Principles and practice of withdrawing life-sustaining treatments

Gordon D. Rubenfeld, MD MSc

Harborview Medical Center, Division of Pulmonary and Critical Care Medicine, University of Washington, 325 Ninth Avenue, Seattle, WA 98104-2499, USA

Most deaths in intensive care units occur after decisions to limit or withdraw life support [1,2]. Despite an extensive literature on whether to withdraw life support, little attention has been given to how to withdraw it [3,4]. For example, a recent edition of a critical care textbook exhaustively covers the ethical and legal aspects of life-support withdrawal, but makes no recommendations for carrying it out [5]. Only recently, in the wake of growing data that problems may exist in providing palliative care in the intensive care unit (ICU), has attention been directed to the practical aspects of withdrawing life support [6–8]. Many practical questions about withdrawal of life support, and specifically about the withdrawal of mechanical ventilation, are perplexing and controversial: Should the endotracheal tube be left in place? Should the ventilator be weaned slowly or quickly? When and how should sedation be increased? How can the concerns about relieving suffering be reconciled with fears of killing the patient? Should neuromuscular blockade be discontinued? These questions are important because clinicians face them frequently and are still confused by the goals and process of withdrawing life support, and because patients who die after withdrawal of life support may receive inadequate pain and symptom management [9,10].

Principles of withdrawing mechanical ventilation

In this era of evidence-based medicine, there is a lack of data to direct clinicians in the optimal management of the dying critically ill patient. Despite the lack of data on optimal management of some aspects of withdrawing life-sustaining treatment, a general consensus exists on the ethical and clinical principles that should guide this care. These six principles are listed in Box 1 [11–13].

E-mail address: nodrog@u.washington.edu

0749-0704/04/$ – see front matter © 2004 Elsevier Inc. All rights reserved.
doi:10.1016/j.ccc.2004.03.005
Understanding that the goal of withdrawing life-sustaining treatments is to remove unwanted treatments rather than to hasten death is essential in clarifying the distinction between active euthanasia (providing drugs or toxins that hasten death) and death that accompanies the withdrawal of life support in the ICU. Ethicists draw a line between withdrawing life-sustaining treatments when the expected but unintended effect is to hasten death and providing a treatment with the sole intent of hastening death. Despite the well-established principle that “withholding and withdrawing are equivalent” some clinicians find it difficult to stop treatments that are currently being provided and choose to withhold future treatments while continuing current levels of support. Frequently, clinicians are faced with multiple decisions about a variety of current or potential life-sustaining treatments. For example, consider a patient with respiratory failure, shock, and worsening acidosis with anuria. A family conference is held and a decision, based on the surrogate decisionmaker’s judgment of the patient’s values, is made to withhold dialysis. In this case, clinicians should strongly consider whether continuing vasopressors and mechanical ventilation while withholding dialysis makes clinical sense. There is no distinction from an ethical or medical standpoint between withdrawing mechanical ventilation, vasopressors, dialysis, antibiotics, blood products, intravenous fluids, or nutrition. All medical treatments, even nutrition and fluids, can be legally, ethically, and compassionately stopped in the appropriate setting. The withdrawal of mechanical ventilation is special in several ways. It is one of the few life-sustaining treatments whose withdrawal can cause discomfort. Mechanical ventilation has profound symbolic significance for clinicians and families. In patients not receiving intensive cardiovascular support, the withdrawal of mechanical ventilation is usually the event that most proximally precedes death [4,14]. The recommendations in this

<table>
<thead>
<tr>
<th>Box 1. Principles of withdrawing life support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) The goal of withdrawing life-sustaining treatments is to remove treatments that are no longer desired or do not provide comfort to the patient.</td>
</tr>
<tr>
<td>2) Withholding life-sustaining treatments is morally and legally equivalent to withdrawing them.</td>
</tr>
<tr>
<td>3) Actions whose sole goal is to hasten death are morally and legally problematic.</td>
</tr>
<tr>
<td>4) Any treatment can be withheld or withdrawn.</td>
</tr>
<tr>
<td>5) Withdrawal of life-sustaining treatment is a medical procedure.</td>
</tr>
<tr>
<td>6) Corollary to 1 and 2: when circumstances justify withholding one indicated life-sustaining treatment, strong consideration should be given to withdrawing all current life-sustaining treatments.</td>
</tr>
</tbody>
</table>
article are based on the premise that the withdrawal of life-sustaining treatments is a clinical procedure, and, as such, merits the same meticulous preparation and expectation of quality that clinicians provide when they perform other procedures to initiate life support. Therefore, the steps clinicians take when they withdraw life-support should parallel the steps they take when they perform a thoracentesis, lumbar puncture, or appendectomy (Box 2). By providing a familiar framework to guide clinical practice and proposing a protocol for the procedure we hope to improve the quality of care to patients at the end of life.

