



POINT OF VIEW

End of life decisions, the Dutch form through Spanish eyes

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Abstract Abroad, but also in The Netherlands, there are many misunderstandings concerning end of life decisions and euthanasia.

In general, euthanasia does not play any role in the intensive care units, simply because it does not fulfill the conditions to carry it out. However, there is still confusion, merely due to the assumption that the Dutch situation is different because of their legislation on euthanasia. The use of the unclear terminology such as “passive euthanasia”, “voluntary euthanasia” or “involuntary euthanasia” contributes to the confusion of lay people and physicians, and should therefore be avoided.

End of life decisions in intensive care patients are in fact a structural part of work of intensivists. Collecting all necessary information including the wishes and will of the patient, medical expertise and acknowledging limitations of medical treatment will help to determine futility of treatment goals. Once it is determined that surviving the intensive care unit with a quality of life acceptable for the patient is beyond reach, the goal of treatment should be improved and the dying process optimized.

Stopping a treatment modality at the request of a will-competent patient or because of futility is not euthanasia.

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PALABRAS CLAVE

Eutanasia;
Países Bajos;
Medicina intensiva;
Final de la vida

Toma de decisiones al final de la vida, el modo neerlandés a través de ojos españoles

Resumen Todavía hay confusión acerca de la toma de decisiones al final de la vida y la eutanasia, tanto en el extranjero como en los Países Bajos.

La eutanasia no tiene ningún papel en las unidades de medicina intensiva, en general, simplemente porque no se cumplen las condiciones necesarias para llevarse a cabo. Aun así sigue prestándose a confusión, meramente por la presunción de que la situación en los Países Bajos es diferente debido a la legislación de la eutanasia. El uso de terminología confusa como «eutanasia pasiva», «eutanasia voluntaria» o «eutanasia involuntaria» genera confusión entre los médicos y la población general, y por ello deben evitarse.

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Las decisiones al final de la vida forman, de hecho, parte del trabajo diario de los intensivistas. Para determinar la futilidad de los objetivos terapéuticos, son importantes la experiencia médica previa, recoger toda la información necesaria y conocer las limitaciones de un tratamiento médico, pero también tener en cuenta las voluntades y los deseos del paciente.

Una vez determinado que el objetivo de sobrevivir a la unidad de medicina intensiva con una calidad de vida aceptable para el paciente está más allá de su alcance, el objetivo del tratamiento debería ser la optimización y permisión del proceso de la muerte.

Retirar u omitir el tratamiento fútil de soporte vital en un paciente que lo solicita no es eutanasia.

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Introduction

Intensive Care Medicine (ICM) has evolved enormously in the last 50 years. The technical sophistication, organization and the presence of highly trained personnel have contributed to improve the survival of critically ill patients in the last two decades.¹ The profile of the critical patient has also changed, and it is increasingly common to treat patients with situations that are no longer so irreversible, due to advanced age or underlying chronic diseases.

In the past, patients “died”, while today we speak of “letting them die”. Furthermore, we now have additional control over how and when our patients die. The taking of decisions at the end of life forms part of the daily work of intensivists. In this context, it is essential to distinguish between putting an end to the life of a patient who expressly wishes to die (euthanasia), and leaving the patient to die. In the former case it is the physician who actively intervenes to put an end to the life of the patient. In the latter case, the therapeutic objective is no longer to prevent death.

Interest in end of life decisions has increased in recent years. Working as an intensivist in The Netherlands has led colleagues in our Unit to often collaborate with societies and international companies with a view to debating or discussing this issue - simply due to the assumption that the situation in the Netherlands is different because of its legislation on euthanasia.²

Writing about end of life decisions seems to be an ethical issue, though undoubtedly it constitutes an act of medical judgment, good communication, teamwork and leadership, conditioned of course to the laws of each society and country.

After one year of experience in a Dutch Unit of ICM, it is clear that unfortunately, limitation of life support management (withdrawal or omission) and palliative care are often confused with euthanasia.

The present study thus describes the considerations that play a key role in end of life decisions and the mistaken concepts about euthanasia in Units of ICM in the Netherlands.

Presentation of the subject

Terminology

The term euthanasia comes from the Greek words *eu* (good) and *thantos* (death), i.e., it refers to “good death”.

Euthanasia means that a physician actively puts an end to the life of a person in response to a patient request to die, because of unbearable suffering.

In turn, “physician-assisted suicide” is defined as the administration, provision or prescription of drugs with the explicit intention of allowing the patient to put an end to his or her life.

At present, euthanasia is legally permitted in the Netherlands, Belgium^{3,4} and Switzerland,⁵ while physician-assisted suicide is allowed in the states of Oregon and Washington (United States).⁶

The expressions “voluntary euthanasia” and “involuntary euthanasia” are unnecessary and confusing, because by definition euthanasia is always voluntary, and involuntary euthanasia is not euthanasia but homicide. The same can be said of expressions such as “direct euthanasia” or “active euthanasia”, since by definition euthanasia is always both things, and the problem with the opposite expressions (i.e., indirect and passive) is that they do not constitute euthanasia.

