CONSELHO NACIONAL DE ÉTICA PARA AS CIÊNCIAS DA VIDA
NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES
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OPINION ON THE ETHICAL ASPECTS OF HEALTH CARE REGARDING THE END OF LIFE

(June, 1995)

I - REPORT

A. PREAMBLE

1. The natural history of many diseases, the aggressiveness of modern life, especially of motor traffic, and the ageing process bring human beings closer to the final period of their biological life. In modern societies, we can also speak of some loss or devaluation of the meaning of life when life is not pleasant for the person concerned.

During this final period, doctors are called upon to develop a very delicate aspect of their professional activity, which is not the practice of curative medicine, but the practice of caring medicine (also called "palliative" medicine).

Today, this new aspect of medical activity has its "leges artis" already as well established as those of preventive and curative medicine (1).

The first rule is that, while there is reasonable hope of bringing about a cure or an improvement from the morbid state, along with a quality of life acceptable to the patient, the rules that must be followed by the doctor are those of curative medicine, both the scientific and the ethical ones. The emphasis is, then, given to informed consent and to the principles of beneficence and nonmaleficence, at the ethical level, and to the accurate clinical analysis of the situation, at the scientific level.

When there is no reasonable hope of cure and the expected improvement depends on heavy physical sacrifices imposed on the patient by the several treatments, the rules of caring medicine must prevail.

The fundamental purpose of this form of medical care is to offer the patient in a stage of incurability the greatest possible comfort and well-being, physically, mentally and emotionally.

The treatments are applied to symptoms indicating suffering and acute situations, curable through immediate medical or surgical operations (pneumonia, acute appendicitis, etc.).

Medical decisions in the field of caring medicine have a scientific basis, but, above all, they have a very significant ethical structure. It is not only the technician who decides what to do with a body whose biological life is coming to an end; it is the doctor, as a human being with a long tradition of respect for his patient, codified since Hippocrates, the doctor as a member of a certain society and also as part of a culture with historical traditions, who faces the situation of attending his fellow human being during his last days.

Consequently, rendering health care in the final period of someone's life is a worthy ethical act.

2. It is this ethical nature of medical decisions that the present report will analyse as the basis for an opinion. It will do so in the light of the doctrine already exposed in this Council's Report-Opinion on Medically Assisted Procreation, the main points of which are here reproduced:

> "This Council wishes to develop an ethical reflection that, on the one hand, will be shared by every citizen in our pluralist society, but that, on the other hand, will not be confined to an ethical pragmatism, to a deontology with no critical grounds or to the passive acceptance of practices or positions commonly maintained in our country, as well as in others.

In this perspective, this Council believes that the ethical grounds should rest on a concept of human nature, without limiting it to its purely biological aspect, nor extending it unduly to a point where it cannot be distinguished from non-human nature.

Dimensions of rationality, temporality, historicity, end in itself and liberty are all part of the nature of the human being. They all make him a constantly developing being in search of self-fulfilment, with the possibility of resorting to external help, as well as to medical operations that will not essentially contradict his nature, regarded as such.

In this sense, a behaviour that seeks, promotes and respects its own self-fulfilment in the constitutive relationship with and towards others, in the context of fair institutions, is ethical.

This ethical need for personal and social self-fulfilment (which reveals itself in each person's awareness of his rights and responsibilities in his own life and in that of others) requires the necessary freedom to be fully exercised. That freedom implies that no person will be used as a means or an instrument for whatever purpose. Each human being must be treated as a separate entity (...).

The recognition of each person's non-instrumental value is an important achievement of our civilization and has been demonstrated in a variety of ways: in the abolition of all kinds of slavery (including that of children); in the universal declaration of human rights and fundamental liberties; in the recognition of the right to conscientious objection, religious freedom, and so on.

