1st ed. Epub Edition: Scribd, 2012, pp. 64-66.

³⁴ Legal advisors committee. "The Right to Refuse Treatment: A Model Act" *American Journal of Public Health* Vol. 73, No. 8, (August 1983): pp. 918-921, p. 918.

³⁵ Jonsen, Siegler & Winslade *op. cit.*, p. 82.

concerning the relationship with the advancing medicine in the management of someone's health. Without having a good advance planning, the cost of prolonging someone's life can be painfully, very expensively and against his/her will. With a prior declaration, it is considered that the patient will gain some control over the medical treatment received by avoiding the technological imperative to make whatever is possible to save his/her life.³⁶

Firstly, the patient may have or not the desire to prolong his/her life, depending on the personal perception of his/her medical condition. We assume, in this case, that his/her health cannot be improved; or the costs and risks, at the moral/ethical level, for its possible improvement are very high for the patient: this individual will have to give up on the personal values. And, secondly, it is about the views of the community where he/she belongs on that medical condition, but also about the medical principle of justice: the necessity to distribute righteously the medical resources to the patients. The resources to be allocated for one patient are limited and some other patients would have a higher need for them or they have better chances to live a life with a good quality after their recovery. Therefore, the healthcare system may encounter divergent views on the topic: despite of the previous considerations, the patient may express the preference to preserve his/her life in any medical conditions. In a society with the justice as the highest value, this context will find an ending point in the depletion of the resources that are allowed to be used with one patient: the medical care is based on the principle of increasing the number of the patients helped / recovered by the use of the medical means. The community has an analogical approach on the topic: the individual has value as long as he/she is productive and can be medically recovered as a productive agent. Society still keeps an approach based on productivity-consumption construct.³⁷ Is it morally acceptable or not to not allocate medical resources to an individual who will never be recovered – a person who continuously needs important resources for living without even being able to fully enjoy his/her life? According to Kant's moral approach, the human being must always be treated as a purpose and not as means.³⁸ Therefore, from a moral approach, the value of the human being will not be the result of his/her ability to have a positive contribution to the community where he/she belongs. This ethical approach will not consider justice to be the most valuable principle, but the autonomy.

³⁶ Legal advisors committee, *op. cit.*, p. 918.

³⁷ Hirsch, Emmanuel, ed. *Ethique, médecine et société. Comprendre, réfléchir, décider*. Paris: Vuibert, 2007, p. 863.

³⁸ Kant, Immanuel. *Critica rațiunii practice*. Traducere de Niculae Bellu. București: Ed. Științifică, 1972, p. 46.

What leads the patient to elaborate a paper to express his/her refuse for certain medical interventions? Is it due to the physical pain felt, to his/her respect for justice as the highest moral value or to the psychological suffering generated by the personal perception of the community's approach? The patient and the health professional are prone to have a bias concerning the patient's own life quality after performing a medical procedure or concerning the apperception of the incurable medical condition's embodiment. Most of the patients with some undesirable medical procedures, seen as having a major impact on the quality of life had a quite well the accommodation with their new condition: that living conditions becoming the new normal. The patients had the tendency to forget about the past, not being so drastically affected by their lost as expected previous. Moreover, despite the negative perception of the aging at the society level, many older people reported a fairly good quality of life and higher satisfaction. If the patient has a misperception or misunderstands concerning the life that he/she may experience in certain medical conditions that may occur someday, this person would make a completely wrong decision.³⁹ This issue could be a topic with a good research potential in the bioethics – at the intersection of humanities and theology with the medicine. Even if the society lives with the permanent risk of the scarcity of the medical resources, the mentioned fields above still have a mission in empowering the patient to believe that a life with some serious medical conditions may still be enjoyable and worth living. This positive attitude toward life and living may have a positive contribution in building trust between the patient and the health professionals for finding the best medical decisions possible at that moment with the respect of the fundamental values and principles of the medical care.

In this context, the professionals with deep interests in the bioethics will have to pay attention to the following questions: How will the issue of advance planning be addressed to the patient, in what moment and by whom, in order to not make this person perceive a certain pressure in the decision making process? How do the patients feel about the request of writing papers for *advance planning*? Is it possible that the patients have in their mind the following statement "I do not want to be a burden for others"⁴⁰? Who may determine, from an ethical approach, when a life is no longer worth living? What are the grounds in establishing the uselessness of a person for the society and the futility of the medical care? Does the human being have an intrinsic, unalterable, value – the same in any medical condition – or is it changed in some cases? How

³⁹ Ubel, *op. cit.*, pp. 146-156.

