Terminal extubation in 5 end-of-life patients in intensive care units

Summary

Introduction Decisions to withhold or withdraw active life support treatment in situations with no hope of improvement remain difficult for critical-care specialists and families; they are not always well understood by the public. This report describes terminal extubation, a particular method of withdrawing ventilator support.

Methods This retrospective analysis examines the records of patients who died in our intensive care unit after a decision to withdraw active life support by stopping artificial ventilation. Terminal extubation was proposed for patients with irreversible neurological damage and was always performed only after a standardized collective decision-making process. This process included three stages: in the initial phase, withdrawal of ventilator support was discussed at a department staff meeting. The meeting’s conclusions were transcribed into the medical file, and the possibility of extubation was raised with the family during a planned interview. At least a 24-hours period of reflection was necessary before a new interview, and any opposition, hesitation or lack of understanding by the family at this first interview resulted in suspending the decision. The technical procedures for terminal extubation were also standardized.

Results In 5 cases (4 men and one woman, with a mean age of 65 ± 4 years), extubation was decided in cooperation with the family, following an average of 3 interviews, 16 days after admission. All patients died within 3 days.

Discussion So-called “terminal” extubation, very common in the United States, but much less so in France, reinforces the transparency of end-of-life decisions in intensive care units and immediately makes tangible the end of the aggressive treatment for which critical-care specialists have been reproached. Since this first series of patients, terminal extubation has been practiced in our department, principally in situations of irreversible neurological damage.

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In 1979, Maurice Rapin proposed stopping resuscitation (“heroic measures”) when there was no more hope of recovery. Since then, as the Latarea study revealed, the withholding or withdrawal of active life support has become relatively common practice in French resuscitation and intensive care units, sufficiently widespread to justify the publication of recommendations by the Société de réanimation de langue française (French-speaking intensive care society) in July 2002. Withholding treatment consists of not instituting or not intensifying active treatment (specific treatment for the condition that led to ICU admission and/or symptomatic treatment providing life support); withdrawing active treatment consists of not continuing active treatment that is essentially unreasonable to pursue. The failure of the treatment to benefit the patient, the existence of an incurable and irreversible disease, the impossibility of survival after the ICU, and predictions of a poor quality of life are therefore the principal determinants of the futility of continuing treatment. Most authors consider that withholding and withdrawing treatment are morally equivalent. In 2004, 90% of the ICU deaths in the United States and 50% of those in France were preceded by decisions to withhold or withdraw treatment. These decisions concern approximately 10% of the patients admitted to ICU and are generally made within a timeframe after ICU admission that varies from country to country: 2 days in the United States and Canada, 6 days in Israel, and 10 days in France. The life support treatments most often withheld or withdrawn are cardiopulmonary resuscitation (“Do not resuscitate” or DNR orders), mechanical ventilation, and vasoactive drugs. The bill about “patients’ rights and the end of life” introduced by Jean Leonetti and approved after its first reading in the National Assembly on 30 November 2004 includes in the civil code the possibility of “withholding or withdrawing treatments that are futile or unable to improve the patient’s condition”. Should it become law, it can only reinforce this strategy of refusing heroic measures and improving transparency towards families by reassuring critical-care specialists that these actions do not subject them to penal liability.

Stopping mechanically assisted breathing is the key element in withdrawing life support. The 2 most frequent methods are progressive withdrawal (or “terminal weaning”) and terminal extubation. Terminal weaning, described by Grenwik in 1983, involves reducing ventilatory support, that is, progressively diminishing, over a period that may last several days, the inspiratory settings (FiO2, respiratory rate, tidal volume, positive expiratory pressure), which may finally lead to its complete removal. If so, the endotracheal tube may be left in place, to facilitate continued aspirations and airway control, or it may be removed. Complete removal is called extubation: the patient is left to spontaneously breathe humidified air.
that is more or less oxygen-enriched. Withdrawing mechanical ventilation is generally proposed after other life support has been stopped. In France, withdrawing mechanical ventilation is perceived by 60% of health-care personnel as different from withdrawing other life support. French (Latarea) and European (Ethicus) multicenter studies show that extubation is the least-used method for withdrawing ventilator support; it was reported, respectively, in 6 and 9% of cases. Two thirds of the personnel interviewed by Ferrand et al. in 2001 felt that extubation should never be considered because it might worsen the patient’s distress or because of the direct causal association it may appear to have with death. The major difference between terminal weaning and extubation ultimately lies in the possibility of respiratory distress. The primary objective in either case is the patient’s comfort and in all such cases the administration of sufficient doses of sedation and analgesia is essential. One or the other of these two methods—extubation or maintenance of the endotracheal tube—can be used, depending on each patient’s particular situation or the perception of family or caregivers. Those preferring extubation note that it does not prolong the final agony of death and that, because it is unambiguous, it transparently restores the “natural” end-of-life process, freeing the patient from all artificial technological support. Its negative aspects lie in the fact that the family may interpret the ensuing noisy respiration or agonal breaths as discomfort. Those preferring terminal weaning argue that slower withdrawal retains more control by keeping the airways free for tracheobronchial suction and creates an “emotional distance” between ventilator withdrawal and the patient’s death. Progressive weaning, however, can also be associated with prolongation of the decision-making process because of the “physical” interposition of the respirator between the family and the patient, which can preclude any possibility of verbal communication and allow the family to continue to hope that survival is a treatment objective.