Ethical freedom does not mean arbitrary choice, permissiveness or moral relativism. What it does mean is the possibility of ensuring the full potential of every human being. In this sense, not only does ethical freedom concern the absence of external constraints, but it also requires freedom from internal pressures, both originating in scientific, economic or political interests and based on cultural prejudice or religious

positivism not freely integrated. It also requires internal liberation from minor concerns, vice or self-destructive egoism, as well as from economic or hedonistic absolutism."

B. TYPOLOGICAL ANALYSIS

1. Terminally ill patient treated with understanding and respect, no futile treatments, at home, surrounded by family, all conditions ensuring him a dignified, socialized, recognized and accepted death:

This is the common situation of very old people who receive support from their families or from a quality social team and do not suffer from any treatable disease, but only from senility or irreversible sequelae from cardiac or cerebrovascular accidents.

The medical decision to practise caring medicine complies with the above mentioned ethical principles.

2. Seriously ill patient, hospitalized, entering a terminal stage:

The health team, dedicated and competent, decides to interrupt treatments that, according to the best clinical judgement, became clearly ineffective, refusing to obstinately proceed with them, considering it wrong medical practice, but using all the necessary means to ensure the patient's comfort and well-being, so that the process of death can go on with respect for the dignity of the individual.

In order for this medical decision to be ethically correct, it is necessary that:

— during the final period, the patient be personally and constantly attended by the health team;

— the presence of relatives be permitted 24 hours a day, as well as that of other people that the terminally ill patient might wish to see, including religious ministers;

— in the terminal stage, the patient be easily discharged from hospital if he or his family so wishes.

As long as these requirements are fulfilled, death in a hospital environment (or outside it) can occur with respect for human dignity and medical decisions will be ethically correct and good medical practice.

In the light of the above mentioned principles, it is not ethically acceptable that the hospitalized, terminally ill patient be isolated and abandoned until death occurs in the most complete loneliness.

3. Patient regarded as terminally or incurably ill, humiliated by his disease or having no more will to live, who asks his doctor or any other member of the health team, or any other person, relative or not, to provide him with a substance that he can administer to himself and that will be surely fatal.

In this case, the decision will be to aid in suicide. *

From the ethical point of view, this is not the moment to judge the decision of the person who asks to be killed, since it derives from his intimate and personal condition.

The decision to perform the person's request by providing him with the necessary means to kill himself does not have an ethical justification. The person receiving the request

must, therefore, neither accept that the patient should kill himself, nor contribute to the fulfilment of a desire that is not his and that results in the destruction of a human life.

4. Patient who does not wish to live because he considers his potential quality of life to be unbearable, who is psychologically competent to exercise his personal autonomy and who insistently asks his doctor, or any other person, to kill him with drugs or other means:

If the doctor (or any other person) performs such a request and kills the patient because of that request, he will be practising active voluntary euthanasia.

As in the previous case, we must not form any ethical judgements on the decision of the person who, in making the request, is freely exercising his personal autonomy.

However, the way in which the will to perform, or not, the patient's insistent request takes form in the doctor's professional and moral conscience is worth careful ethical reflection. *

For many doctors in Portugal, the fact that this is homicide, therefore punished by penal law, and that the Deontological Code explicitly forbids doctors from practising euthanasia (with no qualifications) is reason enough not to regard the patient's insistent request as viable.**

Others, however, in situations where being alive is the cause of intense suffering for the patient, which the doctors can not (or do not know how to) render tolerable for that person, wonder if fulfilling the patient's desire in such extreme situations should not be

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* This decision is punished in Portugal with a 6 months to 3 years imprisonment penalty, if the patient is imputable, aggravated to a 2 to 8 years imprisonment penalty if he is not imputable, and implies social condemnation, translated into law, of this medical behaviour (Art. 135 of the Penal Code).

** Juridically, in Portugal, this is a case of homicide at the victim's request (Art. 134 of the Penal Code). The doctor who might practise it is punished with a 6 months to 3 years imprisonment penalty.

regarded as the best procedure and, therefore, ethically justified by the principle of beneficence.

