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# Care for the dying in intensive care in The Netherlands

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## Introduction

Withdrawal of treatment and palliative end-of-life care are the most challenging ethical issues in intensive care medicine. This article reviews existing legislation and guidelines concerning withholding and withdrawing treatment, euthanasia, palliative sedation and palliative administration of opioids in adult patients in the ICU in the Netherlands. Although Dutch ICU physicians support the idea of national guidelines addressing end-of-life care for ICU patients [1], these still do not exist.

## Withholding and withdrawing treatment

The decision not to initiate, or to terminate, life-prolonging ICU treatment is made on the assessment that further treatment is non-beneficial or disproportionate, or if a competent patient asked for it. This is covered in the Dutch 'Law on Contracts for Medical Treatment', which became effective in 1995. The law states that a health-care worker should act as a 'good care provider', which includes the professional responsibility to act in accordance with the existing professional standards. The physician who abstains from treatment necessary for the preservation of life (e. g. mechanical ventilation), but which is regarded as non-beneficial, is not regarded as having killed the patient, in the sense of homicide, even if the patient dies following the withdrawal. Death is considered to have occurred due to natural causes. Withdrawing ICU treatment will, in most cases, induce death or shorten the patient's life, but death is not intended because this is not the purpose of treatment withdrawal, but merely its side-effect. Some will state that a result foreseen is as certain an intended result, but although the two *can* coincide, they do not *always* do so, and so are not identical. Some patients will not die (directly) after withdrawal of intensive care treatment. Shortening of the dying process is not 'euthanasia'.

A competent patient has the legal right, for whatever reason, to refuse (further) treatment, even if the treatment is considered as necessary to prolong or preserve life. If a patient of 16 years and older who cannot be considered capable of coming to a reasonable assessment of his or her interests has made a written statement to the effect that he or she refuses treatment under described circumstances at a time when he or she was competent to do so, physicians, nurses and representatives of the patient are legally bound to follow the contents of the advance directive. It can only be ignored for well-founded substantial reasons, which should be exhaustively documented. An appointed representative or close relative can exercise the right on the patient's behalf, taking in account the known wishes and general outlook of the patient concerned. Physicians are compelled to inform the patient (if competent) and/or representatives (if the patient is competent or incompetent) that they propose to withhold or withdraw treatment they considers futile. The patient or representatives have

the right to seek, within a reasonable time, a second opinion. Physicians and nurses are *not* required to accede to the wishes of a patient or his or her representatives on providing or continuing treatment the health-care providers consider as futile or disproportionate, as is ruled in court in the following case. In 1999, a 80-year-old patient with incurable rectal cancer and severe emphysema was admitted to a Dutch university hospital ICU for respiratory support, and remained there for 7 weeks. After discharge, the ICU staff agreed that, given the age and general condition of the patient and the incurable nature of his malignant disease, it would be futile to admit him again if his condition deteriorated. The patient's daughter took out a civil action against the hospital, arguing that it had previously agreed to keep her father alive at all costs. The judge ruled that physicians were not obliged to carry out treatment regarded as futile or disproportionate. The decision to withhold ICU treatment accorded with professional standards. Patients and their relatives do not have the right to force health-care workers to provide futile care. The final decision rests with the ICU team.

Does artificial feeding constitute medical treatment, and if so, can it be withdrawn when treating the patient is considered futile? This issue is covered in the following case. In March 1974 a young Dutch woman underwent a cesarean section under general anesthesia. She was erroneously intubated and ventilated in the esophagus, suffered cerebral hypoxia, and ended up in a persistent vegetative state (PVS). Her husband requested the court to order that artificial feeding be stopped. The court ruled that tube feeding is medical treatment and it was in the physician's authority to withdraw futile treatment, but also that the decision to keep the patient alive was legitimate, and refused to intervene. In 1989, the Court of Appeals argued that judgments concerning medical treatment should be made by physicians and confirmed that tube feeding is medical treatment, which can be stopped, when considered futile. Following this decision, the physician decided to stop artificial feeding, upon which the woman died in January 1990 after 16 years in a PVS. Withdrawal of artificial means of nutrition is legally permissible in the Netherlands. The likelihood is that the patient will die, but the intention is that futile therapy should be withdrawn.

Although reliable numbers are not available, it is recognized that every year, a significant number of patients in the Netherlands die in ICUs following withdrawal of life-support measures. One recent study estimates 52% of all ICU deaths [2]. A majority of such cases involve withdrawal of mechanical ventilation.

