POINTS OF VIEW ABOUT THE MORAL-ETHICAL APPROACH OF TERMINAL STATES

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Abstract: *This paper presents possible approaches to the delicate matter of terminal states, using three moral-ethical models: utilitarian, kantian and principialist. It is important to acknowledge the special needs of terminal patients and also their rights, even though their disease is incurable. It is necessary to alleviate the physical sufferance, but also the mental one. During the entire palliative care, there is a need to respect human dignity; we also have to address the spiritual needs of these patients. This analysis brings us to the conclusion that the optimal approach of terminal states is the integrative medicine. The easy and sometimes very tempting solution offered by euthanasia cannot be accepted from a moral-ethical point of view, and even less from a deontological and legal point of view.*

Cuvinte cheie: *stări terminale, îngrijiri paliative, etică, morală*

Rezumat: *Lucrarea prezintă modalităţile de răspuns la problematica delicată a stărilor terminale, prin prisma a trei modele moral-etice de abordare: utilitarist, kantian şi principialist. Este subliniată importanţa recunoaşterii nevoilor speciale ale pacienţilor terminali, precum şi a drepturilor pe care aceştia le au, chiar dacă afecţiunea lor este incurabilă. Accentul este pus pe necesitatea cupării suferinţei somatice, dar şi a celei psihice, cu respectarea demnităţii umane pe tot parcursul acordării de îngrijiri paliative, ţinând cont inclusiv de nevoile spirituale ale acestor pacienţi. Analiza conduce la concluzia că abordarea optimă a stărilor terminale este aceea oferită de medicina integrativă. Varianta facilă (şi uneori foarte tentantă) a eutanasiei nu reprezintă o soluţie acceptabilă din punct de vedere moral-etic şi, cu atât mai puţin, din punct de vedere deontologic şi legal.*

"Terminal states" … It is an apparently ordinary phrase, that almost penetrated common language, but it conceals individual, family and even social dramas that are difficult to understand by those who were never involved in the painful universe of the desperate battle with death.

From the medical point of view, terminal states are characterized by the following traits:

- a serious pathological or posttraumatic condition, that determines severe physical or mental impairment;
- a grave, hopeless prognostic;
- futility of the treatment: only palliative care is available in the absence of any etiological treatment;
- physical suffering (pain being frequently the main and most important symptom) and also mental suffering (generated by the fight with the spectre of the lethal end and, frequently, by the abandonment of these patients by society or even by their family).

Those who are involved in the management of terminal patients can chose one or more of the following manners of response:

- palliative care – at home, in an hospital, in asylums or preferably in hospice institutions;
- treatment may include powerful pain-killers (morphine and its derivates);
- the necessity of a complex approach, that addresses the emotional, psychological and spiritual needs of the patient and of his/her family;
- due to the frequent loss of social functioning, terminal patients always need family and social support in order to die with dignity;
- a possible "solution" – that generates many moral-ethical conflicts – would be euthanasia, perceived by some as being the only way to ensure the right of these patients to die in a dignified manner; especially voluntary euthanasia is regarded as a way to elude suffering, to avoid the physical and mental deterioration determined by the unavoidable evolution of the terminal illness that is incurable in now-a-days medical context.

None of these possible approaches is exempt from ethical dilemmas; their systematic analysis can be made based on three models: a. the utilitarian model, B. the kantian, model, C. the principialist model.

A. The utilitarian model

The utilitarian doctrine stems from the ethically correct idea of maximizing good among most members of the society. The morality of an action is appreciated by its consequences: i.e. it is moral to act in the manner that determines the most positive consequences and the less negative ones.

But the fragility of this concept becomes obvious in the context of a now-a-days indisputable reality: the resources available for the health system are limited, while its needs are growing constantly. That is why, from the point of view of the health providers and of the political governors, there is a need to make an evaluation of health expenses that is based on statistical-mathematical and economical criteria, in order to allow a balanced allocation of the limited health resources. Especially in the case of terminal patients (due to the futility of the treatment), there is a growing interest regarding not only

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how much is spent, but mainly how efficient the allocated resources are used.

The motive behind this pragmatic approach lies in the finding of a disproportionate growing trend of health expenses in the last month of the terminal patients' life:

- in USA, studies have shown that 40% of the health insurance system's expenses are allocated in the last month of life;(3)
- a third of the terminal patients were bound to spend most of their life savings on health services that weren't covered by the health insurance system (e.g. home care).

B. The kantian model

The basic idea of this concept is that people can't be treated merely as objects. People have the ability to reason and, based on their reasoning, they become able to make their own decisions in an autonomous manner. Immanuel Kant views a person's (and, implicit, a patient's) autonomy as being derived from the liberty to decide, associated with the ability to reason. Thus, this model puts in the foreground the right of the terminal patient to make decisions based on his/her own reasoning, as opposed to the previous model, that takes into account only the consequences.

By recognizing this autonomy we must conclude that people have certain rights that must be respected (other people having correlative obligations in this sense). There are:

- negative obligations (implying other people's obligation not to intervene) and
- positive obligations (incumbent for other people's duty to take positive action in order to ensure these rights).(1,2)

Based on this model, we can also speculate the existence of one's "right to die" in the manner he chooses, that includes a negative right (correlated with other's obligation to abstain from useless treatments that generate suffering – passive euthanasia) and a positive one (that would imply the duty of those who are treating terminal patients to end their suffering by active means – active euthanasia).

C. The principialist model

This model is eminently synthetic; it includes the basic elements that characterize the two previous models. Ethical dilemmas are evaluated through the four fundamental principles of bioethics:

- beneficence,
- non-maleficence,
- autonomy and
- justice.