With all respect for particular cases, which are worth analysing with sensitivity and lucidity so as to understand their profound motivations and their precise and avoidable nature, the ethical reflection should focus mainly on the general framework of the situation. Otherwise, we would be using a "pragmatistic or merely casuistic ethics", formally rejected on the above mentioned grounds.

In this general framework, there exists manipulation of the doctor's will (or any other person's) by the patient who asks, almost demands, to be killed through a positive action carried out by the doctor himself (or by any other person). We should bear in mind that, juridically, the main characteristic of the crime lies in the circumstance of this being an impulse dominated act provoked by the patient's condition.

The ethical judgement on this (medical) decision resulting from manipulation should be of disapproval.

5. Terminally ill patient, unconscious and, therefore, incapable of expressing his will. The doctor (or any other person), strongly influenced by what he regards as the patient's unbearable situation, for which he does not have a treatment, decides to kill him with pharmacological or other means.

This (medical) decision embodies the act of active, involuntary (because the patient did not express his will) euthanasia.[***]

[***] Punished in the Penal Code, Art. 133, as voluntary manslaughter, with a 1 to 5 year imprisonment penalty.

Objectively, this is an unacceptable medical decision, because the doctor, out of real or supposed compassion, has elected himself the right to dispose of a human life; and, in the ethical perspective on which this analysis is based, he does not have that right.

A similar negative ethical judgement is made in situations in which the terminally ill patient is conscious, does not show any will to be killed and the doctor decides to kill him.

The fact that it is possible for the doctor to make this decision creates the conditions for the manipulation and instrumentalization of the patient's will, both by third parties with a personal interest in that decision and by the political power, of which we have well known historical examples, some of them from this century.

Apart from this real and observed risk, such a medical decision offends the ethical and deontological principles generally accepted in medical practice (with the exception of Holland [2]).

6. Patient who, under normal circumstances and perfectly conscious, has left detailed instructions forbidding the application of certain treatments in situations where he may not be able to express his will (the so-called "testament of life"), even if these situations should seriously threaten his life;

When a situation like this occurs, the doctor must decide on whether he is going to obey the will freely expressed by an autonomous person at an earlier time or not.

The ethical analysis is difficult [3]. Should he obey?

In the light of the autonomy principle, it seems that he should; but how can we be sure that the decision made by the person when he was healthy is his real wish, now that he is seriously ill? If he could be informed about his real, present situation, would he not give consent to a treatment he refused in the past, when he did not have this information?

Most ethicists suggest that, when in doubt and when it is not a question of futile treatments, or “heroic” treatments with little chance of success or causing great suffering, not proportional to the estimated benefits, in which, in practice, the patient's will coincides with the medical decision not to treat him, the doctor is not ethically obliged to follow the previous instructions; especially if there is reasonable probability of saving the patient's life by using the proportionate therapeutic measures that the patient had refused beforehand. These ethicists take into consideration, namely, that the expressed will is neither "current" nor "informed".

In case the doctor decides to comply with the patient's will by not introducing, or by suspending, therapeutic measures whose only effect is a prolongation of the process of death, and which the patient expressly refused by means of a previously written document or refused before he became unconscious (e.g. in irreversible coma), this decision is ethically defensible as long as it is followed by all the necessary measures to ensure the person's comfort and well-being during the process of death, even though those measures may, presumably, and should there be no alternative, reduce the duration of the process of death.

It is not legitimate to call this decision passive euthanasia, for it is no more than good medical practice.

7. The medical decision not to introduce extraordinary respiratory and cardiac supporting measures when these are not medically useful, as well as the decision to suspend them as soon as brainstem death is observed, are worth the same favourable ethical judgement.