The decision to withdraw life-sustaining treatments

Ethical and legal guidelines for decisions to withdraw life-sustaining treatments are well established, and have been presented elsewhere [12,15]. Competent, informed patients may refuse any life-sustaining treatment. For incompetent patients, appropriate surrogates may refuse life-sustaining treatments based on written advance directives or, in almost all states, the patient’s previously stated wishes, values, or best interests. In some circumstances it is ethically appropriate for physicians to limit treatment in the absence of a surrogate or advance directive [16].

There should be consensus among the health care team about the decision to withdraw life support. Frequently, members of the critical care team will reach the conclusion to limit life-sustaining treatment at different times. Although the attending physician must take ultimate responsibility for the decision, it would be imprudent to insist on a plan in the face of persistent, thoughtful disagreement by members of the health care team. Withdrawing life support is seldom an emergency decision, and time should be taken to resolve disagreements among the staff and with family members. Strategies to improve consensus include allaying fears of legal liability, encouraging face-to-face discussions between health care professionals who disagree on the prognosis, eliciting the views of

Box 2. Routine steps in performing a procedure

- Decision is made to perform the procedure
- Informed consent is obtained
- An explicit plan for performing the procedure and handling complications is formed
- The patient is moved to an appropriate setting
- Adequate sedation and analgesia are begun
- The plan is performed
- The process is documented in the medical record
- The outcomes are evaluated in an attempt to improve the procedure
clinicians who are providing bedside care, and consulting with a senior clinician or ethics committee. When engaging in these discussions, clinicians should temper the certainty of their convictions about the utility of life-sustaining treatment with the knowledge that a large body of data shows that clinicians apply personal values and biases rather than ethical principles and outcome data when making clinical decisions [17–19]. All team members, particularly those in direct patient care roles, should feel that they have had meaningful input into the final plan.

Informed consent

Like other medical procedures, withdrawal of life support should be accompanied by informed consent, or at least assent, and documentation of this process in the medical record. Informed consent for the procedure of withdrawing life-sustaining treatment does not refer to the process of signing a consent form. It refers to a process of communication between caregivers and families that focuses on the burdens and benefits of life-sustaining treatment and the options for alternate care. Competent patients or the surrogates of incompetent patients should understand and agree with the decision to withdraw life support. In many cases, patients or families will initiate the request that life support be withdrawn. In rare cases, patients or surrogates may insist on interventions that the health care team regards as futile. Although there is no ethical obligation to provide futile care, there is considerable controversy over what interventions are futile and can be withdrawn over the objections of the patient or surrogate [20]. Fortunately, almost all patients or surrogates eventually agree with physicians’ recommendations to withdraw or withhold interventions [21]. Even in the few extraordinary cases where consensus cannot be achieved and life-sustaining treatment is withdrawn over the determined requests of a family member, the ethical principles of truth-telling and respect for persons dictate that they should be informed of the decision or clinicians should determine that the decision makers do not wish to be informed. These discussions can be uncomfortable for clinicians and family members, but this is not a justification for covert clinical activity like “slow codes” or replacing vasopressor drips with normal saline.

Physicians must provide clear recommendations while respecting the right of patients or their surrogates to make decisions about the process. It is important to explain to the family members how interventions will be withdrawn, to solicit their feedback, and to respect strong preferences regarding how interventions will be withdrawn. Some patients or their families may assign particular symbolic significance to certain aspects of care. For example, there may be strong wishes to remove the endotracheal tube while mechanical ventilation is being withdrawn, or to continue feeding and hydration when dialysis and vasopressors are stopped. These wishes should be respected as long as they do not interfere with the primary goal of enhancing patient comfort and removing technology that does
not fulfill the shared goals. Although it is important for patients and families to have some control over the dying process, it is confusing and inhumane to ask family members to give specific consent for each step of the withdrawal process. Clinicians should specifically avoid providing patients with an entire menu of life-sustaining treatment options to choose from. Families who are not medically sophisticated may have unrealistic expectations and understanding of life-sustaining technology [22]. Generally, once families set the goals of care, for example, to maximize comfort and forego attempts to prolong survival, it is up to clinicians to decide how to meet these goals.