However, the term “euthanasia” is often used wrongly in place of “palliative care” with morphinomimetic agents and anxiolytics, in the same way as “killing without patient request” versus “homicide”.

Palliative care with morphinomimetic agents and anxiolytics can shorten the life of the patient, though the intention of the treatment is not to shorten life but to ensure that the natural process of dying is as comfortable as possible, while also treating unbearable pain, anxiety and/or dyspnea. Of course this type of treatment only should be provided in the presence of such symptoms, and the dosage must be conditioned by the latter. The administration of high morphinomimetic drug doses, with or without anxiolytics, in the absence of pain, dyspnea or other tractable symptoms with the purpose of accelerating death constitutes either euthanasia (when in response to patient request) or homicide (in the absence of patient request).

Limitation of therapeutic effort

The limitation of life support management (LLSM) involves withdrawing or withholding life support measures when these prove futile.

We often hear that physicians should suspend treatment in certain situations. In fact, physicians never suspend treatment, though they may modify the objectives of treatment.

Although it is logical for people to die at the end of their lives,⁷ they do not necessarily have to die in an Intensive Care Unit (ICU), intubated and subjected to mechanical ventilation. In the Netherlands there is the Nederlandse Vereniging voor een Vrijwillig Levensinde (www.nvve.nl; in English, "Right to die"), a society with the main aim of informing society of the different legal possibilities for citizens to freely resort to the end of life. The society also processes documents such as anticipatory patient will declarations, though the practical application of such documents in the Unit of ICM is sometimes very difficult when not impossible. Nevertheless, this does illustrate how in the Netherlands the patient organizations are implicated in the end of life decisions.

In a comparative study, the mortality rate among the patients admitted to a group of Spanish Units of ICM during the years 2004 and 2005 was 15% in 12 general hospitals and 18.2% in 13 regional hospitals.⁸ In the United States, almost 20% of all deaths occur in Intensive Care or shortly after discharge from Intensive Care.⁹

Although in a critical situation it is easier to "do everything possible" than to omit life support management, starting all possible interventions is not always best for the patient.

In ICM, cardiopulmonary resuscitation (CPR), mechanical ventilation, extrarenal filtration techniques, vasoactive drugs, artificial nutrition, blood products, etc., are regarded as life support management. Not admitting a patient to Intensive Care may be a form of treatment omission.⁸

Limitation of life support management (LLSM) is fundamented upon respect for the patient (autonomy and freedom) and on the principles of non-maleficence and justice.

The physician is not obliged to provide or maintain treatments that are futile¹⁰ - such treatments being understood as therapies unable to reach the objectives expected of them. In this sense, continuing futile treatment is considered poor clinical practice, in that it goes against human dignity. On the other hand, the futile consumption of healthcare resources goes against the principle of distributive fairness.¹¹

Evaluation of futility

It is important to determine whether the treatment provided for a patient at the end of life is futile or not. A given treatment is considered futile when the maximum quality of life afforded by it is poorer than the minimum acceptable quality of life (for the patient). Medical judgment is therefore decisive for establishing the existence of futility. When a given treatment is considered to be futile, the aim of management should become palliative treatment.¹²

The problem arises when we have to decide what is the maximum quality of life for a given patient. A Swiss study evaluated the prediction of futility on the part of physicians and nurses in reference to 521 patients admitted to an Intensive Care Unit.¹³ From this and other studies (whether scoring systems are used or not), it is concluded that both physicians and nurses are scantily concise in perceiving futility in critically ill patients.¹⁴

It is therefore very important to take the necessary time to analyze the clinical data, assess all the opinions and observe the course of the disease and the response to treatment. In turn, evaluation is also required of the patient will and of the information of relatives and friends, as well as of family counseling on the part of the physician.¹⁵ To this effect, our Unit has adopted a protocol for the limitation of life support management (Table 1).

According to the American Society of Critical Care, iatrogenic complication should be taken into account when contemplating LLSM. This is a misunderstanding, however, since an iatrogenic complication merits no treatment different from that indicated in the case of a non-iatrogenic complication. All complications merit optimum treatment, regardless of their underlying cause. And, of course, in some cases the best treatment may be palliative care.

According to the policy of our Unit, and that of the Netherlands, it is undesirable (and even dishonest) to ask the family to take the decision to change the objective of therapy - though in some cases this practice remains the norm.

Role of euthanasia in the Netherlands

There is still confusion regarding end of life decisions and euthanasia, both in the Netherlands and in other countries, and not only among patients and their families but also among professionals, the communications media and politicians. Part of this situation is due to the singular legislation of euthanasia in the Netherlands, which was the first country in the world to legalize euthanasia, in April 2002.

Limitation of life support management should be distinguished from euthanasia, which implies that the physician actively puts an end to the life of the patient, in response to a request from the latter, because of unbearable suffering. There is no indication for euthanasia in ICM, in general. In our center there are protocols for euthanasia, though not specifically in ICM, simply because the conditions for application are not met. In the Netherlands no cases of euthanasia in patients admitted to Intensive Care have been published.¹⁶ In contrast, it is known that each year a significant number of patients die in the Intensive Care Units in the Netherlands after LLSM. A recent study estimates the proportion to be 52% of all deaths in ICM,¹⁷ mostly after the withdrawal of mechanical ventilation.

