

# Humane terminal extubation reconsidered: The role for preemptive analgesia and sedation\*

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**Patient comfort is not assured by common practices for terminal extubation. Treatment guidelines suggest minimizing dosage of opioids and sedatives. Multiple lines of evidence indicate that clinicians are limited in their ability to recognize distress in such patients and tend to undermedicate patients in distress. Yet suffering of any significant degree should be unacceptable. For painful procedures, such as surgery, the analogous practice of postponing anesthesia until the patient evidences discomfort would never be tolerated. Waiting for signs of suffering before**

**initiating excellent analgesia and sedation inexorably subjects patients to distress. Therefore, when death is inevitable and imminent after extubation, suffering should be anticipated, concerns about respiratory depression dismissed, and vigorous preemptive deep sedation or anesthesia provided. (Crit Care Med 2012; 40:625–630)**

**KEY WORDS:** analgesia; extubation; palliative sedation; preemptive medical ethics; terminal weaning

**T**erminal extubation” is the term broadly used to denote the procedure of removing ventilatory support—either mechanical ventilation or noninvasive positive pressure ventilation—from a patient who is expected to die very soon after withdrawal of such support. The procedure is also called “terminal weaning” or “immediate extubation,” depending on when and how an endotracheal tube is removed, and is also sometimes labeled “compassionate extubation.” This essay argues that clinical guidelines and policies have not adequately acknowledged or addressed the suffering that may be experienced by alert or even partially conscious patients in anticipation of, and especially after, initiating the extubation procedure. Heightened attention to suffering near the end of life and accumulating research data, including remarkable new perspectives from the brain sciences, compel a fresh approach to this procedure.

The argument presented here deals with removing ventilatory support for patients who have some degree of con-

sciousness. Likewise, these patients are terminal, meaning that survival lasting beyond a few minutes or hours would be unprecedented. It cannot be directly applied to brain dead patients or to the many persons for whom prolonged survival is a possibility after extubation.

## The Procedure

Terminal extubation entails either: 1) reduction and eventual cessation of ventilatory support (e.g., by lowering oxygen concentration, pressure support, and/or assisted respiratory rate), typically called “terminal weaning”; or 2) “immediate extubation” (or similarly, removal of a positive pressure mask); or 3) some mixture of both. Additionally, opioids or sedatives may be administered either in a preemptive manner to anticipate and prevent symptoms or in a reactive approach that treats symptoms when they arise (1).

Studies comparing the outcome of various approaches to withdrawing ventilatory support or of particular analgesic or sedative regimens are lacking. Thoughtful and detailed clinical guidelines are available to help clinicians (2–12). However, both the medical literature and anecdotal reports (13, 14) describe instances of patients gasping for air, breathing rapidly, and becoming cyanotic while still apparently conscious during terminal extubation, as well as serious distress on the part of families and staff. Consider this patient with amyotrophic lateral sclerosis, who had appeared com-

fortable immediately after withdrawal of ventilatory support:

*However, five minutes into the vigil, his condition changed. He slowly opened his eyes, looked around the room, and grimaced in the only way his muscles would allow. The quiet of the room was deafening. We were all as paralyzed as he was, as he stared deeply into our eyes. Was he suffering? Was he gasping for breath? Was he trying to scream? Was he saying his last goodbyes? Was he truly aware?—Anonymous, personal communication.*

## The Growing Importance of Terminal Weaning

Withdrawal of life-sustaining measures, such as terminal weaning, is now a common and increasingly frequent procedure before hospital death (15–17). As many as 90% of deaths in intensive care units (ICUs) involve withdrawal of life supports (16), typically for sedated or unconscious patients (18). In a recent review of 851 patients who received mechanical ventilation in an ICU, 63% were successfully weaned, but 17% died while being ventilated and the remaining 19.5% died after mechanical ventilation was withdrawn (19). Notably, most patients undergoing terminal extubation are considered decisionally incapacitated. In one study, only 4% of patients participated in the decision to extubate (20). Terminal extubation of the alert patient involves unique psychosocial, ethical, legal, and procedural considerations (21).

### \*See also p. 700.

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## How Is Suffering Treated in Terminal Weaning?

Many articles about terminal weaning state that distress can be avoided or palliated, yet emphasize treating distress only when it is recognized—reactive treatment rather than preemptive management. Thus, if respiratory distress occurs during the procedure, as judged by observation of the patient's breathing pattern or changes in vital signs, opioids and/or sedatives are initiated or increased until the patient seems comfortable and the weaning can continue. Campbell (22) describes three cases of gradual weaning in great detail, lasting 5–12 hrs, but larger series show a shorter average interval from withdrawal to death, with deaths occurring from 35 mins to 34 hrs (10, 23–29). The possibility of suffering that is not readily observable is not mentioned.