**Appropriate setting and monitoring**

Transforming the ICU into a suitable place to fulfill the new goals of terminal care is not a simple task. The ICU and its staff are poised to respond to minor physiologic changes. Comfort, dignity, family access, and quiet may not always receive the highest priority. Particularly when family members and friends will be in attendance, the goal should be to have the patient clean and comfortable in a quiet room devoid of technology and alarms that affords the patient and family privacy. The following are suggestions for creating a humane and private environment for the dying patient and family or surrogate:

- Separate the patient from the commotion of the ICU by moving the patient to a separate area or an isolated room. In open units, curtains should be closed.
- Turn off monitors and, if possible, remove them from the room. Remove electrocardiographic leads, pulse oximeter, and hemodynamic monitoring catheters. There is no point to monitoring physiologic parameters when the data generated will not alter care. Families attending the dying patient can become preoccupied with irrelevant numbers and waveforms instead of focusing their attention on the patient. Removing monitors also eliminates the alarms that will sound as patients die. Intensive nursing care supplemented by physical examination of the patient for blood pressure, pulse, and respiratory rate is sufficient to identify manifestations of suffering, and to determine when death occurs. We feel that removing patients from electronic monitoring is an essential step in the transition from curative to comfort care. Unfortunately, it is extremely difficult for clinicians to give up this technologic tether, precisely because this step symbolizes the break from the physiologic monitoring that identifies the intensive care unit.
- Remove all tubes, lines, and drains if this can be done without significant discomfort. Catheters whose removal would lead to painful obstruction, for example, Foley catheters or biliary drains, may be left in place. Intravenous access should be maintained to administer analgesic medication. Remove unused intravenous pumps, resuscitation carts, and other mobile technology from the room.
Liberalize visitation to the extent that it does not interfere with the delivery of care to other patients. Children should be allowed to visit if their parents approve.

Do not obtain further laboratory or imaging studies.

**Sedation and analgesia**

Before performing uncomfortable procedures, clinicians provide patients with adequate medication to prevent anxiety and suffering. Critically ill, hemodynamically unstable patients may not receive optimal sedation when drug-related hypotension or respiratory suppression compromises the goals of maintaining life or liberation from mechanical ventilation. However, when the goal of care is changed to assuring patient comfort, any dosage of medication that is required to meet this goal is justified, even if it hastens death. The sole purpose of administering sedatives to dying patients is to relieve symptoms associated with this process. Although rare in the modern ICU, patients capable of communicating their wishes during the withdrawal of life-sustaining treatments should determine how much sedation they receive. Before patients are removed from life support, they should be completely comfortable, as judged by the cessation of tachypnea, grimacing, agitated behavior, and autonomic hyperactivity. This is accomplished by titrating medication until objective signs of discomfort have been eliminated. In many cases this will require medication sufficient to induce unconsciousness. Doses should not be increased in the absence of demonstrable signs of discomfort or for behavior that cannot plausibly be interpreted as distress. Distinguishing signs of true discomfort from autonomic responses that are purely physiologic is challenging [23]. When these goals are achieved, further increases in sedation are unnecessary and ethically problematic.

Although variations in clinical practice are expected, some regimens are unacceptable. Large boluses of medication similar to those used for the induction of general anesthesia are excessive unless smaller doses have failed to provide adequate sedation. There is an important ethical difference between escalating sedative doses to achieve rapid relief of symptoms and administering a large initial bolus intended to induce apnea or hypotension. There is no role for paralytic agents in the withdrawal of life-sustaining treatments. In fact, these drugs are contraindicated because they will hide manifestations of discomfort like grimacing and tachypnea.

Given the variability in individual responses and drug tolerance, it is impossible to outline a single pharmacologic regimen to apply in every case. Current guidelines on the management of pain and anxiety in critical care recommend a combination of morphine or similar narcotic with a benzodiazepine [24]. These medications, dosed appropriately, will provide adequate analgesia and sedation in virtually all cases when life support is withdrawn. The individual clinician’s experience or the failure of the opiate/benzodiazepine combination may justify the use of barbiturates, haloperidol, or propofol [25].
We suggest the following guidelines for therapy:

- Specific doses of medication are less important goals than titration to achieve the desired effect. In patients with painful surgical wounds, high ventilatory drives, or prior exposure to narcotics, large doses of narcotics may be necessary to relieve discomfort. Perhaps the most important concept is that no ceiling should be placed on dosage if the goal of relieving patient distress has not been achieved. There is no substitute for close bedside evaluation in assessing the efficacy of the sedative medication.

