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End-of-life practice in Belgium and the new euthanasia law

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Introduction

End-of-life decisions are taken by physicians every day in hospitals, care facilities, and at home. A study performed several years ago in Belgium [1] which reviewed some 4,000 death certificates reported that death was unexpected in one-third of the cases, but that an end-of-life decision was made in 39.3% of the deaths. More recently van der Heide et al. [2] studied records of 20,480 deaths in six European countries (Belgium, Denmark, Italy, The Netherlands, Sweden, and Switzerland) and found that the proportion of deaths preceded by an end-of-life decision varied between 23% (Italy) and 51% (Switzerland), with Belgium at 38%. These end-of-life decisions include withholding or withdrawing treatment and in some cases alleviating pain with opioids, even when it is suspected that this may shorten life. Deliberate drug administration with the explicit intention of shortening patient life is also widely practiced across Europe, with one study reporting that 57% of Belgian intensive care unit (ICU) physicians, compared to an average of 40% across Europe, said they sometimes deliberately administer large doses of drugs to patients with no hope of a meaningful life, until death ensues [3].

Legal situation in Belgium

Until recently there was no law in Belgium relating to end-of-life care in the ICU, including withdrawal/withholding of therapy, apart from the 2002 law regarding patient rights stating that all patients have the right to be fully informed about and to consent to all treatments and interventions [4]. There are also no laws or guidelines to control management of the patient in a permanent vegetative state, although many Belgian physicians believe that it is sometimes appropriate to withdraw feeding tubes in such patients [5]. The only option in all these cases has been to invoke "the law of necessity", whereby otherwise criminal conduct may be excused if the defendant commits the act in order to avoid a greater evil or to achieve a greater good. Using such law, a physician faced with the choice of two evils, for example, a prolonged, painful death or a rapid, pain-free, and dignified death, and who chooses the lesser evil by, for example, deliberating administering sedative agents until death ensues, may be excused of what would otherwise be a crime. Bioethical principles supported by the Belgian Medical Association (Ordre des Médecins) and the Belgian Society of Intensive Care Medicine [6] also defend autonomy and nonmaleficience and discourage "futile" therapy (in French: *acharnement thérapeutique*). However, interpretation of these situations is potentially highly subjective, a situation appreciated by the courts, and physicians often fear the legal consequences of their actions.

In 2000 a highly publicized case involving the end-of-life treatment of a patient in a Belgian ICU highlighted some of the potential difficulties with the lack of legal directives [7]. In this case two physicians were arrested for homicide after giving large doses of morphine and thiopen-

tal to a 74-year-old patient who had been admitted to the ICU 10 days earlier with end-stage pulmonary fibrosis. Members of the nursing staff had reported the case to the police. The physicians claimed that the patient and family were aware of the poor prognosis and were agreed that aggressive therapy should not be pursued. On the morning in question, in view of the worsening condition of the patient and lack of hope of survival, it was decided to discontinue mechanical ventilation and administer morphine with the deliberate intention of speeding the dying process. One of the two physicians was imprisoned for 5 days before being released on bail. The final court case, more than 1 year later, concluded that the decision to withdraw therapy had been acceptable in view of the patient's severe condition and poor prognosis, but that the way in which it was conducted and, in particular, the lack of communication within the medical staff between physicians and nurses was seriously inadequate. The importance of good communication between the medical and nursing staff involved in the care of a patient in whom it has been decided to withdraw or withhold life-sustaining therapy, and the patient and his family, is also stressed in guidelines issued by the Belgian Society of Intensive Care Medicine [6].

The euthanasia law

Against the background of widespread, but often clandestine, euthanasia already taking place, and with changing societal values and beliefs, the creation of a "euthanasia law" was promoted as providing a legalized exception to the prohibition to kill, in certain clearly defined and controlled medical situations. Opponents of the law cited primarily the ethical position that life must be preserved at all costs, and that deliberate killing is against all human ethical and moral standards. Fears were also raised that if the law were ratified, it would be abused by some to their own ends, or that terminally or chronically ill or elderly patients who were a burden to their families would feel obliged to request euthanasia to spare their families the continued stress of looking after them. Other opponents were upset by the need to deal with signed documents, believing that the end of life should remain a natural process. Furthermore, some would argue that accompanying a patient at the end of his/her life is a general duty of every physician, rather than an exceptional option. Proponents believed that the introduction of this law would clarify a murky and often underground practice, and that carefully written and meticulously applied administrative documents would avoid the law being abused.

The current Belgian law on euthanasia started with the submission of a joint legislative proposal concerning euthanasia to the Belgian Senate in December 1999 by six senators from the government coalition. After considerable discussion and some amendment the law on euthanasia was ratified on 28 May 2002 (published in the Belgian *Monitor* 22 June 2002) and took effect on 23 September 2002. It would be too long to translate the entire law here; moreover ensuring the accuracy of translation of all the judicial terms would be a considerable challenge, and although I try below to provide a true and faithful translation, the present report should not be considered a legally authorized translation. I summarize what I believe to be the most important points.

The new Belgian law defines euthanasia as action on the part of a third person intended to end the life of someone who has requested it. Under this law, committing euthanasia is no longer a criminal offence if several strict conditions are fulfilled:

- The patient is older than 18 years, legally competent, and conscious at the time of the request.
- The patient has a serious and incurable condition as a result of which he is suffering constant and unbearable physical or psychological pain which cannot be alleviated with medical or other treatment.
- The request for euthanasia must be voluntary, carefully considered, repeated, and not the result of any external pressure.

