



Editorial

End-of-life care in the French ICU: Impact of Claeys-Leonetti law on decision to withhold or withdraw life-supportive therapy



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Recently published by Sprung et al., the ETHICUS 2 observational study confirmed considerable variations in end-of-life care practices across European intensive care units [1]. This study especially revealed changes over the past decade in end-of-life practices: life-sustaining therapies withdrawal and withholding (LSTW) are occurring more frequently, whereas deaths without limitations are occurring less frequently; survival after LSTW is increased; median times from ICU admission until LSTW, and from LSTW until death are shortened. These changes could be related to changes in ICU end-of-life attitudes, legislation, recommendations, protocols, education, research, palliative care, and family interventions. While European legislative frameworks are diverse (legislation or case law), France adopted in 2016 a new law on end-of-life, known as Claeys-Leonetti law, which amends the 2005 law, known as the Leonetti law. While French ICUs did not participate to the ETHICUS 2 study, Claeys-Leonetti law probably accompanied the same changes in France [2]. In a context where end-of-life issues are still on debate in all European countries, it seems important to discuss the main point of this law.

Refusing futile therapeutics at the end-of-life is the cornerstone of the French law. Being defined as treatments that seems to be “useless, disproportionate” or “that have no other goal than artificially maintaining life”, the precise threshold where the escalation of commitment becomes unreasonable remains difficult to define in singular situations where uncertainties are common. Among biological life, psychic life, social life, quality or quantity of life, which issue is being addressed? While this law was meant to protect patients from futile therapeutics, conflicts are more concerning cases where relatives are demanding that therapies are being pursued, against the medical team’s advice.

Respecting the patient’s wishes is central to the decision-making process. When the patient can express himself, the medical team has the obligation to respect his will. Thus, in such a case, the patient has the right to refuse any treatment, even vital. When the patient is unable to express his wishes, as it is often the case in intensive care, these laws reinforce the obligation to respect the patient’s wishes by making the advance directives binding, by insisting on the role of the “person of trust” and by guiding the decision-making process through a collegial procedure. Even though advance directives must be applied by medical teams, they are very rarely available in practice. Their place and impact on the medical decision deserve to be better known by the citizens and an accompaniment in their writing seems necessary. Similarly, the designation of the “person of trust” must be generalised, prior to events leading to hospitalisation in intensive care. However, are these advance directives stable over time, independent from health status? The law describes two situations as exceptions on the application of the advance directives: vital emergency awaiting a decision to be made, and clearly inappropriate directives. These two exceptions must not be used to modify the spirit of the law. When the patient is unable to express his wishes, a collegial procedure frames the end-of-life decisions and aims at respecting the patient’s wishes. This procedure, triggered by the patient’s relatives or by the physician, consists of a consultation with the medical team and a physician, appointed as an external consultant. It must be centred on the patient and meaning of the care. It may lead to a decision of withdrawing life sustaining therapies, as well as a reinforcement of the treatments provided. The aim of the procedure is to define clearly the care plan adapted to the patient’s situation. The decision is made by the physician in charge of the patient. However, in intensive care units, teamwork makes it difficult to designate a single physician as the one being in charge. In addition, medical teams must question the subjectivity implying the choice of an external consultant. Consensus is not legally required but it is advocated. The decision made after the collegial procedure must be notified to the relatives and be applied after a reasonable period to guarantee their right to appeal.

Finally, this law establishes a right to “a deep and continuous sedation, leading to an alteration of consciousness and maintained until death (DCSUD), associated with analgesia and withdrawing of all life sustaining therapies”. When the patient suffers from a severe and untreatable condition, that his vital prognosis is engaged on a short term and his suffering is refractory to treatment, this sedation can be initiated at his request, after a

collegial procedure. But how to precisely define a severe and untreatable condition, a vital prognosis engaged on a short term, a suffering being refractory to treatment, an unbearable suffering? This sedation may also be given to patients unable to express their will, when a decision of withdrawing life-sustaining therapies has been taken, even when their suffering is impossible to evaluate due to their cerebral condition. DCSUD differs from proportional palliative sedations and concerns the terminal palliative phase prior to death. DCSUD is not proportional to the symptoms: it is proportional to the deep level of unconsciousness. The objective is always to obtain unconsciousness to achieve the relief of actual or potential suffering. It also differs from euthanasia. Death is meant to be linked to the evolution of the patient's condition, without being precisely anticipated. This is essential to preserve physicians from believing they are transgressing a major principle of their practice: "a physician has no right to provoke death deliberately". The slightest drift from this principle would risk aggravating the confusion between deep and continuous sedation maintained until death and euthanasia. This confusion could provoke discomfort among professionals and misunderstanding of the relatives about the motivation of the decision. It would compromise the relationship of trust that must exist between the health care team and the patient or relatives. In all situations, the physician has the obligation to provide palliative care to preserve the patient's dignity and ensure his quality of life until death. The role of the physician is that of the accompaniment, the relief of suffering, either physical or psychic, and not to deliberately cause death.

The 2016 Claeys-Leonetti law is recent. Its application is heterogeneous and its major breakthrough remains insufficiently known by the population. Before considering new legislative changes, it now seems important to provide the means to guarantee the application of these texts by continuing the training of the professionals and by increasing communication with citizens. Its wider and more homogeneous application will ensure a decent end-of-life to our fellow citizens, without any discrimination against the most vulnerable people. Harmonisation of European legislation seems more than hypothetical.

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- [2] Lesieur O, et al. Changes in limitation of life-sustaining treatments over time in a French Intensive Care unit: a prospective observational study. *J Crit Care* 2018.

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