- Because of its flexibility and reliability, continuous infusion is the route of choice for drug delivery. Increases in dosage should be preceded by a bolus so that steady-state levels are achieved rapidly.

- Critical care nurses, who have extensive experience in evaluating suffering in patients who cannot communicate, should be afforded wide latitude in drug dosing, with clear indications for changing the dose. For example, the order might read: “Titrate morphine drip to keep respiratory rate < 30, heart rate < 100, and eliminate grimacing and agitation.”

- It is essential that nurses be trained to document the objective rationale for escalating doses of palliative medication. For example, charting Morphine drip increased to 15 mg/hr after 15 mg iv bolus administered for grimacing and agitation is preferable to simply documenting the dose increase. This allows chart auditing for quality of care, and provides a factual response in the unlikely event that the nurse is accused of overdosing medication at the end of life.

A plan for withdrawal

Before physicians perform procedures like intubation or central venous catheterization, they have a clear plan of action as well as contingency plans for complications. A similar plan should be developed for withdrawing mechanical ventilation. Physicians need to consider which life support measures will be discontinued, in what order, and by whom.

Once a decision has been made to orient the patient’s care to comfort, the only criterion to use to judge whether a treatment should be initiated, withheld, or withdrawn is whether it contributes to the patient’s comfort. All treatments can be withdrawn including vasopressors, drugs, antibiotics, blood transfusions, and nutritional support. Many health care workers feel more comfortable withholding treatments rather than withdrawing them after they have been initiated [26]. Unfortunately, this leads many clinicians to a strategy that withdraws life support in a series of steps over several days [14]. The decision to provide “partial” life support, that is, to provide some forms of life-sustaining treatments while withholding or withdrawing others, should be carefully scrutinized. In some cases, these decisions are justifiable. Rarely, patients may have strong reservations about specific medical treatments based on personal experience with the
treatment, strongly held religious beliefs, or an assessment of the treatment’s burdens and benefits. However, the decision to provide “stuttering withholding and withdrawal,” for example, orders such as “no second vasopressors drug” or “no further increases in PEEP,” is likely to reflect clinicians’ values rather than patients’ or surrogates’ [27,28]. Rarely, such measures are indicated as negotiating techniques with family members or to fulfill specific goals such as trying to sustain life until a relative can arrive while still minimizing burdensome treatments. Clinicians may engage in this stepped withdrawal because a gradual series of steps minimizes the psychologic linkage between their actions and the patient’s death [29]. Although potentially psychologically reassuring, a gradual approach to withdrawing life-sustaining treatments over several days is not ethically or legally necessary, and runs the risk of exposing the patient to pain and suffering without a significant chance of benefit and prolongs the grief experience for the family. Generally, circumstances that justify withholding one indicated life-sustaining treatment also justify the withdrawal of current life-sustaining treatments [30]. When partial treatment strategies are entertained, clinicians should be clear about the goals of care and the rationale for their decision and to ensure that this rationale is based on a specific family request rather than their own discomfort with withdrawal of a particular life-sustaining treatment.

**Withdrawing life-sustaining treatments**

The time course over which a life-sustaining treatment should be withdrawn is determined by the potential for discomfort as the life-sustaining treatment is stopped. The only rationale for weaning or slowly tapering any life-sustaining treatment is to allow time to meet the patient’s needs for pain relief. Mechanical ventilation is one of the few life-support devices whose abrupt termination is likely to lead to profound discomfort due to dyspnea, and therefore deserves specific attention to the time course of its withdrawal. There is little justification for “weaning” other interventions. After adequate sedation has been achieved, vasopressors, pacemakers, intraaortic balloon pumps, and other therapy not oriented toward meeting the comfort goals of care should be turned off. Tapering these treatments serves no role other than delaying death and prolonging the patient’s potential discomfort. Because the withdrawal of mechanical ventilation poses the greatest problems with insuring comfort, all other life-support devices should be withdrawn before the ventilator. Patients requiring high levels of hemodynamic support may sustain a rapid cardiac death just by withdrawing hemodynamic support before any attention can be devoted to withdrawing the ventilator. Physically turning these devices off can be an emotional task, and the attending physician should be prepared to perform this task or be present when it occurs. Physicians-in-training do not perform other medical procedures independently before demonstrating their competence in a supervised setting, and the same rules should apply to the withdrawal of life support.
Withdrawning mechanical ventilation

