OBJECTIVES

- Review medical interventions available for EOL symptoms experienced after discontinuing ventilators
- Understand options to improve family care and participation
- Understand options for improving the hospital environment
- Discuss the importance of educating hospital administration and staff in best EOL practices

INTRODUCTION

- "To cure sometimes, to relieve often, to comfort always."
  - Edward Livingston Trudeau (5 October 1848 – 15 November 1915) was an American physician who established the Adirondack Cottage Sanitarium at Saranac Lake for treatment of tuberculosis. Dr. Trudeau also established the Saranac Laboratory for the Study of Tuberculosis, the first laboratory in the United States dedicated for the study of tuberculosis.
- There is always something that we can do.
- If we define death as failure, we will always fail.
ETHICS

- Withholding and withdrawing life support are equivalent;
- There is an important distinction between killing and allowing to die;
- The doctrine of “double effect” provides an ethical rationale for providing relief of pain and other symptoms with sedatives even when this may have the foreseen (but not intended) consequence of hastening death.


BARRIERS

- Common Ethical Misconceptions
  - Withdrawal of ventilatory support is a form of patient abandonment
  - Forgoing ventilatory support violates the principle of beneficence
  - There is a difference between withholding and withdrawing ventilatory support
  - It is unethical to administer sedatives and analgesics to dying patients if doing so may hasten death

Douglas B White, MD, MHS. Withholding and withdrawing ventilatory support in adults in the intensive care unit. UpToDate.

BARRIERS

- 46% of families perceived conflict during their family member’s ICU stay;
- Most conflicts were between families and the medical staff
- Involved communication or perceived unprofessional behavior (such as disregarding the primary caregiver in treatment discussions).
- 62% of family members previously had spoken with the patient about their end-of-life treatment preferences, which helped to lessen the burden of the treatment decision.

BARRIERS

- Not all hospitals have an established culture on allowing a natural death and the use of opioids/sedatives for terminal symptoms
- Some hospitals may have paperwork that does not communicate to the patient/family that allowing a natural death is a reasonable, normal, and physician recommended treatment option
- Hospital staff often lack education and experience with the medications and techniques that are the standard of care for treating end of life symptoms

HOSPITAL POLICY

- Code status policies
- Do-not-escalate treatment orders
- Visitation policy (children, pets, time, accommodations for overnight visitation)
- Specialty units/rooms with experienced staff
- Ventilators outside the ICU
- General inpatient hospice care in the hospital
- Opioid/sedative infusions outside of the ICU
- Palliative sedation policy

NURSING AND STAFF CONCERNS

- Nursing and respiratory therapist comfort with allowing a natural death and the medications used to treat terminal dyspnea
- Having staff comfortable with the process available to assist
- Having necessary medications available at the bedside
- Developing a training program to educate staff on protocols if they are discontinuing ventilator support without a physician/practitioner at the bedside
SETTING GOALS

- Start conversations early and revisit as the condition progresses
- Spikes protocol
- Surrogate decision makers
- Avoid asking “What do you want?” or offering non-beneficial treatments

WORDS MATTER

- Avoid saying:
  - “withdraw care”
  - “There is nothing left to do”
  - “I think it is time to stop aggressive care”
  - “Can asking you to agree to stop care”
  - “Do you still want us to do everything?”
- Avoid referring to end of life breathing pattern as “agonal respirations,” since this term may erroneously imply to the family that the patient is in “agony.”

FAMILY INVOLVEMENT

- Anticipate the families’ emotional reactions and needs.
- Families may believe they are causing the patient’s death by agreeing to withdraw life support.
- Feelings of guilt should be explored directly and discussed openly.
- Relatives may feel less burdened by guilt if physicians strongly recommend that life support be withdrawn rather than asking the family to make the decision.
- Focusing the family on what the patient would want rather than what the family wants may also reduce the family burden.
- Extubation before death was associated with higher family satisfaction with care (9).

FAMILY INVOLVEMENT

• Allow time for any rituals and for saying a final goodbye.
• Address particular needs of young children.
• Social worker, nurse, or chaplain may stay with the family by the bedside or in the waiting room.
• Check family perception of the level of patient comfort, and address appropriately.
• Incorporate their wishes about sedation and analgesia.

J. Andrew Billings, M.D., Massachusetts General Hospital, Medical ICU Project/Ventilator Withdrawal Guidelines

SETTING

• Remove unnecessary equipment, creating bedside space for the family.
• Provide tissues and comfortable chairs.
• Remove mitts and Poseys, lower bedrails, and set bed height to facilitate family-patient touching or handholding.
• Discontinue monitors and alarms in the room, including but not limited to: oximeters, vital sign monitors and/or alarms (may recommend but some families may not agree), ECG recording, unneeded pumps, and respirator alarms.