Once a request for euthanasia has been made, the physician is obliged to:

- Fully inform the patient about his health status and life expectancy and discuss all possible options with the patient, including palliative care.
- Agree with the patient that there is no other reasonable option.
- Ensure that the patient does indeed experience unbearable suffering, and that the request is not transient; discussions must therefore be held repeatedly over a reasonable period of time.
- Consult another physician about the patient, discussing the incurable and serious nature of the disease process and the unbearable suffering and the request for euthanasia.
- Discuss the request with other members of the care-team, and with the family if this is what the patient wants.

The patient's request must be written, dated, and signed. If the patient is unable to sign, the request must be written by someone without material benefit in the patient's death. The patient may revoke this request at any time. All documents must be included in the medical chart. No physician is obliged to perform euthanasia, but if, when asked, the physician feels unable to perform euthanasia for moral, religious, or other reasons, the medical chart must be handed to another physician chosen by the patient.

Advance directives

Any individual may write a declaration in anticipation of a state in which euthanasia may be an option, but in which he would no longer be able or competent to make a decision. This declaration may designate one or several trusted individuals (with an order of preference)—other than physicians or members of the caring team—who would inform the physician about the presence of an advance directive and about the patient's preferences. The declaration can be made at any time, provided that it carries the signatures of two witnesses. It is valid only if signed less than 5 years before such a state develops.

Control process

The physician who performs the euthanasia must complete two documents: the first includes details of the patient, physician, and consultations related to the request for euthanasia; the second covers in more detail the reasons for and nature of the request, and the method of euthanasia used. These documents must be sent within 4 working days to the National Commission of Control and Evaluation, composed of eight physicians (at least four of whom are professors at Belgian universities), four professors of law from Belgian universities, and four individuals involved in the care of the terminally ill. The second document is examined to determine whether the process complied with all the conditions of the law, and only if there are concerns that not all conditions were respected is the first document opened and the case referred to the coroner.

Experience with the new law

In a country of just over 10 million inhabitants, relatively few cases of euthanasia have occurred since the law was approved. In the first 2 years just over 500 cases were reported. In the first 15 months there were 259 cases [8]. This represented 0.2% of the estimated total deaths in Belgium during that period. Interestingly, 83% of cases were in the Flemish part of Belgian and only 17% in the French-speaking community. Only one patient was unconscious (with euthanasia performed according to an advance directive). Death was expected soon in 91.5% of the cases. The two sexes were equally represented, and 64% of cases were in patients aged 60 years or over. The underlying terminal disease was cancer in 83% and neuromuscular disease in 13%. The physician was a specialist in 48% of cases, general practitioner in 32.5%, and specialist in palliative care in 19.5%. Euthanasia was performed in hospital in 54% of cases and at home in 41%. The drugs used to induce euthanasia included barbiturates in 81.5% of cases and midazolam in 10% [8].

Implications for intensivists

The required conditions for euthanasia limit its applicability in critical care where the patient is often comatose, confused, or simply too weak to organize his thoughts. This law obviously primarily concerns patients with incurable cancer or other progressive disease (e. g., neurological degenerative disease, severe incapacitating and painful arthritis) and is not relevant to many critically ill patients in the ICU. Nevertheless it may impact on end-of-life care in the ICU. Life-supporting treatment and interventions are frequently withdrawn or withheld prior to death in critically ill ICU patients with no hope of a meaningful survival [9, 10, 11, 12, 13]. However, without a specific request from the patient, some might now see these actions as illegal. As many patients in the ICU are no longer able to make such a decision and will not have prepared an advance directive, does this mean that all ICU care should therefore be continued ad infinitum even when acknowledged as futile by all involved? Even if an advance directive has been established and a surrogate nominated, will this surrogate really be able to understand the complexities of the situation and the options available. For example, a patient may have informed his surrogate that in the event of a situation in which he cannot decide for himself, he does not wish to receive mechanical ventilation. How should this surrogate react if the physicians suggest that mechanical ventilation is merely a temporary measure, for example, as part of the active management of pneumonia? Does this action contradict the patient's advance directive? In addition, is it fair for a surrogate to have to make such decisions at a time of heightened emotional stress and anxiety?

Over the past decade or so care of dying patients in the ICU has begun to receive considerable attention. Most would agree that a "good death" (interestingly, this is the etymological meaning of the term "euthanasia") should be dignified, peaceful, and pain-free and should take place in the presence of family and friends wherever possible [6, 14, 15]. Effective communication and open discussion with patient and family are essential when dealing with end-of-life issues [16, 17].

In our own experience so far no one has requested euthanasia in our ICU. We stress the importance of a team approach, encouraging discussions with nurses and other health care professionals to reach a consensus. We believe the end of life should not be associated principally with signed documents but with open and honest discussion of all options for the patient and his relatives. We believe that withholding and withdrawing care are similar [18], and that careful adherence to bioethical principles should limit suffering at the end of life. Many patients need to be helped to achieve a "good death" at the end of their life, but we do not believe the best way to achieve this is to increase bureaucracy. Increasing doses of sedatives and analgesic agents at the right time does not require

a formal, signed approval. Legalizing euthanasia with the required form-filling and controls may, in fact, have removed some of the options and made it more difficult for an ICU patient to have a dignified and peaceful death. Part of good medical practice is to ensure the well-being of our patients, and this includes helping them as they approach death. Perhaps legislation should recognize this.

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