## Euthanasia (deliberate termination of life)

The Netherlands is the first country in the world with a law on euthanasia, which came into force on 1 April 2002. The term 'euthanasia' is used in the Netherlands *only* and *strictly* for deliberate (intentional) termination of the life of an adult patient at his/her request by the deadly injection of a sedative and a muscle relaxant by a physician. This presupposes voluntariness (explicit request by the patient) and a deliberate active act (termination of life by the physician). The definition *excludes* every form of intentional, active, direct, *non-voluntary* termination of life. When physicians use exceptional large doses of opioids or sedatives *without* proper indication of symptom relief and with the only intention of hastening death, this is considered as deliberate termination of life *without* request, which is illegal in the Netherlands.

In Chapter II (article 2) of the Dutch 'Termination of Life on Request and Assisted Suicide Act' the requirements of due care are described. In order to obtain exemption from criminal liability the attending physician must:

- Hold the conviction that the request by the patient was voluntary and well considered
- Hold the conviction that the patient's suffering was lasting and unbearable
- Have informed the patient about the situation and about the prospects
- Hold the conviction that there was no other reasonable alternative in the light of the patient's situation
- Have consulted at least one other independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to above
- Have terminated the patient's life or provided assistance with suicide with due medical care and attention

These due care criteria must also been met in case of deliberate termination of life in a ICU patient. There are no reports of the incidence of euthanasia on ICUs in the Netherlands, and no case reports have been published.

## Palliative sedation and palliative administration of opioids

In the Netherlands, palliative sedation and palliative administration of opioids are considered as normal care for treating (suspected) pain, dyspnea, terminal tachypnea, terminal agitation, anxiety and restlessness. It is an ethical obligation to relieve patients and their relatives in the dying phase of the patient [3, 4, 5]. Sadly, however, the use of opioids and sedatives in the terminal phase has become synonymous with hastened death [6, 7]. When life-sustaining ICU treatment is withdrawn, death will in most cases have been induced or hastened. There is no evidence that appropriate use of opioids and sedatives in the dying phase requires the doctrine of double effect as a defense [8].

Although palliative sedation and palliative administration of opioids is considered as normal care, a Dutch

physician was prosecuted for murder in 2003. The patient concerned was a 77-year-old man who was admitted with a severe stroke. For reason of severe dyspnea and terminal agitation, the physician administered 20 mg morphine and 5 mg midazolam intravenously. The patient died soon afterwards. The physician was subsequently charged with murder and spent 9 days in custody. Based on the evidence of an expert, who stated that administering morphine and midazolam in the dying phase is normal palliative care, the court acquitted him. It explicitly rejected the prosecution's claim that the physician intended to accelerate the death of the patient. The public prosecutor appealed, but in July 2005 the Appeal Court dismissed the charges. No further appeal has been made.

Subsequently, in December 2005, the Dutch Medical Association laid down guidelines on the use of sedation in dying patients [9]. Adequate palliative sedation with a sedative such as midazolam or propofol is considered as normal medical palliative care that does not accelerate death, and any association with euthanasia (or murder!) is incorrect. The guidelines consider the employment of opioids for sedation as incorrect use of these agents. 'Sedation' with high doses of morphine is considered malpractice, as this drug is inappropriate for sedation purposes. The chairman of the Board of Public Prosecutors stated in December 2005 that physicians acting within this guidance should not be prosecuted.

## Flowcharts for palliative care

Withdrawal of treatment does not equate to withdrawal of care. Both literature reports and anecdotal experience suggest that many patients in ICUs have inadequately controlled symptoms after withdrawal of ICU treatment [10, 11]. Many physicians and nurses are ill-prepared to provide optimal palliative care and symptom control anticipating or following withdrawal of treatment. To improve the decision-making process and patient care practice, in 2005 the Erasmus MC Department of Intensive Care developed a set of 40 flowcharts covering all possible end-of-life decisions, including withholding care, withdrawing care and (anticipating) palliative care. We hope that these flowcharts will form the basis for national guideline end-of-life care on ICUs.

## Conclusion

In the Netherlands, withholding and withdrawal of intensive care treatment is legally covered in the 'Law on Contracts for Medical Treatment'. Deliberate termination of life (euthanasia) is legally possible, but very rare in Dutch ICUs. Palliative sedation and palliative administration of opioids after withdrawal of treatment is common practice, normal care and an ethical requirement. National guidelines on end-of-life care in ICUs do not yet exist in the Netherlands.

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