PREPARATION

• Update the code status per hospital policy.
• Document medical decision making in the chart.
• Ensure that anesthetics and sedatives are at the bedside.
• Discontinue interventions that do not provide comfort.
• Monitor vital signs, disease directed medications, neuromuscular blocking agents, lab tests, x-rays.
• Have medications at bedside to treat symptoms.
• Have extra towels to manage secretions, position the patient’s head, manage bleeding.
PREPARATION

- Prepare family by describing the processes, explaining the purpose of each step, and offer to answer any questions they may have.
- Counsel the family as to the patient’s life expectancy using time ranges and make them aware that the patient may live hours or days and sometimes many weeks (based on risk factors and clinical judgement) and explain the plans for how and where the patient will be cared for during this time.

PATIENT ASSESSMENT

- Determine if premedication is necessary
  - If distress is anticipated based on the patient’s current condition and sedation/pain requirements while on the ventilator, then continue existing benzodiazepine sedation and/or pre-medicate with opioids and benzodiazepines
  - Consult with ICU staff about results of weaning trials
  - If patient had been experiencing discomfort with suctioning, repositioning, or reduction in ventilatory support, then they may experience distress with withdrawal of ventilatory support.

MEDICATIONS

- Anticipatory dosing of opiates and sedatives immediately prior to extubation should be implemented.
  - Properly dosed medications do not hasten death (5)
- Typical opioids used will be morphine, fentanyl, or hydromorphone
  - Morphine dosed usually 2-10mg IV/1h or 10mg IV/4h; hydromorphone 0.5 to 2mg IV
  - In renal failure, morphine and to a lesser degree hydromorphone may cause neurotoxicity manifesting as myoclonus then seizures when frequent dosing is required
  - Effective to reduce cough

MEDICATIONS

- Adjustments to infusion rates take hours to become effective. Boluses are still required to treat symptoms.
- Opioid doses are patient dependent so tolerate patients may require higher doses while frail patients may do well with lower doses.
- Frequent dosing and titration is best.
- Avoid treating the breathing patterns typical of a dying patient as dyspnea (“agonal” respirations are not dyspnea and not usually thought to be a sign of patient distress but this is open to debate).

MEDICATIONS

- Fentanyl infusion: Continue at current rate (assuming patient is comfortable) then bolus with ¼-½ the hourly dosage and increase infusion rate by 25% OR begin with a bolus of 25-100 mcg/hr and start the infusion at 25-100 mcg/hr. For signs of discomfort after the bolus, give an additional bolus of up to 50% of the hourly infusion rate every 3-5 minutes and titrate the infusion q10 minutes in increments of 25-50%.
- Morphine infusion: Continue at current rate (assuming patient is comfortable), then bolus with current hourly infusion dose and increase rate by 25% OR begin with a 10 mg IV bolus and begin infusion at 5-7 mg/hr. For signs of discomfort, give a bolus equal to the hourly infusion dose and increase the infusion rate by 25-50%. Repeat upward titration every 10 minutes, as needed.

Benzodiazepines are effective in reducing anxiety and also offer anticonvulsant effects that may protect from hypoxemia-related seizures.
- Benzodiazepines do not hasten death when used appropriately.

J. Andrew Billings, M.D. Massachusetts General Hospital Medical ICU Project/Ventilator Withdrawal Guidelines

DISCONTINUING THE VENTILATOR

- There are generally two approaches:
  1. Gradual wean over 10-30 min. 
     - If distress occurs, settings are increased to last comfortable level and medications are given and wean resumed once meds effective.
     - Once patient is at low settings or optimal comfort attained the ET tube is then usually removed (some patients may benefit from leaving the ET tube in place with a ventilator attached).
  2. Immediate removal of the ET tube and ventilator with premedication given prior and additional medications immediately available to treat increased distress.

DISCONTINUING THE VENTILATOR

- At this point, the patient is likely on an infusion of an opioid and may have received additional premedication or boluses.
- Some patients may develop an upper airway obstruction after the ET tube is removed.
  - The jaw thrust maneuver can offer temporary relief until medications are effective.
  - A nasal trumpet can be used temporarily in extreme cases where medications fail to resolve distress but consider as last resort.