Unless the patient specifically requests otherwise, sedation and analgesia sufficient to prevent grimacing or response to painful stimuli should be provided before withdrawing mechanical ventilatory support. When adequate sedation is achieved we reduce the inspired oxygen concentration to 0.21, remove positive end-expiratory pressure, and set the ventilator at an intermittent mandatory ventilation (IMV) rate equal to the spontaneous respiratory rate or a level of pressure support (PS) sufficient to fully meet ventilatory requirements. These ventilator settings give the patient a fully supported ventilator breath with every inspiratory attempt, and allow clinicians time to modify the sedation before completely removing ventilator assistance. Air hunger, as manifested by tachypnea or agitation, should be treated with a bolus of the chosen medication followed by an increase in the continuous infusion. After the patient is comfortable, ventilatory support is weaned rapidly in either IMV or PS mode until the patient is comfortable with an IMV rate of zero or a PS of zero cm H₂O at which point the patient can be placed on a T-piece on humidified air. Unless extraordinary levels of dyspnea are encountered or in the unusual case of an awake patient where clinicians are trying to withdraw ventilatory support and maintain some level of consciousness, there is no reason for the transition from full ventilatory support to T-piece or extubation to take more than 15 to 30 minutes. Families may wish to be present for this process or not—if they choose to attend, they should be prepared for the possibility of some transient increases in agitation or respiratory rate as sedation is being titrated. It is extremely important to disable ventilator alarms during this period, as patients’ terminal hypoventilation may trigger them. Some ventilator’s alarms cannot be disabled, and this should direct clinicians to use a T-piece or to extubate rather than to leave the patient attached to the ventilator. An experienced physician should attend this early phase of withdrawal from the bedside to reassure the patient and family and observe for complications like intractable discomfort that would require immediate intervention.

There are no specific data to guide the decision about managing the endotracheal tube after withdrawal of mechanical ventilation. It may be appropriate to extubate the patient, particularly when the patient may be able to communicate or when prolonged survival off of life support is possible. Some families or providers may feel strongly about whether to remove the endotracheal tube. These wishes should be respected. If the endotracheal tube is removed, specific plans should be formulated to anticipate secretion problems and agonal airway obstruction, and the family should be prepared for these possibilities. If other aspects of the withdrawal of life-sustaining treatments are managed well including communication with the family and adequate sedation, the decision to remove or leave the endotracheal tube may not be of paramount importance.

The time course leading to death will vary according to the clinical situation, and cannot be predicted accurately in every case [31]. However, caregivers should inform the patient and family of the probable course of events once life support is withdrawn. The critically ill patient on several vasopressor agents who
is pacemaker-dependent will survive for only a few minutes when these are discontinued. A neurologically devastated teenager with a closed-head injury whose only life support is an endotracheal tube, antibiotics, and enteral nutrition will have a more prolonged course. Plans should be made for alternative care sites if death is delayed. When patients are transferred out of the ICU, the ICU team should communicate the goals and plan communicated to the new team and introduce the new team to the patient and family, so that continuity of care is maintained.

**Pastoral, nursing, and emotional support**

Before interventions are withdrawn, the family should be asked if a priest, pastor, rabbi, or other religious advisor should be called. Caring for patients after life-sustaining technology is withdrawn can require the same level of vigilance and time that aggressive life support requires. Nursing attention should be directed to hygiene, skin care, interacting with family members, and maintaining a quiet environment within the busy ICU. Treatments that may alleviate or prevent uncomfortable complications should be instituted or continued. For example, cooling blankets, antipyretics, and anticonvulsants fulfill the goals of patient comfort and usually should be continued. Suggestions and feedback from the family members should be regularly solicited. Members of the health care team should ask the family in an open-ended manner how they feel things are going, and whether they have any questions or suggestions for supportive care. Our approach is to invite the family to play an active role in the care, without making them feel responsible for how interventions are withdrawn.