In an effort to increase transparency of the end-of-life intensive care procedures for both caregivers and families at the medical intensive care unit of Henri Mondor Hospital in Créteil, since 2001 we have been developing a procedure of controlled extubation in selected cases in which withdrawal of life support is justified, especially in cases of irreversible neurological damage (as in post-anoxic comas). We analyzed our initial experience with 5 patients.

Methods

This could thus be considered a retrospective file or cohort analysis and accordingly does not require approval by the CCPRPB (Ethics Committee) or any other institutional review committee. It includes the records of the patients who died in our ICU from January through June 2001. We analyzed the files of patients for whom a decision was made to withdraw or withhold active treatment and from whom ventilator support was then withdrawn. Extubation was proposed for patients with irreversible neurological damage and in all cases was performed only after a standardized group decision-making process that included:

- **full (medical and paramedical) staff conference** to consider the ethical issues;
- **open debate**;
- **consensus reached without haste**;
- **discussion and conferences with the family**;
- **planning of extubation**.

This decision-making process took place in several stages.

**Staff deliberations**

When withdrawal of mechanical ventilation was considered, extubation in particular, it was discussed during a department meeting of all available medical and paramedical staff, especially the personnel caring for the patient. The discussion involved an assessment of the patient’s medical situation and as complete an analysis as possible of information about the patient’s wishes and values. Extubation was envisaged only if this group deliberation led to a consensus supporting it. The meeting’s conclusions were transcribed into the medical file, as a “treatment plan” accessible to all:

- **acknowledgment of treatment failure**, incurability, and/or an unbearable impairment of future quality of life;
- **knowledge of the wishes** of the patient and family;
- **withdrawal of ventilatory support**, possibly combined with withdrawal of other active treatments;
- **appropriate and effective sedation-analgesia** and other comfort measures;
- **expanding visiting hours**.

**Family participation**

Once a staff consensus was reached, we (physicians, nurses and charge nurse) raised the possibility of extubation with the family during a scheduled interview, in a quiet closed room. It allowed us to ask for any information we did not already have about the patient’s “end-of-life” wishes, “advance directives”, or designation of a health-care proxy. The physician described the patient’s situation and explained that the medical team had concluded that, given current medical knowledge and treatment possibilities, the patient had no chance of acceptable survival; in this situation, the healthcare team suggested that mechanical ventilation be withdrawn; there was no rush in implementing this decision, which should be perceived as a proposal and not a hasty one. The family needed to understand that this suggestion was based on the absence of any possible curative treatment and that such a withdrawal would signify the deescalation of treatment, irreversible once begun and leading inevitably and pro-
bably soon to death. The family also needed reassurance: analgesia, sedation, and hygienic and comfort care would be provided, and visiting hours extended. Extubation is a concrete expression of the end of interventions for life support and symbolizes the – accompanied – passage to the end of life. The family was assured of continuity of care: if possible, patients remained in the same treatment unit with the same caregivers; otherwise they would be transferred to a single room in the adjacent “step-down” unit to allow as much family contact as desired. A period of reflection of at least 24 hours was necessary before a new interview, and any opposition, hesitation or lack of understanding by the family at this first interview suspended the decision. Several meetings between the medical staff and family could be necessary before they could serenely accept the proposal to withdraw mechanical ventilation.

