

**LEMAIRE FRANÇOIS**

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End of life (EOL) care has recently become a major concern in European Intensive Care Units (ICU). Aggressive treatment of devastating diseases and the support of failing organs were, and still are the main objectives of ICU specialists. However, many patients ultimately die in ICUs despite human efforts and sophisticated machinery: the average death rate in French ICUs is 20%. Reports, scientific publications and lay press articles express more and more frequently the view that the conditions of such deaths and, more specifically, the care offered to patients' families is far from optimal. In April 2003, The European Society of Intensive Care (ESICM), jointly with the American Thoracic Society, the French Society of intensive care (SRLF), the (American) Society of Critical Care Medicine and the European Respiratory Society organized in Brussels a consensus conference on "Challenges in End of Life Care in the ICUs" (1). The first question was: "EOL care in the ICU: is there a problem?" and the answer of the jury was: "Definitely: yes!" The final document lists a worrisome issues, such as confusing terminology (is withdrawal of mechanical ventilation "passive euthanasia"?), the extreme variability of practice between countries, ICUs or doctors, our inability to know our patients' wishes, the persisting lack of good communication with families, ambiguity as to the identification of the ultimate decision-maker: should it be the family or the physician in charge?

We shall review here the recent European epidemiological studies, the ethical concepts underlying the withdrawal of lifesupport measures and its legal aspects.

**EPIDEMIOLOGICAL STUDIES**

During the past decade, a number of questionnaire surveys and incidence studies have provided a good perspective on the end of life practices within Western Europe. By surveying the members of the ESICM, Jean Louis Vincent produced an initial assessment of the diversity of these practices in Europe(2, 3). He demonstrated that physicians from the Northern countries were more prone to issue DNR orders and to withdraw life support (LS) than their Southern counterparts. A disturbing finding was that many physicians from France, Belgium, Switzerland, the Netherlands and Germany said they "*sometimes practiced deliberate administration of medication to speed death in patients with no real hope of recovering a meaningful life*". More recently, the ETHICUS study, published in JAMA in 2003(4), confirmed and expanded these findings. More than 4,000 patients who ultimately died were surveyed over 14 months in 317 ICUs in 17 European countries. Life support (LS) was withdrawn in 47%, 34% and 18% of ICU deaths in the North, Central and Southern Europe respectively. In this paper, Charles Sprung et al (4) showed that EOL practices were strongly associated with doctor's religious beliefs.

Esteban et al(5) surveyed ICU deaths prospectively in Spanish ICUs and showed that 34% of 644 patients died after LS had been withdrawn or withheld. The family was not involved in 28% of cases, and physicians and family members took the decision together in 41% of cases. In London, Turner et al found (6) that therapy was limited in 87% of deaths, in a single centre study published in 1996. In the Netherlands, Groenewoud et al (7) demonstrated that when mechanical ventilation was withdrawn, competent patients were informed in 96 % of cases, and, were they incompetent, that their family was informed in 63% of cases. In 2003, Giannini et al carried out an interesting opinion survey in 20 ICUs in Milan (8). 83% of 225 respondents believed the rate of LS limitation before death in their ICU was less than 10%. Of these, 58% said they would not respect the expressed desire of patients to forgo LS treatment. Ferrand et al (9) showed that 50% of all deaths in 113 French ICUs were preceded by a limitation of LS. Similar data were subsequently reported by Pochard et al(10).

**ETHICAL ASPECTS OF WITHDRAWAL OF SUPPORTING-LIFE TREATMENTS**

It is difficult to get a clear picture of all national regulations or ethical codes concerning EOL care in ICUs within European Union countries. During the last decade, some official recommendations have been published by national scientific societies or ethics committees. In 1999, the British Medical Association (11) produced its recommendations concerning "Withholding and withdrawing life-prolonging medical treatments: guidance for decision making". In 1999, the Swiss Academy of Medical Sciences published its "Directives concernant les

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problèmes éthiques aux soins intensifs” (12) and the Ethics Committee of the Geneva Hospital Cantonal its internal regulations as to a DNR code (13). Italian and Spanish Intensive Care societies have published their own (14, 15). In Belgium, the Intensive Care national society drafted recommendations shortly after the chief of an ICU in Liège was charged with murder after mechanical ventilation was withdrawn from an end stage COPD patient (16). In France, the French Society of Intensive Care published “Les limitations et arrêts de thérapeutique(s) active(s) en réanimation adulte” in 2002 only(17), long after Maurice Rapin, a founder of and a prominent figure in French intensive care, had implemented a strategy of limitation of ICU care in the late 1970s (18).