Just as potential medical complications should be anticipated, the health care team needs to plan how to respond to the family’s emotional reactions and needs. Family members, as well as some members of the health care team, often believe that they are causing the patient’s death by withdrawing interventions. The physician should address these issues directly: “Many family members ask themselves whether they are causing the patient’s death by agreeing to withdraw the ventilator. Do you feel that way?” Generally, people feel more comfortable with withdrawing interventions after these feelings are acknowledged, legitimized as common reactions, and discussed openly. Until these issues are addressed on an emotional level, it is unproductive to discuss the lack of philosophic and legal distinctions between withdrawing and withholding interventions.

If the patient survives longer than expected, family members and health care workers may feel impatient, frustrated, or angry. Again, the best course is to address the issue directly. A simple comment may broach the topic: “It’s hard to have to wait like this, isn’t it?” Our approach emphasizes that the exact time of death is out of the hands of the physicians and nurses. Some health care workers may feel comfortable saying, “It is now in God’s hands.” Death is traditionally marked by ceremonies and rituals that extend support and sympathy to the survivors. Health care workers can ask open ended questions such as, “Tell me
about his life as a young man.” After the patient dies, the attending physician can observe a moment of silence, say a few words of remembrance, and console the family. Empathetic comments such as “It must be hard to accept”; “This must be very painful for you”; and questions such as “How can I be of help” are better received than identification with the family, such as “I know how you feel” or reassurance, such as “Time makes it easier”; or “God had a purpose.” Physicians and nurses need not hide tears they shed. Physical acts of sympathy, from a handshake to a hug, are appropriate; but will vary with the cultural and personal backgrounds of the health care workers and families.

Documentation

Progress notes in the medical record should document the meetings leading up to the decision to withdraw support, the specific plans for withdrawal, and the pharmacologic plan for sedation. This is particularly important because nurses or covering physicians who implement the plan may not have been involved in the original decision or discussions. Although meetings with surrogates need not address specific decisions regarding every piece of life-support technology, communication with other health care providers must be detailed. This is particularly important when clinicians choose to withhold some life-sustaining treatments while continuing others. In these cases, the rationale, proscribed treatments, and plan should be clearly documented in the progress notes and orders.

Specific orders for withdrawing interventions and for sedation should be written in the medical record (Fig. 1). Orders that simply say “no heroic measures” or “comfort care only” can be confusing to a covering physician who must make decisions about antibiotics or blood transfusions. Institutions should develop guidelines, pathways, preprinted orders, and nursing and respiratory care documentation standards for the withdrawal of life support, as they currently do for other common clinical situations. At Harborview Medical Center we developed an order form for withdrawal of life-sustaining treatments (shown in Fig. 1). This order form underwent a “before–after” evaluation as part of a continuous quality improvement project, and its implementation was found to be associated with high levels of physician and nurse satisfaction [32] In addition, implementation of this order form was associated with increased use of narcotics and benzodiazepines during the process of withdrawing life support, but was not associated with any change in the time for ventilator withdrawal to death, suggesting that medications were used to increase patient comfort without hastening death.

Evaluation

Quality improvement procedures are important for evaluating the withdrawal of life support and the process of dying, just as they are for other hospital
procedures. Members of the hospital critical care committee should review the circumstances of these deaths to evaluate the care. Those involved in the withdrawal of care, including family members, should have the opportunity to evaluate the quality of dying and suggest improvements for the future. These suggestions should be incorporated into the processes in this document and made a part of the local ICU guidelines.

**Special cases**

*Noninvasive mechanical ventilation*

The increasing availability of noninvasive mechanical ventilation provides another option for managing ventilatory support. At least some patients with respiratory failure who were expected to die without intubation and mechanical ventilation can be managed with noninvasive mechanical ventilation [33]. To determine whether this is appropriate, it is essential that clinicians clarify what a patient is refusing when they request not to be “intubated.” Clinicians should view noninvasive mechanical ventilation in these cases as either (1) a form of life-sustaining mechanical ventilation that does not use an endotracheal tube for patients who are specifically refusing intubation but not mechanical ventilation, or (2) a palliative modality where the goal is relief of discomfort. If a patient is specifically refusing an endotracheal tube because of the lack of ability to communicate with family or concerns over discomfort, then noninvasive mechanical ventilation may be an option. In this situation, clinicians would offer all other forms of life-sustaining treatment except an endotracheal tube. In these cases, if the patient’s condition worsens and a trial of noninvasive mechanical ventilation fails, the goals of care would shift to palliation. Noninvasive mechanical ventilation in the patient who refuses ventilatory support because they no longer wish the burdens of aggressive life-sustaining treatment is purely palliative. The sole rationale for using noninvasive mechanical ventilation in these cases is that it objectively improves the patient’s symptoms. Although improvements in gas exchange and other physiologic measures are reassuring for intensivists, the primary goal of palliative noninvasive mechanical ventilation in the patient who has refused life-sustaining treatment is palliation of symptoms. Under these circumstances, if the patient does not receive symptomatic benefit from noninvasive ventilation, it should be stopped.