DISCONTINUING THE ET TUBE

- Airway can be suctioned prior to removing ET tube once wean is complete and premedication is effective.
- If NG/OG tube is also to be removed, feedings should be stopped, if high residuals consider suctioning stomach contents to prevent emesis.
- Have a towel over the patient’s chest ready to wrap the ET tube and other removed tubes in (have extra towels available).
- Shut off the ventilator. Deflate the ET tube cuff, and remove the ET tube and all other tubes.
TRACHEOSTOMIES

• The ventilator is stopped and tubing disconnected from the tracheostomy and humidified air or oxygen (FiO2 29% = 2l) is connected via a T-piece.

POST-EXTUBATION CARE

• Continue to monitor patient for signs of discomfort
• Average life expectancy post extubation was 0.9 hours (0.25 – 5.5 hours) in one study (10)
• Many different factors influence life expectancy (opioids/benzodiazepines may prolong life slightly). Use clinical judgement to guide family expectation and in planning for transfer out of ICU if appropriate.


POST-EXTUBATION CARE

• Possible signs of dyspnea in an unresponsive patient:
  • Tachypnea
  • Tachycardia
  • Grasping
  • Diaphragmatic or paradoxical breathing
  • Use of accessory muscles
  • Nasal flaring

POST-EXTUBATION CARE

- Supplemental oxygen should not be routinely used
  - For hypoxemic conscious patients, oxygen may relieve dyspnea
  - For unresponsive and otherwise comfortable patients, oxygen may prolong the dying process artificially with no improvement of symptoms. Hypoxemia is inevitable in the dying patient.
  - Be sure to discontinue any oxygen/respiratory protocols that would prompt pulse oximetry and/or titration of FiO2.
  - Fans at the bedside may offer similar relief.

AIRWAY SECRETIONS

- Discontinuing non-essential IV fluids or enteral feedings combined with positioning the patient on their side helps move the secretions out of the airway.
- Poor evidence to support the use of medications to manage “death rattle.” Atropine no better than placebo. Glycopyrrolate (0.2mg IV/SQ q4-6 h) is preferred. Scopolamine patch is also an option. Again poor evidence to support routine use.
- Good mouth care is very helpful
- Gentle suctioning can also be considered
- Excess secretions tend to be more distressing to caregivers and family members than to the patient themselves. Counsel family members and staff about the unlikelihood that the patient is experiencing discomfort from excessive secretions and about the lack of benefits and potential harm of treatment.

ARTIFICIAL NUTRITION/HYDRATION

- Some patients may survive for many days or weeks while requiring ongoing pain and symptom management.
- This possibility should be discussed prior to discontinuing the ventilator and plans made in advance regarding nutrition/hydration
- Natural and nutrition/hydration should be offered depending on the patient’s desire and ability to tolerate
- Artificial means may prolong the dying process and increase pain and symptoms
- These decisions should be tailored to the patient’s wishes
SEIZURES

- Not common but be prepared with lorazepam/other benzo
- If on morphine/hydromorphone infusion consider neurotoxicity as renal failure is also a natural part of the dying process
- Consider continuing anti-seizure medications if they had been required prior to extubation

PALLIATIVE SEDATION

- Using sedation to relieve a patient’s uncontrollable physical symptoms typically at the EOL
- Benzodiazepines, barbiturates, and anesthetics are typically used
- Physicians need to have conversations with patients and families about the purpose of alleviating symptoms
- PS versus euthanasia
  - Relieving a patient’s physical symptoms at the EOL vs. intentionally ending a patient’s life to relieve a patient’s physical symptoms
  - Not hastening death vs. hastening death

EMERGENCY SEDATION

- Refers to the use of sedation to provide urgent relief of overwhelming symptoms in dying patients
- Emergency situations may include
  - Massive hemorrhage
  - Asphyxiation
  - Severe terminal dyspnea
  - Overwhelming pain crisis
- If a catastrophic situation is anticipated, advance care directives should be discussed with the patient, family members, and health care providers.

Douglas B White, MD. Withholding and withdrawing ventilatory support in adults in the intensive care unit. UpToDate
AFTER DEATH

- Allow family and staff to be with patient.
- Allow family to help with postmortem care, if they choose to.
- Assess family member's state of grief and ability to travel.
- Assist with decisions, if relevant, about tissue, organ, or body donation, autopsy, rituals.
- Notify involved staff and allow time for health care team to debrief.

J. Andrew Billings, M.D.
Massachusetts General Hospital, Medical ICU Project: Ventilator Withdrawal Guidelines

Check out ZDoggMD's Ain't the Way to Die
https://www.youtube.com/watch?v=NAInRHiqgWs
REFERENCES

2. J. Andrew Billings, M.D. Massachusetts General Hospital, Medical ICU Project. Ventilator Withdrawal Guidelines.

REFERENCES