# End of Life Care—Answering the Tough Questions

Clinical Perspectives for Respiratory Therapists and Nurses

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# Learning Objectives

- By the end of this session participants will be able to discuss the following:
  - Demonstrate key bioethical principles most relevant to end-of-life situations
  - Differentiate among various key terminology and legal documents related to end-of-life.
  - Attempt to answer key questions related to end of life, including:
    - Do Advance Directives need to be followed?
    - Can a patient/family demand treatment providers think is medically inappropriate or futile?
    - How & Why do We Perform an Apnea Test?
    - What is the role of life support alternatives & adjunctive therapies near end-of-life?
  - Identify at least three key elements of organ donation protocols for patients receiving respiratory support near the end-of life and advocate why they are important in care planning.
  - Demonstrate an understanding of the palliative extubation or terminal weaning process(s) including the major steps which should precede it.
  - Review and debrief cases related to end-of-life dilemmas and situations.
  - Provide additional resources for this wishing to learn more about this topic.

# Core Ethical Principles

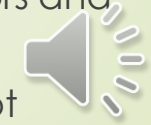
- ***Autonomy***: Respecting patient rights to make informed choices about their treatment, including the refusal of life support.
- ***Beneficence & Nonmaleficence***: Balancing benefit and harm when deciding whether to initiate, continue, or withdraw therapies including mechanical ventilation.
- ***Justice:*** Ensuring fair allocation of resources and equal treatment of patients in critical care settings.

# Palliative Care vs Hospice?

- ***Palliative Care*** targets patient comfort, and can begin at any stage of a serious illness and may be provided alongside curative treatments.
  - Goal: Improve quality of life by managing symptoms (pain, fatigue, anxiety, etc.) and providing emotional, social, and spiritual support
- ***Hospice Care*** is specifically for people nearing the end of life (usually with a prognosis of six months or less) and focuses entirely on comfort rather than cure.
  - Goal: Provide comfort and dignity at the end of life, focusing on symptom relief and emotional support rather than cure

# What are the Key Documents:

- ***Informed Consent***: A formal document which is signed by the patient or surrogate documenting an understanding of risks, benefits, and alternatives to medical interventions, including those which are life-sustaining such as mechanical ventilation.
- ***Advance Directives***: Signed by the patient or surrogate that documents and clarifies patient wishes regarding ventilation and resuscitation, if they become incompetent and unable to make the decision when that event occurs.
- ***Physician Order for Life Sustaining Treatment (POLST)***: A physician order, preceded by a discussion/dialogue with the patient or surrogate as to the patient's wishes regarding life sustaining interventions such as CPR and mechanical ventilation.
- ***Do Not Resuscitate (DNR) Order***: A physician order specific to a patient's wishes as to whether or not they wish to be resuscitated.
  - DNR-B: No CPR but active treatment with NIPPV, vasopressors and similar medical interventions.
  - DNR-A: No active treatment. Hydration and nutrition but not treatment interventions.



# Must Advance Directives (ADs) be Followed?

- In general, Yes…Provided the patient is incapacitated.
- If the patient is competent, then the AD is not effective.
- Advance directives (ADs) are witnessed statements about medical care preferences made by an adult patient of sound mind in advance of permanent loss of decision-making capacity.
  - As such, these documents legally control what should happen with end-of-life treatment when a person loses the capacity to make decisions
  - Surrogate or substitute decision maker should ensure that the patient's prior written wishes prevail
  - If the substitute decision maker feels unable to participate in decisions, or disagrees with the patient's prior decisions, then the only appropriate action is to withdraw from the substitute decision-maker role, in favor of a secondary decision maker

# Medical Power-of-Attorney (POA)

- A Medical Power of Attorney lets the patient assign a trusted person — called an "agent" or "surrogate" — to make medical decisions on the patient's behalf if they cannot communicate their wishes.
- Unlike a financial power of attorney, this type of POA does not give your agent access to your finances.
- A medical POA only takes effect if you become incapacitated.
- Some states require an advance directive combining the medical power of attorney with a living will.