*Dosing With Opioids and Sedatives.* Guidelines on terminal weaning regularly indicate that small doses of opioids or sedatives may be prescribed before weaning, or that current doses may be increased. Liberal sedation practices may sometimes be encouraged by statements that the alleviation of suffering is essential and that no maximum analgesic dosage exists (30–34). One guideline notes that “the total amount of drugs required for any individual patient may far exceed any preconceived notions of usual ... doses” (8). On the other hand, some articles caution against high doses, and the majority of articles advise that opioids and sedatives should be carefully titrated with dosages “commensurate with patient distress” (8). The provision of analgesia and sedation is described as a “difficult balance,” since “sedation, especially heavy sedation, virtually ensures that the patient will die” (35). Another guideline asserts that drugs should be titrated to “cessation of symptoms—not the cessation of life” (36). Thus, minimization of opioid and sedative doses receives greater emphasis than minimization of suffering (37).

Remarkably, physicians vary by greater than a ten-fold difference in how much morphine and sedatives they prescribed for terminal weaning, suggesting that the considerable variation in practice is not simply based on patient need (18). As discussed in the following sections, physicians identify three major concerns that guide their choices about medication: 1) patient comfort; 2) family percep-

tions; and 3) ideas, values, and personal feelings about clinician agency in a death (38, 39).

### Patient Comfort: Terminally Weaned Patients Suffer Needlessly

Many lines of evidence suggest that patients may suffer during terminal weaning:

*Anticipatory Distress.* First, suffering is present in patients who are aware of the decision to initiate withdrawal of ventilatory support and not treated preemptively. Many of these patients will have already experienced serious dyspnea, including during weaning attempts. The prospect of terminal extubation and fears of inadequate symptom control—air hunger, choking, and suffocation—can be terrifying for the patient who is about to die. Among the reasons for requesting hastening of death, fear of choking was present in 70% of patients who decided on euthanasia or physician-assisted suicide in The Netherlands (40). Honest reassurance that the patient will not experience such symptoms can only be provided if the patient will be deeply sedated or anesthetized for the procedure.

*Undertreatment of Symptoms.* Neglect or undermedication of physical discomfort has been widely documented in patients with terminal conditions (41). Common clinical procedures, such as chest tube removal or tracheal suction, regularly cause pain and are not managed with preemptive analgesics (42–45). The SUPPORT study reported that 70% of conscious patients dying with lung cancer or with multiple organ failure and a malignancy had severe dyspnea (46). In a retrospective review, death rattle was present in 23% of patients (48), while stridor occurred in 30% of patients after routine extubation (47). During withdrawal of life supports in a neurology ICU, 59% of patients showed signs of agonal or labored breathing, and 34% developed tachypnea while receiving an average morphine dose of only 6.3 mg/hr (29). In a study of British specialists, 17% used only morphine or another opioid for terminal weaning (49). Even when palliative sedation has been prescribed for intractable distress, 17% of patients have inadequate symptom control 4 hrs after initiating treatment (50).

*Delay in Symptom Alleviation.* Reports on terminal weaning consistently show that significant amounts of opioids

and sedatives are added or increased to the previous regimen after withdrawal of ventilatory support (i.e., reactive treatment) (10, 23, 27, 38, 51). This confirms that starting doses were not adequate to prevent suffering. And, of course, none of these drugs will instantly alleviate distress; relief of suffering awaits the onset and perhaps the peak effect of intravenously administered analgesics and sedatives.

*Inadequate Recognition of Distress.* Relying on the observation of clinical signs of respiratory distress—restlessness, moaning and agitation, and changes in vital signs—does not guarantee that significant suffering is detected or adequately addressed. Ill patients who are cognitively impaired may not be able to express their discomfort, yet their unresponsiveness does not mean suppressed awareness of distress. Campbell (52) has recently reported on the ability of patients who are near death to report dyspnea: over half of patients could not provide a yes/no answer, and only half of those who provided an answer could quantify their distress with a visual analog scale. Neuromuscular conditions and sedation may dampen or obliterate observable responses to noxious stimuli without adequately interfering with pain or dyspnea. Even anesthesia for surgery can be accompanied by a low incidence (0.007% to 0.7%) of awareness, including pain, helplessness, fear, and panic (53–55).

Recent progress in the neurosciences also should lead us to doubt our ability to recognize suffering reliably. A variety of studies suggest that seemingly high-level brain processing continues in the persistent vegetative state (56–59) and during deep sedation (60). For these patients, distinct electrophysiological patterns or functional images of the brain appear the same as what is observed in normal persons in response to noxious stimuli, and may be detected without outward signs of distress (61–64). Of course, the presence of such patterns alone cannot be equated with suffering.