The recent International Consensus Conference (1) gave an up to date summary of generally accepted concepts and relevant standards of care in this field:

- recognition of the 4 basic ethical principles: 1. respect for autonomy; 2. beneficence; 3. non maleficence; 4. distributive justice
- limitation of LS is usually made on the basis of “futility”; but, additionally, many of those decisions are actually based on the anticipated patient’s quality of life, which, obviously, is often difficult to predict...
- when patients lack decision-making capacities, which is a common situation in ICUs, a surrogate decision-maker needs to be identified. It is usually a family member. However, recent studies have showed how vulnerable and fragile ICU patients families may be (19)
- in Europe the final decision making is not left to families, in contrast with the US tradition, where the family is “the ultimate source of authorization” (20, 21). The Belgian, French and British recommendations make it clear that it is the physicians’ responsibilities. However, the International Consensus reminded that nurses have to play an active role in that process.
- The jury of the Consensus advocated the “shared decision model”, which implies that decisions are taken jointly by the family and the caring team.
- When conflicts arise, which is not rare in the ICU setting, external advice and mediation may be sought from an external body, for instance an independent Ethics Committee.

## LEGAL ASPECTS

No current European legislation (including Dutch and Belgian law) or regulation deals specifically with the limitations of acute care in the ICU. Even the Dutch and the Belgian laws do not. Jurisprudence is also rather scarce.

We already mentioned the Liège case on January 2000 (22). Despite the fact that the physicians were initially indicted of murder and jailed, the charge was ultimately dropped when the Belgian Parliament, two years later, voted its law on euthanasia. In France, the only legal decision handed down so far concerned an anaesthetist who had withdrawn mechanical ventilation from a 30 year old woman who was critically ill after a car accident. He was convicted of “involuntary homicide” and sentenced to 18 months in jail. But several pending –as of this writing- legal cases in France received a large media coverage and prompted a huge national debate about the legalization of euthanasia and/or withdrawal of LS therapies. The most spectacular was when a young fireman, quadriplegic, blind and mute after a car accident asked President Jacques Chirac to be allowed to die. As this was repeatedly denied, his mother administered Nesdonal® via his feeding tube. He was first mechanically ventilated and admitted to an ICU. After 36 hours of intensive therapy, he was eventually extubated, and given IV barbiturates and KCl. The responsible chief of service, Doctor Fr Chaussoy, is now facing a charge of “poisoning”. After a national outcry and global support of the physician by the public, the Parliament created a commission for studying the legal and judiciary aspects of end of life care in France(23).

Usually, courts are embarrassed when they have to judge physicians who have withdrawn life supporting therapies. Two recent examples of such judgements are especially enlightening: In Canada, in 1997, withdrawal of mechanical ventilation and extubation were followed by an IV injection of KCl (24). The responsible physician was charged of first degree murder, which in Canada means 25 years in prison. But after a while, charges were dropped, because “...the legal team successfully argued that the femoral venous line might have migrated from an intravenous position. Thus the injection of potassium chloride could not have been the proximate cause of death.” The case was dismissed. Similarly, in Pavia, Italy, a man with a gun entered the ICU room where his wife was stuck to a ventilator, and disconnected her. He was finally freed by justice, on the argument that no one knew whether she was or not alive before. Actually, an EEG has been performed four hours before, which showed activity...These two cases illustrate how judges feel ill at ease when such cases are put to the Court, and the kind of escape they can elaborate, at odds with any medical common sense...

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In the year 2002, two interesting cases have been reported in England. In the first one, Mrs B., quadriplegic as a result of a spinal cord haematoma, and permanently on a ventilator, asked her physicians, (who refused), and subsequently the Court, to be disconnected from her ventilator and permitted to die(25). Dame E Butler-Sloss gave way to her demand, stating that: “A competent patient has an absolute right to refuse to consent to a medical treatment for any reason, rational or irrational, or for no reason at all, even when that decision may lead her to his or her death...There is a danger, exemplified in this case, of a benevolent paternalism which does not embrace recognition of the personal autonomy of the severely disabled patient.” At about the same time, Diane Perry, another British female afflicted with a terminal lateral sclerosis, asked the Court that her husband “be authorized to help her when she would be agonizing”. The High Court of the United Kingdom ruled out her plea, and so did, in appeal, the European Court of Human Rights in Strasbourg(26). The basis of such a decision is that, in the latter case, the act would have been an active one, equivalent to assisted suicide, which is prohibited by nearly all European laws. The message here, which goes much further than the UK borders, is that doctors are allowed to interrupt life saving therapies, when intensive care is hopeless and futile, and by doing so letting death happen, but they cannot provoke it. In other words, doctors can defend themselves in the Court as long as they do not cause their patients to die. They are only allowed to let them die.

In conclusion, it appears that limitation of life saving therapies is common place in European ICUs these days, though with important geographic variations. National legislations and justice systems do not have a comprehensive view of these practices. It is a major and urgent commitment for the Intensive Care community to explain restlessly the reality and constraints of end of life care in our ICUs. For years, the medical community in Europe has not asked for a specific legislation concerning end of life care and/ or euthanasia. As the number of legal cases grows, it is possible that this attitude could change in the near future.