Although we use the term “noninvasive” to describe mechanical ventilation provided by mask, it is somewhat of a misnomer when applied to option (1) above. Remember that most of these patients will be managed in an ICU, require arterial blood gas and other blood draws, and may receive less than optimal sedation or require restraints to guarantee a more secure airway. Therefore, it is essential, particularly when using noninvasive mechanical ventilation, that the goals and limits of care be established.
Withdrawal of mechanical ventilation with potential survival

Some patients and families, particularly in cases of severe pulmonary or neuromuscular disease, request that ventilatory support be withdrawn when survival off the ventilator is unlikely but possible. Such requests pose a dilemma for clinicians because the goals of care are mixed. It is difficult to provide palliative sedation and simultaneously maximize respiratory function to provide the best chance at survival without a ventilator. In cases when survival is possible and families hope to maximize this goal, sedation should be held to a minimum, respiratory function optimized with bronchodilator therapy, antibiotics, diuresis, and pulmonary toilet; and the patient should be extubated to supplemental oxygen. If it is consistent with the patient’s goals, noninvasive ventilatory support can be used as a bridge to unassisted breathing. Before and just after extubation the medical team and patient must formulate specific plans regarding recurrent respiratory failure. Clinicians have two options in this situation: to reinitiate mechanical ventilation (either using an endotracheal tube or mask) or to initiate aggressive symptom management of dyspnea without ventilatory support. Waiting until the patient develops respiratory failure to formulate a plan leads to chaotic decision making in the middle of the night with an acutely ill and dyspneic patient. If the patient and family choose not to reinitiate mechanical ventilation, then sedation and other treatment as outlined elsewhere in this document are begun, acknowledging that the goal of unassisted breathing is no longer attainable. Clinicians may be tempted to “make sure” the patient still refuses intubation at the time of respiratory compromise, however, intubation need not be specifically offered if the patient has already participated in a decision to withhold it.

Despite clinicians’ best efforts to clarify the choices and formulate a prospective plan for patients who develop respiratory failure after extubation, some patients or their families who initially refuse reintubation change their minds. These situations can be harrowing for providers because of the urgency of the decision to choose between reintubation and palliative sedation; and the difficulty in ascertaining which request represents the patient’s true wishes. Because mechanical ventilation can be ethically, legally, and humanely withdrawn later, an informed request by the patient for intubation should be fulfilled even when it violates prior requests. Complex and subtle discussions regarding end-of-life treatment choices should never occur at the bedside of a dyspneic acutely ill patient in imminent danger of cardiopulmonary arrest.

Survival despite withdrawal of life-sustaining treatment

Patients who survive the withdrawal of life-sustaining treatments present clinicians with several dilemmas. Families and clinicians can become frustrated and hope for some means to expedite death. These requests should be dealt with honestly and compassionately. Although the evidence suggests that measures are taken to hasten death in the ICU, treatments solely intended to hasten death or increases in sedation that are not necessary to relieve discomfort are not justified.
under current ethical and legal consensus [12]. Families should be reassured that their loved one is comfortable, and that the timing of death is out of the control of the clinical team. It is appropriate to transfer these patients out of the ICU to an area in the hospital with more privacy as long as the family has been prepared for the move. Prolonged survival may cause those involved to question their decision to withdraw life-sustaining treatments. The available data suggest that prolonged survival after a decision to withdraw life support is uncommon [34]. However, these cases are particularly difficult for clinicians who must approach family members recently resigned to the death of a loved one and discuss a change in plans. Because so little is known about the timing of death after withdrawal of life support, clinicians should be wary of revising their plans and prognosis based on a perceived delay in the expected timing of death. These changes in plans can have a devastating effect on loved ones and staff.