**EXTUBATION PROCEDURE**

The extubation procedure was standardized. The attending physician, assisted by the patient’s principal nurse, performed the extubation, and family members who so wished were present. Nasal oxygen therapy was systematically administered immediately afterwards. In the case of dyspnea corticosteroid treatment was administered by nebulizer. Sedation and analgesia were administered in accordance with the staff’s assessment of the patient’s general and respiratory comfort, immediately and as needed thereafter. In case of major respiratory discomfort (stridor, asphyxia), sedation and analgesia were increased. Tracheobronchial aspiration and antisecretory treatment with scopolamine were administered in accordance with the amount of respiratory secretions, which were assessed before extubation. Vital sign surveillance was reduced, and blood samples and radiologic examinations stopped. The family’s presence at the bedside was organized.

**Results**

From January through June 2001, 93 (19%) of the 494 patients admitted to the unit died. A decision to withhold or withdraw active treatment was made for 30 (32%) of these patients, and artificial ventilation was withdrawn for 5 (16%) of them. History, clinical and other treatment data were collected for each of them (table 1). The reasons for ICU admission were cardiopulmonary arrest that revealed severe ischemic heart disease (n = 1), massive stroke (n = 2), suicide attempt by a patient disabled by Parkinson disease (n = 1), and terminal heart failure with bilateral stenosis of the renal arteries (n = 1). Two patients had already expressed their desire to avoid heroic measures at ICU admission (“I do not want to be resuscitated”); in three other cases, the family expressed a refusal to continue active treatment, which it described as “too much”
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O R I G I N A L A R T I C L E

("be (sbe) would not have wanted to continue to live like that"). In all cases, a decision to withhold treatment or cardiopulmonary resuscitation (“DNR order”) had been made while in the ICU. The presence of irreversible neurological impairment, with no hope of recovery, influenced the ethical decision-making process with regard to extubation. On average, it took at least 3 interviews with the family for them to understand the meaning of extubation, accept it and finally plan it. Because the immediate course after extubation is unpredictable, we routinely asked the families if they wanted to be present at the extubation. All the families chose to be in the unit for the extubation, but only 2 were present in the room; the other three remained in the waiting room during the procedure. One patient developed major stridor, which required the immediate administration of an intravenous bolus of morphine and midazolam, in the family’s presence. All the patients died after extubation, with death occurring on average in 3 ± 2 days, with a range of 40 minutes to 6 days. Four of the five patients remained hospitalized until death in the same unit; one was transferred to the adjacent “step-down” unit 48 hours after extubation. Sedation and analgesia were administered according to the assessment of the patient’s comfort. Morphine and midazolam doses were progressively increased after extubation, and again in the hours before death, but their “titration” was not standardized.

Although we did not measure the experience of either caregivers or families, we noted neither verbal aggression nor lack of understanding. The family of the patient transferred into the post-ICU unit perceived the transfer as an abandonment of the patient by the health care team that had previously cared for him. Two families clearly stated their relief after the procedure, and no family expressed regret. We routinely offered families an opportunity to return to discuss the death with us, but after two years, none had chosen to do so.

Discussion

Withholding and withdrawing active treatment are increasingly frequent practices in ICU; they involve 10% of adult ICU patients and account for 50% of the ICU deaths in France and Europe, and 90% of those in the United States.2,5,6,19 Withdrawing respiratory assistance is a key element here20. A 1991 survey of practices in Minnesota showed that only 15% of the clinicians questioned never withdrew mechanical ventilation and that among those who sometimes did, 33% used only terminal weaning and 13% only extubation16. Extubation is the method of withdrawing ventilatory support that is least used in France and Europe – in 6% of the cases in the Latarea study2, and 9% of those in the Ethicus study5. Findings from practice
surveys in North America and France partially explain these figures. Faber-Langendoen et al. found that 26% of physicians feel there is an ethical difference between not starting ventilation (“withholding”) and withdrawing it from patients at the end of life.

In France, similarly, most medical personnel perceive stopping mechanical ventilation to be different from other types of treatment withdrawal; 63% of the paramedical staff and 58% of the medical staff share this opinion.

Even more caregivers (90% of the paramedical and 87% of the medical personnel) perceive a difference between extubation and terminal weaning; two thirds (70% of the paramedical and 71% of medical staff) think extubation should never be considered. Decisions to withhold active treatment are better accepted: 78% of the paramedical and 90% of the medical personnel reported agreeing with a decision to desist from initiating ventilation for end-of-life patients who develop respiratory distress.