# Who Decides—and in What Order?

- Who is the appropriate decision maker?
  - If a patient has decision-making capacity, then the patient decides.
  - A Recent Advance Directive should override POA/ Surrogate Wishes
  - If a patient has permanently lost decisional capacity and does not have an AD,  providers turn to an appropriate substitute decision maker
    - POA
    - Health care surrogate
    - Health care proxy

# Can a Family Demand Treatment if it seems futile?

- Consider the use of cardiopulmonary resuscitation (CPR) and advanced cardiovascular life support (ACLS) at the end of life
  - CPR is often not effective in the setting of terminal illness and may prolong suffering
  - CPR/ACLS is generally provided unless there is an order countermanding it; these orders are called Do-Not-Resuscitate (DNR) orders or Do-Not-Attempt-Resuscitation (DNAR) orders
  - What if the patient/family insists that CPR/resuscitation be performed against medical advice?
    - No consensus on the matter; many providers simply accede to the wishes of the patient/family.
- **Texas** is the only state that allows physicians to say no to patient/family demands for treatment the provider deems medically inappropriate

# Can a Patient Refuse Any Treatment?

- The answer is almost always "yes", if the patient is an adult with decisional capacity, who has made the decision after giving informed consent.
- The right to refuse unwanted medical treatment includes the right to refuse life-saving medical treatment
  - Includes antibiotics, transfusions, short-term mechanical ventilation, etc.
  - Many early court cases established the right of a competent patient to refuse unwanted treatment even if life-saving.
    - Legally, it doesn't matter if the treatment is refused in advance or refused after treatment has already been started
  - There are rare cases where courts have forced treatment on patients over their objections (e.g., in forced c-section cases)
- The exception is if they may be a harm to others (TB or Tx for Severe Psych Disorders)

# Is tube feeding medical treatment or basic care?

- Is nutrition and hydration provided via a medical tube (artificial nutrition and hydration, aka ANH) a form of medical treatment, or are nutrition and hydration basic needs that must be provided by any means possible, including medical feeding tubes?
- The courts in the US that dealt with this issue, including the US Supreme Court,  have consistently ruled that ANH is a medical treatment and as such, it can be refused even though the envisioned outcome might include the death of the patient.

# What are Life Support Alternatives & Adjunctive Therapies?

- Many patients with end-stage respiratory disease may have a POLST or advance directive which precludes intubation and mechanical ventilation, but which may permit other interventions such low-flow oxygen therapy, high-flow nasal cannula (HFNC) and non-invasive positive pressure ventilation (NIPPV).
- The goals of care, determined by the patient and/or family, with guidance from the physician and palliative care team, should dictate whether and which such interventions should be employed.
- As such, it may be agreed upon that temporary use of HFNC or NIPPV is appropriate as a short-term measure, especially if awaiting for family and friends to arrive from afar or to facilitate transporting the patient home or to a hospice care facility.
- However, those therapies, especially NIPPV can detract from a patient's comfort and may be countermanding to the hospice philosophy. So, any respiratory inventions near end-of-life should be initiated, continued and discontinued with this in mind.

# What's an Apnea Test?

- Where brain death is suspected on a mechanically ventilated patient, an apnea test may be ordered.
- The rationale behind the test is to determine if the breathing centers of the brain (pons & medulla oblongata) respond to increasing PCO2 levels by signaling the patient to breathe.
- Steps:
  - First normalizing PCO2 levels, body temperature and hemodynamics (if possible),
  - Then removing the patient from ventilatory support while leaving the ET tube in place and insufflating 100% oxygen through it.
  - If the patient resumes breathing, the patient should be placed back on full ventilatory support and the test is classified as a "negative apnea test". In other words, they are not apneic in the face of rising PCO2 levels.
  - However, if the patient remains apneic for 8-10 minutes and an ABG reveals that PCO2 levels rise by 20 torr or equal or greater than 60 torr, it is classified as a "positive apnea test" helping confirm a diagnosis of brain death.

# What is a Registered Organ Donor?

- Individuals must register as an organ donor to donate their organs and tissues to someone in need after death.
- In many states, the decision to, or not to be an organ/tissue donor is embedded as part of the driver's license application and renewal process.
- In addition, many states have a centralized organization for integrating essentially all aspects of organ and tissue donation, including registering as a donor.
- In New Jersey, this organization is the Sharing Network which can be found at: https://www.njsharingnetwork.org/ .

# Organ Donation

- If apnea testing determine brain death (Positive Apnea Test) and a palliative extubation is being considered, it is critically important that any organ donation protocols be followed.
- If the patient or surrogate has indicated that they wish to be an organ donor, then it is common to screen the patient for suitability in terms of pre-existing conditions such as cancer, organ dysfunction and infections.
- Protocols call for maintaining vital signs, blood chemistry (e.g., ABG's) and overall clinicals status within certain ranges to help preserve tissue and organ viability.
- If the patient is determined to be a donor, then the extubation is typically performed in the operating room with the organ procurement team present.