### Family Perceptions (65, 66)

Attention to the impact of terminal weaning on the family is also a major concern for the clinician. According to Brody:

*Family members should be assured that the patient's comfort is of primary concern, that sedation will be used even*

to the point of unconsciousness to provide comfort, and that involuntary movement or gasping does not reflect suffering if the patient is either in a coma or properly sedated (5).

The management of pain and other symptoms is a major source of conflict between family and staff (67, 68). Agonal breathing may be interpreted as suffering. Family members also report distress about death rattle, which occurs in 36% of patients, as well as about stridor after extubation (69–74).

### **Staff Perspectives: What Are the Barriers to Preemptive Anesthesia for Terminal Weaning?**

Clinicians are often uncomfortable about terminal extubation. They voice emotional distress about both the decision and about participating in the procedure, and they express concerns about professional ethics and legality (35, 75–79). In a large Canadian study on terminal extubation, at least one ICU clinician expressed discomfort with the care plan on at least one occasion for 43% of patients, and nurses were more likely to express discomfort than physicians (80). Clinician reluctance to perform terminal extubation in alert patients is reflected in the fact that a number of patients have had to go to court to plead for withdrawal of ventilatory support and preemptive anesthesia (81). Prendergast and Puntillo (9) suggest that: “Support from unit leaders, hospital chaplains, or members of the ethics committee can and should be made available to ICU clinicians who struggle with ethical and other practice issues during their care of dying patients”.

*Does the Patient Really Want to Die?* A patient’s or surrogate’s request for terminal weaning does not mean that the procedure should be performed. Appropriate evaluation of requests to hasten death include attention to symptom control, decisional capacity, depression, durability of wishes, absence of coercive influences, and the impact of the act on family (82). Such an evaluation requires knowledge, skill, and time, and consideration should be given to consultation with psychiatry and palliative care. Regardless, staff uncertainty or ambivalence about such a drastic action is common.

*Is the Patient Really Going to Die?* If the patient has a reasonable chance to survive in acceptable health after with-

drawal of ventilatory support, clinicians should not preemptively suppress respiration, lest they hasten or cause the death of a patient who might have survived weaning. Clinicians will, of course, err on the side of preserving life, and should engage in shared decision making with the patient or surrogate on whether terminal extubation is appropriate.

Clinician confidence about decisions to withdraw life support in the ICU has been studied in a survey using 12 patient scenarios. Respondents were very confident about their decisions less than a third of the time (83). Certainly, even patients who have undergone prolonged mechanical ventilation may eventually survive extubation and enjoy an acceptable quality of life (84, 85). A few retrospective reviews cite survival to discharge after terminal extubation at a rate of 11%–14%, (28, 86). Unfortunately, these retrospective studies provide no information about how the prognostication was made or the clinicians’ degree of certainty.

Prognostic models that rely on objective measures have not been useful in predicting survival or making end-of-life decisions for individual patients (87). Indeed, prognostic uncertainty is a pervasive issue in medicine; physicians regularly need to estimate prognosis to make good decisions, some of which have life-or-death implications (88). Avoiding such decisions, such as never choosing to withdraw life supports, presents its own terrible problems.

But some prognostic judgments are clear or clear enough. When acceptable survival would be unprecedented, terminal extubation may be appropriate.

*Is it Ethical?* As stated by Schneiderman (89): “Is it morally justifiable *not* to sedate this patient before ventilator withdrawal?”

Typically, terminal extubation is justified by the principal that double effect justifies terminal extubation (90–94) and distinguishes it from euthanasia (95). The intent of sedation is to prevent and treat grave distress, while the unintended but possibly foreseen effect may be hastening death. Appealing to the importance of intention (96) and the principal of double effect, one ethicist concluded:

*When appropriate doses of narcotics and sedatives are used and the intent of the physician is clear and well documented, preemptive dosing in anticipation of pain and suffering is not eutha-*

*nasia nor assisted suicide but good palliative care* (8).

*Is it Legal?* Fear of prosecution for committing euthanasia is also cited as a barrier to preemptive anesthesia (8). However, U.S. courts, including the Supreme Court, have repeatedly affirmed the right of patients to receive sedation to prevent or treat suffering (81).

*... a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death* (97).

No provider has ever been prosecuted successfully or held civilly liable for such treatment (95). Still, the legal basis for the practice is not widely appreciated, putting the clinician who performs preemptive sedation at risk for professional or legal censure.

*What if the Family Objects?* Even if preemptive anesthesia is seen as the “right thing to do” for terminal weaning, staff are faced with potential misunderstanding and conflict with the family (61, 98, 99), a topic beyond the scope of this article.