**Coma and brain death**

Many of the patients from whom life-sustaining treatments are withdrawn have neurologic impairment [2]. In these cases, the decision to use sedation during withdrawal of life support is complicated by concerns that unconscious patients, by definition, cannot perceive pain and therefore may not require sedation or analgesia. Patients with diminished levels of consciousness also may not be able to manifest signs of discomfort. Studies indicate that physicians do use sedation when withdrawing life support from patients with catastrophic neurologic injury [35]. The problem is that we have no gold standard test for perception of pain. Although facial electromyography and augmented electroencephalographic techniques may be helpful in determining level of arousal, they have not been validated in this setting. Given the inherent uncertainty in assessing suffering in neurologically impaired patients, we believe that clinicians should err on the side of administering some sedation rather than withholding it completely. One approach to care for comatose patients is to select the average adult dosage of medication used in a large series of patients receiving withdrawal of life support (diazepam 10 mg/h and morphine sulfate 10 mg/h) that is not adjusted unless objective signs of breakthrough suffering are detected [34]. If patients had been placed on sedatives earlier in the course of their critical illness and show no signs of discomfort, we would not reduce this level of sedation for the purposes of withdrawing life support. Obviously, if patients show signs of clinical distress during the withdrawal of life support, then this dose should be increased. We acknowledge the possibility that this approach may lead to undetected discomfort in some comatose patients while others may have their death hastened by the sedation without any benefit. Brain-dead patients do not need sedation during the withdrawal of life support.

**Pharmacologic paralysis**

Managing pharmacologic paralysis during the withdrawal of mechanical ventilation presents unique challenges [36,37]. Agents like pancuronium and
vecuronium are used in critically ill patients to improve ventilator synchrony and reduce oxygen consumption. However, they serve no purpose in fulfilling the comfort goals during the withdrawal of life support. Although the argument has been made that paralytic drugs ease the family’s distress by making the dying patient appear comfortable, they actually prevent clinicians from adequately assessing patients’ discomfort, and therefore may contribute to the patient’s suffering. Paralytic drugs are also problematic because they may hasten death by preventing respiration without offering any beneficial effects to the patient.

The primary concern about withdrawing ventilation in the face of pharmacologic paralysis is its masking effect on patient discomfort. For this reason, paralytic drugs should be stopped as soon as the withdrawal of life-sustaining treatments is considered. Some clinicians may choose to try to reverse pharmacologic paralysis in an effort to restore some of the patient’s ability to manifest discomfort to help guide sedation requirements. Unfortunately, after an extended course of these drugs, some critically ill patients will not regain normal neuromuscular function for days or weeks [38]. Some physicians may regard withdrawing mechanical ventilation in a partially paralyzed patient as euthanasia, and wish to delay until neuromuscular function returns to normal. We do not feel that this delay is justified. Neuromuscular weakness after pharmacologic paralysis initiated to treat critical illness is a complication of treatment of the patient’s illness. Withdrawing life support in the face of treatment complications is justified because the complications, even if iatrogenic, are part of the patient’s illness, may not resolve, and continued therapy of the complication imposes an unwanted burden on the patient. Patients who are receiving pharmacologic paralysis should have it stopped before the withdrawal of life-sustaining treatments. Clinicians should wait for the return of sufficient neuromuscular function to detect spontaneous movements and attempts at respiration so that sedation needs can be monitored. Therefore, physicians should stop neuromuscular blocking drugs as soon as the withdrawal of life support is anticipated, but need not wait for the effects of these drugs to disappear completely before withdrawing life-sustaining treatments. Obviously, caregivers should be aware, as they are in all patients who have received pharmacologic paralysis, that physical manifestations of discomfort may be blunted by muscle weakness.

**Summary**

The clinician’s responsibility to the patient does not end with a decision to limit medical treatment, but continues through the dying process. Every effort should be made to ensure that withdrawing life support occurs with the same quality and attention to detail as is routinely provided when life support is initiated. Approaching the withdrawal of life support as a medical procedure provides clinicians with a recognizable framework for their actions. Key steps in this process are identifying and communicating explicit shared goals for the process, approaching withdrawal of life-sustaining treatments as a medical procedure, and
preparing protocols and materials to assure consistent care. Our hope is that adopting a more formal approach to this common procedure will improve the care of patients dying in intensive care units.

References