# Withdrawal of Mechanical Ventilation

- AKA; Terminal Wean, One-way or Palliative Extubation
- Clinicians may ethically withdraw ventilation when it aligns with patient preferences and best practices.
- In addition to addressing organ/tissue donation concerns, the attending physician and care team should confirm with the patient or surrogate decision-makers and document in the medical record that the patient will not be re-intubated, and whether the patient may (or may not receive) other support such as HFNC or NIPPV if they start to decompensate.
- Once these issues have been addressed, the physician order obtained, the patient's family needs addressed and the patient is pre-medicated to alleviate pain and discomfort, the most common way to perform a terminal wean is extubate the patient to supplemental oxygen such as a nasal cannula.
- However, other approaches may be used including leaving the ET tube in place but removing the patient from mechanical ventilation and providing oxygen and aerosol, via a T-Piece.

# How should we act when faced with scarce medical resources at the end of life?

- Rare pandemics, limited resources in developing countries and new medical technology may create a situation of scarce medical resources
  - During the worst of Covid, hospitals were running out of ventilators
  - When dialysis was first introduced, it was direly scarce and expensive
    - Ethics committees at the time determined who would receive this new life-saving technology
  - For organ transplantation, there are formulas to determine which patients might be the best candidates to receive organ transplantation
    - The potential for organ survival has become the guiding principle: it is now considered a social responsibility and good stewardship of scarce and precious resources to ensure that we only put organs into those who could be expected to live the longest with those organs
- In sum, resource scarcity modifies the ethical basis on which we act
  - In times of no scarcity, we treat according to medical need; in scarcity, we must utilize resources in a way that maximizes the benefit for all affected (e.g Justice)

# What are Some Resources in the Medical Ethics "Tool Box"?

- **Ethics Committees**: Hospital ethics committees can guide difficult cases involving ventilation withdrawal.
- **Education & Training:** Ongoing ethics education enhances RT competence and confidence in end-of-life care.
- **Interprofessional Collaboration**: Team-based discussions improve ethical clarity and reduce staff burnout in end-of-life care.
- **Communication with Families:** Transparent, empathetic communication supports family understanding and shared decision-making.
- **Cultural Sensitivity:** Cultural and spiritual beliefs may influence patient and family preferences for end-of-life care.

# What About Us?— RTs Involved in EOL

- Exposure to EOL can cause or worsen moral distress for Clinicians including RTs.
- This can lead to Burn-Out or even PTSD.
- There is no secret recipe to Avoid this. But there are strategies which can help (Mahan, 2019)
  - Education & Training-On adopting tested strategies to cope.
  - Talking with Colleagues
  - Professional Help
  - Finding a Ritual—To celibate the patient's life.
  - Incorporating Religious Beliefs
  - Crying physical release & outlets.

- Source: Mahan, K, Death and Dying: Tools to Help Respiratory Therapists Handle Frequent Exposure to End-of-Life Care, Journal of Allied Health, Spring 2019, Vol 48, No 1.

# Are there Accepted Models for Approaching Difficult Ethical Cases?

- Yes-There is too much at stake to leave EOL cases to chance.
- EOL decision making models often involve the following:
  - 1. Identify issues
  - 2. Gather information
  - 3. Evaluate ethical principles
  - 4. Explore options
  - 5. Decide and document.

# Case 1-Right To Refuse

- **Case Summary:** You are a respiratory therapist (RT) working in the step-down unit of a 700-Bed acute-care hospital. One of your patients is a 79 year-old male who was admitted last night for hypoxemic respiratory failure associated with stage-four lung cancer with metastasis to the spine. Since admission the patient has been requiring more support from a high-flow nasal cannula and is currently on settings of 70% oxygen and a flow of 60 L/M, with a SPO2 of 91%, RR of 32 and HR of 110. He complains of bouts of shortness of breath as well as moderate to severe pain in his spine and ribs. He is currently a "full code" because his wife (who is his medical POA) wants it that way. However, he complains that he does not want to be kept alive by a machine or other artificial means. He states that he has "fought the fight and is tired".

- **Discussion:** The ethical principle of autonomy dictates that patients (who are mentally competent) should be self-governing with regard to their care. Hence, this patient's wishes predominate those of his wife. The bottom line is that he has the right to refuse.

# Case 2: Right to Refuse

- A 17 year-old patient with advanced cystic fibrosis indicates that she does not wish to live this way and wants to discontinue therapy.
- Suggestion Action: Inform the nurse & attending physician. Under the ***mature minor doctrine***, the patient may be deemed sufficiently mature to refuse treatment.
- Main Ethical Principle(s):
  - Autonomy-Patient right to self governance
  - Fidelity-Clinician's responsibility to report patient's wishes.