Beneficence: each and any medical or non-medical action must maximize the benefits for the individual(s). Through this principle, in the case of terminal patients the main objective will be to diminish their physical and mental suffering. The ideal way to accomplish that is by high-quality palliative care that will include pain management, conservation of social functioning, psychological counselling and spiritual care that addresses the soul.(1,2,3)

Non-maleficence: treatment measures mustn't generate more harm than relief; thus there is a need to constantly weigh risk and benefits for each method of treatment and investigation.

As we apply this principle to the particular situation of terminal patients, we ca easily see why treatment obstinacy is now-a-days largely condemned. Extraordinary means of therapy that are meant to keep the patient alive at all cost are sometimes *per se* the etiological agent of suffering.

Based on the same principle, there is a legal right of the patient to refuse the acknowledgement of a severe diagnosis or prognostic, in order to avoid consecutive suffering.(1,2)

Autonomy: each person is unique and has his/her own individuality, thus having a right to self-determination. This implies a non-paternalistic physician - patient relationship and the participation of the patient to the medical decision process, including the right to refuse treatment (as a form of passive euthanasia). However, an efficient communication between the physician and his/her patient is essential, in order to ensure a perfectly informed refusal or acceptance of the treatment. For incompetent patients (minors, mentally-ill, comatose patients, etc) there will be a substitute decision regarding treatment (made by parents, tutors, relatives, etc); if there is a conflict of interest, the court has the final saying.

A direct expression of the patient's right to self-determination are the advance directives - "living will" or DNR ("do not resuscitate"):(3)

LIVING WILL
TO MY FAMILY, MY PHYSICIAN,
MY PRIEST, MY LAWYER

If there comes a time when I won't be able to take part to the decisions regarding my own future, this declaration is to be considered as the will of my wishes:

If there is no more reasonable hope of recovering from a physical or mental condition,

I, … (the undersigned), demand to be left to die and not be kept alive by using artificial means and heroic measures. Death is as real as birth, growth, maturity and aging – this is a certainty. I don't fear death as I fear the lack of dignity that comes with degradation, dependency and hopeless pain. I ask that medication shall be given out of pity for my terminal disease, even if it will accelerate my death.

This demand is made after careful deliberation. Although this document has no juridical power, you, those I hope you care for me, will be morally obliged to proceed according to this mandate. I admit that it places a great burden of responsibility upon you, but I make this statement with the intention of sharing this responsibility and to diminish any sentiment of guilt.

Signature: *Date:*

Witnesses:

Justice: this principle implies an equal distribution of health resources among all members of the society, without any discrimination. Based upon this principle, terminal patients have the legally established right to benefit from medical care of the same quality that is given to curable patients. But on the other hand, in the spirit of utilitarianism, one can ask: "To what extent is it just to waste health resources for the treatment of terminal patients?", given the fact that these resources could be used more effectively in other health domains or for treating other (curable) patients.

However complex the ethical decisions regarding terminal states would be, we must never forget that terminal patients have still the same rights as any of us. In order to grant them a dignified passage through the cycle life - terminal suffering - death, we must meet some minimal needs that these patients have. Ebersole and Hess drew a schematic representation of these needs, using a pyramidal shape inspired by Abraham Maslow's pyramid of human needs.(1,2,3)

THE NEED OF FULFILMENT

- acceptance and passing-over this inevitable stage
- understanding the meaning of death

THE NEED OF RESPECT

- preserving one's dignity, despite his/her weakness
- preserving one's autonomy

- to feel human until the end
- preserving one's identity

THE NEED OF AFFECTION

- to love and to be loved
- to talk
- to be listened and understood
- to die in the presence of a close person

THE NEED OF SECURITY

- to trust the care-takers
- to be able to express one's fears
- to feel safe
- to feel that one is told the truth

BASIC PHYSIOLOGICAL NEEDS

- to be protected against suffering and pain
- to preserve one's energy

Correlatively, terminal patients must enjoy **fundamental rights** that are proclaimed in several charters dedicated to this subject. In an attempt to summarize, we can list the following essential rights that should be guaranteed to these patients:

- I have the right to be treated as a living person, until the end;
- I have the right to hope (for salvation, for a future life, etc);
- I have the right to be cared for by people who are capable of keeping my hope alive;
- I have the right to express my feelings and emotions related to death;
- I have the right to be involved in the decisional process;
- I have the right to be cared for, even though healing isn't possible;
- I have the right not to die alone;
- I have the right not to suffer;
- I have the right to be given sincere answers to my questions;
- I have the right not to be lied;
- I have the right to die in peace and with dignity;
- I have the right to preserve and express my religious conceptions and beliefs, without being judged, apart from other peoples' conceptions;
- I have the right to be cared for by people capable to understand my needs, by people who get satisfaction from helping me to cross this final stage of life;
- Man's Sanctity is to be respected even after death.

As a **conclusion**, I want to emphasize that the therapeutically approach of terminal patients should be in the spirit of integrative medicine: treatment shouldn't address only body and mind, but also the soul. In the particular case of these patients it isn't enough to medically cure only their physical and mental problems; there is also a need for psychological advice and especially for spiritual-religious support - a genuine treatment of the soul. That is why I consider that a quality palliative care (preferably at home or in hospice institutions), that addresses all medical, psychological and spiritual coordinates, represents the best management of such cases.

Collaboration between physicians (including psychiatrists), psychologist and priest is absolutely necessary in this respect.

If this desideratum is accomplished, a "good" death won't be anymore considered to be euthanasia (as its etymology would suggest). Instead it will be that kind of death that is peaceful (serenity of mind, reconciliation with fellow-man and with God) and painless, that finds you in a lucid state of mind, surrounded by the loved-ones. It will be that kind of death that the orthodox liturgical service designates as a "Christian end of our life, painless, (…), in peace".

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