8. As a final synthesis of this typological analysis, I suggest that, in the ethical perspective, it is necessary to clearly distinguish between medical decisions representing

active ways of producing the patient's death - "medical death", as Siegler calls it - and decisions to maintain or suspend artificial life-sustaining means, when it is medically recommended, as well as the decision to apply all the techniques that might ease the pain and produce comfort and well-being for dying patients [3].

The ethical evaluation of these decisions leads us to propose that doctors refuse the first ones - no doctor will ever kill his patient - and actively engage in the second ones - no doctor will be indifferent to a patient’s suffering until the last minute of his life - so that human death, inevitable though it is, can be faced with dignity by everyone.

THE REPORTER,
(DANIEL SERRÃO)

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II - OPINION

Whereas the matter of ***EUTHANASIA***, meaning various kinds of behaviour, either originating in the course of medical activity or not, has been the subject of public discussion, both in the media and in the questions people are faced with and on which they are sometimes asked to give their opinion;

Whereas the development of a culture that denies suffering and pain and refuses to face death and transcendence increases the frequency with which the matter is mentioned, and even understood;

Whereas this cultural attitude and the noncritical transmission of information on this matter create a tendency to accept the ***"idea"*** of ***EUTHANASIA***, of which the Dutch legislative initiative, and the information provided on it, is an example;

Whereas, instead of a correct definition of ***"euthanasia***" such as we present in paragraphs 4 and 5 of the preceding Report, we frequently see the same expression being used in situations that have nothing to do with ***"euthanasia"*** and that should be analysed quite differently;

Whereas EUTHANASIA, as well as all the other issues concerning the fundamental value of life, can only be analysed through its humanistic, axiological and ethical framework;

Whereas, even though the issue of ***EUTHANASIA*** does not represent an acute problem in our country, this Council considers this to be a suitable moment to start reflecting

on it and contribute to its calm discussion and understanding, preventing the creation of "apriorisms" and prejudices;

The ***CONSELHO NACIONAL DE ÉTICA PARA AS CIÊNCIAS DA VIDA - CNECV*** **(NATIONAL ETHICS COUNCIL FOR THE SCIENCES OF LIFE)**, taking the preceding **REPORT** as a foundation, holds the **OPINION**:

that there is no ethical, social, moral, juridical or any other argument from the deontology of health professions that might justify in thesis that the patient's intentional killing (even if not declared or assumed as such) by any person, namely by medical decision, be legally possible, even if on pretence of "request" and/or "compassion";

that, therefore, there is no argument that might justify, out of respect for life and the human person, any act of euthanasia;

that the interruption of disproportionate and ineffective treatments is ethical, all the more when they bring distress and suffering to the patient. Therefore, although this interruption may shorten his life, it cannot be regarded as euthanasia;

that the application of drugs designed to ease the patient's pain is ethical, even if it has the side effect of shortening the patient's estimated life span, and cannot be regarded as euthanasia;

that the acceptance of euthanasia by the civil society, and by the law, would lead the patient to lose confidence in his doctor and in medical teams and could give rise to an uncontrollable liberalization of the "licence to kill", and to barbarity;

that, nevertheless, the rejection of the acts of euthanasia, as alleged potential individual rights of doctors (or others) and patients (or others), also creates individual and social obligations that cannot be minimized or forgotten, namely, and most particularly:

* the private and public responsibility of adequately attending terminally ill patients, handicapped people and dependants of any sort;

* the practice of giving continuous care to dependants, with absolute respect for their dignity and integrity as human beings;

* the creation and maintenance of the necessary conditions to offer caring medicine (palliative care) to everyone who might need it;

* the support to the research into pain treatment and to the creation of specialized groups in this field of medical care

* the development, in the field of medical and nursing training, pre- and post-graduat, of a high level of instruction, so that health professionals know and may consciously assume their ethical responsibilities towards the patients in their care, specially those entering the terminal stage, enabling them to die in dignity.

Lisbon, the 7th of June 1995

THE REPORTER,
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