⁴⁰ Lemmens, Christophe. "A New Style of End-of-life Cases: A Patient's Right to Demand Treatment or a Physicians Right to Refuse Treatment? The Futility Debate Revisited,." *European Journal of Health Law* 20 (2013): 167-183.

does society approach the value of the human being as a concept? The individual autonomy, set by Stuart Mill, is a principle built on the request to avoid any interference with the personal choices: on the contrary, the necessity, in the present society, is for actions with the clear purpose to improve its exercise.⁴¹ Therefore, the following question is fundamental for the present topic: how and when will the health professionals present *advance planning* to the patient in order to not create implicit pressures for considering decisions and actions that are actually against his/her deepest desires?

Conclusion

From an ethical approach concerning the patient's autonomy, the *Advance directives* paper is not elaborated just with the purpose to protect the healthcare professionals in the court for their decision to withdraw the medical support. *Advance planning* should, foremost, meet the patient's will: it may provide the assurance of the fulfillment of the autonomy principle by giving to the patient the chance to choose those medical interventions which are in accord with his/her personal values. Therefore, the patient will have the conviction that he/she will receive a medical care as good as he/she would still be able legally to make a decision at that critical moment.

Thus, some good information about the *Advance directives* offered to the patient in a proper moment may really help this person to exercise his/her autonomy; but if this knowledge is provided improperly (concerning the chosen moment and the attitude of the presenter), it will create implicit pressures for the patient. This attitude toward the patient may have a negative effect on his/her trust in the medical professionals – also affecting deeply the clinical collaboration.

The dialog with the patient on the topic of *advance planning* may become a serious issue in a country like Romania, where the specific legislation is still on development: mass-media brings in attention the concerns about the meaning of the *Advance directives* in the common language, the formal aspects of the paper and the rules followed in their interpretation. The patient may become a subject to the social pressures in accepting decisions in opposition with his/her personal will. His/her decision-making capacity may become a kind of pseudo-autonomy: this person will lose the personal freedom, not through his/her medical condition, but because of the views of the society on what decision would be honorable and good⁴². Inspired by the society's views, the patient will, probably,

⁴¹ Sandu, Antonio. *Etică și deontologie profesională*. Iași: Editura Lumen, 2012, p. 102.

⁴² Hirsch, *op. cit.*, p. 863.

remain with the illusion of exercising his/her decisional ability until the last moment by choosing to put the end to his/her life in some well-established circumstances. Autonomy is, of course, a fundamental value of the human existence, but to what extent is it a real one or just an illusion created by the decision to walk the path established by the society?

The history of *advance planning* brought a correlation made between the idea of *Advance Directives* and Living will (*Life testament* being the literal translation of the Romanian expression often used for this document) that may create in the patient's mind a distorted image about the purpose of this kind of paper. In the common language of Romanian people, the word "testament" refers to an unavoidable life ending condition that may last for a short period of time. Will the healthcare professionals be interested in making this person aware about inalienable intrinsic value of the human being or will they behave in a way that may create the impression that the value of the individual is grounded just on his/her active involvement in the community? The language used in the elaboration of that document may recall, in the mind of the patient, the irreversible condition of death. What kind of language should be used to inform the patient without making any implicit pressure on him/her? What behavior would be ethical in this context? How will the risk of the medical resources scarcity be presented to the patient?

By a good attention given to the language used to address the issue of *Advance directives*, the information offered to the patient may just point the necessity of planning in advance for a possible future context. The message should empower the patient by explaining the need to elaborate this paper to have the assurance of receiving the best medical care preferred in a context of decisional inability. The *advance planning* should be presented as the warrant for the preservation of the human being's autonomy, value and dignity in any medical condition.

Despite any supposition came from the relatives, medical staff or community concerning quality of life of a certain patient, his/her intrinsic value and dignity should not be undermined by undesirable actions of other people. Even if the patient is unable, at that moment, to make a medical decision, that person may not get actively involved in the community, he/she still deserve to have the community's support to live the best life possible for that medical condition in a society built for its citizens, based on well balanced moral views.