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## REFERENCES

1. Thijs B, Carlet J. International Consensus conference: Challenges in end of life care. *Intensive care Medecine*. 2004 (In press).
2. Vincent JL. European attitudes towards ethical problems in intensive care medicine: results of an ethical questionnaire. *Intensive care Med*. 1990; 16: 256-264.
3. Vincent J. Forgoing life support in western European ICUs: The results of an ethical questionnaire. *Crit Care Med*. 1999; 27: 1626-1633.
4. Sprung CL, Cohen SL, Sjøkvist P, et al. End of life practices in European intensive care units : the ETHICUS study. *JAMA*. 2003; 290:790-7.
5. Esteban A, Gordo F, Solsona J, et al. Withdrawing and withholding life support in the ICU: a Spanish prospective multi centre observational study. *Intensive care Medecine*. 2001; 27: 1744-49.
6. Turner JS, Michell WL, Morgan CJ, Benatar SR. limitation of life support: frequency and practice in a London and a Cape Town ICU. *Intensive care Medecine*. 1996; 22: 1020-25.
7. Groenewoud JH, van der Heide A, Kester JGC, de Graaff CL, van der Wall G, van der Maas PF. A nationwide study of decisions to forego life prolonging treatment in Dutch medical practice. *Archiv Intern Med*. 2000; 160: 357- 363.
8. Giannini A, Pessina A, Tacchi AM. End of life decisions in ICUs: attitudes of physicians in an Italian urban setting. *Intensive care Medecine*. 2003;29:1902-10.
9. Ferrand E, Robert R, Ingrand P, Lemaire F, LATAREA Group. Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. *The Lancet*. 2001 357: 9-14.
10. Pochard F, Azoulay E, Chevret S, et al. French intensivists do not apply American recommendations regarding decisions to forgo life-sustaining therapy. *Crit Care Med*. 2001; 29:1887-92.
11. British Medical Association. *British Medical Association. Withholding and withdrawing life-prolonging medical treatments: guidance for decision making*; London.; BMJ; 1999. (Books B, ed.
12. Swiss academy of medical sciences. Medical - ethical guidelines for the medical care of dying persons and severely brain-damaged patients. *Bulletin des Médecins Suisses*. 1995; 76: 1226 - 8.
13. Chevolet JC. L'ordre de ne pas réanimer en soins intensifs. Aspects éthiques et position du Conseil d'éthique clinique des Hôpitaux universitaires de Genève (in French). *Réanimation*. 2003 ;12: 78-87.
14. Orsi L. Verso il documento SIAARTI " Raccomandazioni per l'ammissione e la dismissione dalla Terapia Intensiva e per la limitazione dei trattamenti in Terapia Intensiva ". *Minerva Anestesiologica*. 2002 ; 68: 08 - 13.
15. Cabre Pericas L, Solsona Duran J, SEMICYUC YGdtdbdl. Limitacion del esfuerzo terapeutico en medicina intensiva. *Med Intensiva*. 2002; 26: 304 - 11.
16. Ferdinande P, Berré J, Colardyn F, Damas P, et al. La fin de vie en médecine intensive: une déclaration officielle de la Société belge de soins intensifs. *Réanimation*,. 2001;10:340-1.
17. Ferrand E. Les limitations et arrêts de thérapeutique(s) active(s) en réanimation adulte.Recommandations de la Société de réanimation de langue française. *Reanimation*. 2002;11(6 SU -):442-449.
18. Rapin M, Legall J. La thérapeutique palliative de confort en réanimation. *Bull Acad Nat Méd*. 1979; 163: 566-71.
19. Pochard F, Azoulay E, Chevret S, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med*. 2001; 29: 1893-7.
20. Society of critical care medicine. Task force on ethics of the Society of critical care medicine; consensus report on the ethics of foregoing life-sustaining treatment in the critically ill. *Critical Care Medicine*. 1990;18:1435-9.
21. American Thoracic Society. American Thoracic Society Bioethics Task Force. Withholding and withdrawing life-sustaining therapy. *Am Rev Respir Dis*. 1991; 144: 726-31.
22. Damas E, Damas P, Lamy M. Euthanasia: a law in Belgium? 2001; 27: 1683.
23. Saberan H. Le drame de Berck relance le débat sur l'euthanasie. *Libération*. 26 septembre 2003.
24. Rucker G. End of life care in Canada after a murder charge in an ICU. *Intensive care Medecine*. 2003;29:2336-2337.
25. Studd H. Keeping miss B alive was an unlawful act. *The Times*. 23 march 2002
26. Dyer C. Dying woman loses her battle for assisted suicide. *British Medical Journal*. 2002; 324: 1055.