# Case 3—Right to Refuse Limited

- A patient recently diagnosed with TB is placed on isolation and multiple ABX therapy. Once the patient is deemed non-contagious and scheduled for discharge, he indicates "I'm not gunna take no more TB drugs, I'm cured."
- **Suggested Action:** Patients deemed a threat to themselves or others can be mandated to receive therapy. Therefore in this case, the physician should be notified and the patient may be mandated to participate in "Direct Observation Therapy" DOT, with criminal charges if they don't comply.
- **Ethical Principles:** Autonomy ***vs*** Justice.

# Case 4 - Clarifying Re-intubation Confusion

- **Case Summary:** You are given an order to "extubate" an elderly patient who seems cognitively intact and has just clearly indicated he does not want to be re-intubated. The patient's daughter is the POA and wants everything done, including re-intubation.
- **Discussion:** Request to the physician that DNR/DNI status be clarified and documented prior to extubation. A competent patient over-rules a POA every time!

# Case 5 – Right to Futile Care

- **Case Summary:** A patient with a catastrophic head injury's family is demanding that after 15 days of mechanical ventilation, that the patient be trached and receive a peg tube, and be sustained on mechanical ventilation and tube feedings. The physicians and palliative care team have been unsuccessful trying to convince the family that there is no reasonable chance of cognitive recovery. What choices does the hospital have at this point?
- **Discussion:** Given the apparent futile nature of the situation, the most viable choices are:
  - 1. Involve the hospital ethics committee and team and attempt to further persuade the family to consider withdrawing care.
  - 2. Perform a trach and peg tube insertion, maintain the patient on mechanical ventilation and eventually transfer the patient to a long-term care facility.

# Case 6 - Resuscitation Confusion

- A "Code Blue" is called for a 90 year-old patient in apparent acute distress. The patient has a valid Advance Directive, which indicates she does not wish to be resuscitated, ***if the situation is irreversible.*** The daughter who has POA-Medical and wants her mother to be resuscitated.
- **Suggested Action:** Unless the condition is known to definitely be irreversible, CPR should be begin. DNR status should promptly be confirmed. If resuscitation efforts continue, the situation should be re-assessed.
- Ethical principles: Autonomy, Beneficence, nonmaleficence

# Case 7 – Apnea Testing

- **Case Summary:** When performing an apnea test on a mechanically ventilated patient, the patient does not begin spontaneous breaths after 10 minutes off of the vent. However, an ABG reveals that the PCO2 has only risen from 39 torr to 52 torr. What should the RT recommend to the physician at that time?
- **Discussion:** Though the recommended time-off of the ventilator is up to 10 minutes, most Apnea Test protocols call for continuing to keep the patient off of the vent for up to 15 minutes in such situations. At about the 15-minute mark, another ABG should be drawn and if PCO2 has now risen by 20 or more Torr and the patient remain apneic, then the test would be classified as posative.

# Case 8—"Combat Fatigue"

- During a time of high census and acuity such as during the Covid surge, you observe a young RT colleague whose has just removed a patient from a ventilator after a positive apnea test. They appear very upset and are crying. They claim to be fine but over the next few days they seem very withdrawn and upset. When you approach them, they finally admit to being "freaked out" by performing their first terminal wean.
- What action, if any, might be appropriate in this case?
- Discussion: There is no single right answer. However, given the RT's newness the profession and their reaction, it may be appropriate to first talk to them to gauge the level of distress, and then connect them with a member of the management team for additional guidance. The RT may simply need to express themselves and ask questions. After some time, they may be able to put the situation in perspective. However, the incident may have had a more profound effect on them and they may need to be directed for professional help.

# Concluding Thoughts

- Ethical respiratory care requires balancing patient autonomy, clinical judgment, and compassionate practice.
- It seem abundantly clear that RT's have very prominent roles when caring for patients near the end-of-life.
- The impact which death and dying has on RT's and other members of the care team should not be overlooked.
  - Can be a special honor to be with patients and families at such times.
  - However, can also be emotionally hard on clinicians and healthcare organizations should supply appropriate support to their staff.
- Advance planning by patients and their families can help avoid end-of-life dilemmas and confusion.
  - Such planning and documentation via Advance directives, etc can also help honor/respect patient's wishes.
- Hospital Ethics Committees and palliative care teams are potentially valuable resources and should be utilized as such.

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