Chapter II (article 2) of the Dutch "Termination of Life on Request and Assisted Suicide Act" the requirements to be met for euthanasia are described (Table 2). Each case of euthanasia is to be reported to a commission, which in turn checks that all the conditions required by the law have been met. If the conditions have not been met, the case is submitted to the legal authorities.

Table 1 Checklist / protocol for the limitation of life support management (LLSM) of the Unit of Intensive Care Medicine, VUmc

1. Approval of medical judgment by a second intensivist and by the Head of the Unit. These professionals must have in-depth knowledge of the clinical case involved. The names of the supervising physician, the second intensivist and the Head of the Unit must be recorded in the case history within the following 24 hours. The decision preferably should not be taken at the patient bedside but in a multidisciplinary committee
2. The referring specialist is informed of the management restriction. Such approval is to be recorded in the case history, along with the name of the specialist
3. The nurse is to be present at the time of the decision. His or her name is to be registered in the case history. In addition, the nurse will register the decision in the nursing section of the patient case history
4. It must be recorded whether the patient was present at the time of the medical judgment (this refers only to the patient, not to his or her legal representative). If not, the reason is to be recorded
5. Has the personal physician of the patient been consulted? Yes / no. If consulted, what was the result of consultation?
6. The legal representative of the patient is to be informed of the decision within the next 24 hours
7. There are prior instruction documents. If not, the reason is to be recorded
8. Are all the aspects crucial to determination of the futility of a given treatment known?
9. The case history is to record all the medical arguments supporting the decision to limit life support management

Confusion between limitation of life support management and euthanasia

A number of characteristics of the Dutch healthcare system have contributed to the legalization of euthanasia: healthcare coverage of the entire population, patient care not only within the institutions but also in the home, and the fact that the general practitioner is the core of primary care.^{18,19}

Medical care at the end of life is often provided in the home. A full 65% of all patients that die of cancer do so at home.²⁰ According to a recent Dutch study, general practitioners or family physicians are the specialists that most often perform euthanasia. The mentioned study also compares the frequency of euthanasia and other forms of end of life decisions among 6 European countries (the Netherlands, Belgium, Denmark, Sweden, Switzerland and Italy) in 2005.²⁰ At the time of the study, euthanasia was

only legal in the Netherlands, physician-assisted suicide (not euthanasia), in Switzerland. The study was based on a questionnaire guaranteeing the confidentiality of both the physician and the patient. In different proportions, all the countries registered cases of euthanasia, physician-assisted suicide and the termination of patient life without prior request (homicide).

The proportions of treatment omission among countries varied considerably: from 4% in Italy to 28% of all deaths in Switzerland.

Although the Netherlands for years has been characterized by a culture of “death with dignity”, there are a significant number of cases in which intensivists in Dutch Intensive Care Units receive requests for euthanasia due to confusion over the terminology used. An example of the confusion generated in the population is provided below.

A previously healthy 52-year-old woman was admitted to our Intensive Care Unit with severe necrotizing pancreatitis and multiorgan dysfunction syndrome. Despite the high mortality rate associated with this type of diagnosis, there were chances for survival. The husband was informed by the physicians and nurses several times over the weekend. On Monday, he informed the Head of the Unit that the whole family had gathered that weekend and unanimously agreed that treatment should be suspended because the patient “suffered too much”. This request was interpreted as having been based on love for the patient. Apart from the fact that we as physicians failed in providing sufficient information, the husband made an inadequate request for illegitimate and inappropriate measures. He supported his opinion with an anticipatory patient will declaration signed by the patient in person prior to admission, requesting that no artificial means be used to prolong her life in the case of irreversible disease.

The patient was receiving sedation to avoid unbearable suffering, was not conscious, was not informed about her situation and its perspectives, and moreover had reasonable alternatives. Euthanasia has no role in the Intensive Care Unit, except in certain cases.

Table 2 Termination of Life on Request and Assisted Suicide Act in the Netherlands

1. Conviction that the patient request was voluntary and well pondered
2. Conviction that the patient was suffering unbearable and lasting pain
3. Due information of the patient on the situation and the possibilities
4. Conviction that there was no reasonable alternative to the situation of the patient
5. Consultation of at least one other independent physician, who must have seen the patient and written his or her opinion following the above mentioned criteria
6. Having put an end to the life of the patient or have assisted suicide, providing medical care and attention

Conclusions

End of life decisions form part of the daily work of intensivists. As physicians, we should be aware of our limitations in establishing the medical prognosis of critically ill patients. It is therefore useful to implement protocols designed to facilitate multidisciplinary work, taking the necessary time and thus being able to determine whether or not the life support management measures we wish to adopt are futile.

The use of confusing terms such as "passive euthanasia" should be avoided. Withdrawing or withholding futile life support measures in patients requesting them is not euthanasia, and as such has no place in Intensive Care Units.

Conflict of interest

The authors declare no conflict of interest.

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