*How Does One do it?* Preemptive anesthesia for terminal weaning is not taught as a clinical skill nor described in textbooks. Choosing the right doses of medication for preemptive sedation is complicated by individual differences in response to drugs. Anesthesiologists, however, are familiar with this procedure, and can provide appropriate guidelines for choosing agents, adjusting doses, and assessing the level of anesthesia (100).

For most clinicians, using very high doses of opioids and sedatives is unfamiliar and potentially disconcerting. The range of expert opinion on analgesic use is remarkably variable (101), and doses “that are very large by conventional standards may not be ‘excessive’ in certain clinical situations” (102).

*What if it Feels Wrong?* Seeing a patient die in front of you is an extraordinary and daunting experience, and can be profoundly upsetting when you have played a role in allowing it to happen. Withdrawal of ventilatory support places the act of the clinicians in close proximity to the death, highlighting the agency of the clinician in ending life (23, 103).

All the clinical, ethical, and legal arguments for preemptive anesthesia in terminal weaning do not address the

moral distress that may be experienced in performing the procedure (104, 105). As highlighted in a 1992 article, entitled “Disconnecting a ventilator at the request of a patient who knows he will then die: The doctor’s anguish” (35), terminal extubation for a patient who is capable of experiencing suffering can provoke considerable emotional stress for staff. As stated by Edwards, the medical literature provides practically no guidance for this procedure, “especially at the feeling level” (35). Indeed, we would be saddened if clinicians did not struggle over such momentous decisions and thus feel somewhat troubled at times in these situations.

### Sedation, Analgesia, Or Anesthesia?

What is the appropriate preemptive medication for terminal weaning and for ongoing management until death? Deep sedation or anesthesia using intravenous agents requires both opioids (which produce analgesia at doses that do not assure unconsciousness or amnesia) and sedatives (which produce unconsciousness and amnesia without analgesia) (106).

How does one determine whether adequate analgesia and sedation has occurred? The American Society of Anesthesiologists has developed guidelines (107) that are reflected in sedation scales, such as the Ramsay Sedation Scale (108) and the Sedation-Agitation Scale (109). Anesthesia or deep anesthesia is defined by terms like “unresponsiveness to pain” or “minimal or no response to noxious stimuli.” Deep sedation, which is the next shallower form of anesthesia, is defined as a drug-induced depression of consciousness during which the patient cannot be easily aroused, but responds purposefully following repeated or painful stimulation, and is characterized by a “sluggish response to stimulus” in the Ramsay scale, and “rouses to stimuli, does not obey commands” in the Sedation-Agitation Scale. Deep sedation, therefore, does not assure acceptable comfort for the stress and distress of dying from respiratory insufficiency, and general anesthesia is needed to protect fully against suffering. In either case, respiratory drive may be seriously compromised.

### CONCLUSION

Discontinuing mechanical ventilation is a difficult process for the alert or par-

tially conscious patient who may anticipate and experience suffocation. Families suffer too, especially witnessing labored or agonal breathing and “death rattle.” At the same time, the members of the healthcare team may face considerable distress about whether terminal extubation with preemptive anesthesia is the right thing to do and how to do it.

Preemptive medication for symptoms is humane and sensible (102, 110). As stated in the 2001 report of the Ethics Committee of the Society of Critical Care Medicine:

*The concept of “anticipatory dosing”... should guide clinicians in the use of sedation and analgesia at the end of life. The rapid withdrawal of mechanical ventilation is an example of the need for anticipatory dosing. At the time of ventilator withdrawal, the clinician can anticipate that there will be a sudden increase in dyspnea. It is not sufficient simply to respond to this distress with titrated doses of an opioid (reactive dosing) (1).*

For the subset of patients who, to the best of our knowledge, will certainly die after withdrawal of ventilatory support, a preoccupation with avoiding accusations about hastening death and euthanasia can distract attention from the clinical obligation to prevent suffering (36). Just as we inject procaine locally before extracting a molar or provide anesthesia before making a surgical incision, we should preemptively administer analgesics and opioids before a terminal wean (Truog R, personal communication).

Clinical management in such situations is guided not only by the scientific considerations, as described above, but also by a variety of personal values, beliefs, and preferences of the patient, family, and staff that may favor prolonging the weaning process and tolerating some degree of observed or unobserved respiratory distress while avoiding the sense of agency in causing a death when the patient dies quickly after preemptive sedation (109).

### A Humane Guideline is Proposed Here:

*Any potentially conscious and imminently dying patient who is undergoing withdrawal of ventilatory support and hence faces the extreme distress of respiratory failure should be offered preemptive high doses of opioids and sedatives for anesthesia, or at least deep sedation*

*to assure comfort, regardless of concerns about depressing respiratory drive.*

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