While some authors consider that extubation is not consistent with the principle of beneficence, others prefer it because of its transparency, its absence of ambiguity, its restoration of a more “natural” character to the end of life, and finally its speed. Faber-Langendoen et al. showed that the period between withdrawal of mechanical ventilation and death was shorter with extubation than with rapid terminal weaning (1.8 ± 5 hours), in contrast to the findings by Campbell et al. (13 ± 5 hours after beginning a rapid terminal weaning of 15 minutes vs 85 ± 35 hours for extubation). Relatively few objective data in the literature strongly support a choice of either terminal weaning or extubation at the end of life. In Faber-Langendoen et al.’s study of practices, the characteristics associated with the choice of one or the other method depended on considerations including the patient’s comfort and the perception of caregivers and family (table 2). Two studies have failed to show any significant difference between these two methods in terms of patient comfort. The volume of respiratory secretions and the staff’s ability to alleviate discomfort may help in selecting the best method. Family participation is necessary, especially in the case of extubation, where the consequence of stopping mechanical ventilation is directly obvious (the patient no longer has a probe). Transparency was also the reason we systematically asked families if they wanted to be present for the extubation; once mechanical ventilation is withdrawn, it is irreversible and the immediate short-term course is unpredictable. The procedure was not overly dramatized: families received complete explanations of the technical aspects during the various conferences and understood that death would occur after an unknown period but perhaps very rapidly after extubation. Some families therefore wanted to be present and showed a complete understanding and acceptance of the act and its consequences.

The increases in morphine doses in the last hours of life obviously raise the question of the intention of the prescribing physicians: is the aim simply to alleviate the pain of the dying patient and the action therefore in compliance with the principle of beneficence? Or does the intention to commit euthanasia lurk behind this admissible motive? Literature on this difficult subject is plentiful: this is the “principle of double effect”. Physicians prescribe elevated doses of products that may depress the respiratory system – just after withdrawing ventilatory support – to relieve the patient’s pain. The primary motive is pain relief (the “good” effect). Although the physician knows the treatment may accelerate the patient’s death, this secondary “bad” effect is not wanted, but is known and accepted. Here the specialists must “titrate” the morphine doses very carefully, increasing them progressively, to suppress the clinical manifestations of distress or discomfort, but without going beyond that. The action must be perfectly clear at this crucial moment: the confidence of patients and their families, and more generally the support of society, depend on it.
WHAT IS ALREADY KNOWN

- Decisions to withhold or withdraw active treatment, frequent in the ICU, affect half of the patients who die in an ICU setting in France and Europe and 90% of those in the United States.
- Terminal extubation is perceived differently by caregivers than stopping other active treatments: in principle, because of the patient’s perceived distress or because of the direct causal link between withdrawal of treatment and death.
- The legal situation in France is in the process of changing: a new bill related to “the rights of patient at the end of life” presented by Jean Leonetti was approved in its first reading by the National Assembly on 30 November 2004; it includes in the civil code the legal possibility of “withholding or withdrawing treatment that is futile or powerless to improve the patient’s condition”.

WHAT THIS ARTICLE ADDS

- The article describes a particular method of withdrawing mechanical ventilation, terminal extubation, in 5 end-of-life patients in the intensive care unit, with irreversible neurological damage. Extubation was performed following a standardized decision-making procedure involving medical and paramedical staff and the family; its strong points include its collective nature, the open debate, the need for consensus and the refusal of hasty decision-making.

The conditions of the death of these first five patients, the simple control of respiratory manifestations after extubation, the relief, if not the satisfaction, of the families resulting from their involvement in or even their presence at the last moments of their loved one, the rapid acceptance by the nursing team of this method, although it requires more of their time and is more emotionally risky, has led us since then to propose it more routinely to families of end-of-life patients, especially those with very serious post-anoxic brain damage.

Removing ventilatory support is a clear example of treatment withdrawal because of its symbolic meaning for end-of-life patients: it stops their life-breath. The ethical and technical controversies about choosing between these two methods of withdrawing mechanical ventilation – extubation and terminal weaning – do not relate to their intentionality, which is the same, so much as to the visibility of the act of withdrawing treatment and to its consequences for the patient’s comfort and to the perceived transparency of the decision-making process for the family and the caregivers.

Generous and careful prescription of sedation and analgesia cannot be dissociated from the withdrawal of treatment. In cases of severe post-anoxic brain damage, controlled extubation in the setting of appropriate analgesia and sedation appears to us to best match the aim of stopping active treatment while simultaneously providing the patient and the family with transparency and personal involvement and accompaniment.

The integration of more systematic psychological support for families and the use of appropriate scales for sedation and analgesia may reinforce the truly palliative dimension of their care.

Références