



Ethical Issues at the End of Life

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Disclaimer



Dr. Supanich has no conflicts of interest to disclose



Learner Objectives

- Describe three ethical principles that guide decisions at the end of life.
- Apply an ethical framework to decisions regarding withdrawal of mechanical ventilation.
- Increased understanding of two techniques of effective communication with families and/or patients when discussing treatments at the end of life.



EOL Ethical Guides and Principles

- **Autonomy**
 - ability of the person to choose and act for one's self free of controlling influences.
 - coercion from physician, nurse, consultant
 - coercion from family members
 - coercion/pressure from religious group, dogmas
 - ability to make decisions based upon our personal values and pertinent information, which will enhance our personal growth and goals.



EOL Ethical Guides and Principles

- Respect for autonomy requires:
 - honoring each person's values and viewpoints
 - listening to the other person as they share their values and choices and questions
 - to assess capacity, to assure that a person is capable of autonomous decisions



EOL Ethical Guides and Principles

- Elements of Capacity to Make Decisions
 1. Patient appreciates that there are choices
 2. Patient is able to make choices
 3. Patient understands the relevant medical information (dx, prognosis, risk/benefit, alternatives).
 4. Patient appreciates the significance of the medical information in light of her own situation and how that influences the current treatment options.



EOL Ethical Guides and Principles

5. Patient appreciates the consequences of the decision
 6. Patient's choice is stable over time and is consistent with the patient's own values and goals.
- Self-determination:
 - the decision to accept or decline treatment rests with the patient
 - patient's right to refuse treatment is stronger than to demand treatment.



EOL Ethical Guides and Principles

- If the patient lacks the capacity to make decisions, then we:
 - follow advance directives
 - find out patient's choices and follow them
 - act in patient's best interests
- Corollary Principle:
 - responsibility and accountability of both the physician and patient to each other and larger society.



EOL Ethical Guides and Principles

- Beneficence: acting in the best interests of the patient.
- Best case scenario --
 - we interact with the patient in a way which maximizes the patient's values and their understanding of a good quality of life.
- Worst case scenario --
 - we are paternalistic in our interactions with the patient; don't honor their values.



EOL Ethical Guides and Principles

- Nonmaleficence:
 - Do no harm
 - Make no knowing act or decision, or lack of sharing information which will cause direct harm to the patient.
 - more subtle -- not sharing treatment options which you disagree with, but which are beneficial.



EOL Ethical Guides and Principles

- Truth-telling: share all truly beneficial information which will assist the person in making a good decision.
- Confidentiality: duty to respect the privacy of shared information.
 - overridden when
 - we need to enlist others to confront a patient who has made a decision which is inconsistent with prior decisions
 - duty to protect others (homicidal/suicidal)



EOL Ethical Guides and Principles

- Justice: consider our individual decisions in context of the needs of the greater society.
 - we are an integral part and an interrelated part of society.
 - what I do, how I do things does have an influence beyond my own personal sphere.
 - responsible for health status of the community...





Moral Conversations

- Transparency Model of Informed Consent
 - create a participatory and collaborative practice environment.
 - conversational approach, inform of all options (including no treatment).
 - openly (no bias) share pros/cons of relevant treatment options in “English”!
 - offer to clarify info and answer questions.
 - patient then tells us her preference(s).



Characteristics of a Moral Clinician

- committed to professional competence
- respect for colleagues and patients
- respecting patients' value systems
 - ability to hear the patient's perspective of appropriate care.
 - know when to limit actions which would conflict with those values.
 - important to understand our sense of "loss" when values conflict..



Characteristics of a Moral Clinician

- Compassion
 - being with, suffering with, empathy
 - caring by seeing through the eyes of the other
 - gain understanding of what needs to be done and how best to achieve it from the patient's perspective.
 - concern for patient's well-being



Characteristics of a Moral Clinician


- Caring and gentle communication skills
- Openness to understanding a variety of ethical, medical and cultural approaches to health, healing and dying.
- Owe our patients and their families caring and compassionate communication.



Moral Conversations

- Productive Moral Conversations:
 - include people who have a major stake in the issues
 - include others from a variety of backgrounds, interests and perspectives
 - all important facts about the case are discussed, when we disagree - - get the facts or agree to disagree
 - all morally relevant features of case are discussed





Ethical Framework for Conversations with Patients and Families

- ICU setting - -
 - Often complicated, confusing or discordant data
 - Often disagreement among team members regarding initiating, changing or withdrawing certain treatments
 - ICU setting is often overwhelming to the family
 - Only 5% of patients are able to participate in treatment conversations

Curtis, JR. Communicating about end-of-life care with patients and families in the intensive care unit. *Crit Care Clin* 20 (2004) 363-380.



Conversations with Patients and Families

- Communication between families and clinicians is extremely important to family members.
- ICU Family Conferences within 72 hrs of admit
 - Decreased overall length of stay in ICU
 - Decreased the prolongation of the dying process
 - Improved communication among ICU team members, other physicians, and family members
 - Improved family and patient satisfaction



Ethical Approaches to EOL Discussions

- Getting Started
- Assessing patient's knowledge
- Assessing how much patient wants to know
- Sharing the information
- Responding to the patient and family's feelings and responses
- Follow-up Plans



Components of EOL Discussion in ICU

- Prepare for this discussion - -
 - Review the clinical information
 - Meet with all key ICU team members to develop consensus and ensure accuracy and consistency of information to be shared.
 - Gain understanding of family members concerns or questions prior to meeting, if possible.
 - Call other involved doctors or other clinicians to learn about their concerns, questions, and obtain consensus.



Components of EOL Discussion in ICU

- Introduce everyone present
- Attend to the environment - - silence beepers and cell phones, etc.
- Set the tone - - “This is a conversation we have with all of our patients/families.”
- Ask what they currently understand and what is confusing or needs clarification.
- Ask them how much they want to know ...



Components of EOL TX Discussions

- Don't talk in "Medicalese" !
- Discuss prognosis
 - In context of this person's complications and underlying illness
 - In context of who the patient is as a person
 - In context of patient's goals and values
- We are NOT withholding CARE – we ARE transitioning the focus of care when any treatment is no longer beneficial to the patient.



Components of EOL Tx Decisions

- Discussion of benefits and burdens of treatment choices
 - Initial choice (s) for care
 - Decision for withholding or withdrawing treatments
- Use active listening
- Use majority of time to listen to family
 - Be comfortable with emotions of family members
 - Be comfortable with silences



Components of EOL Tx Discussions

- Concluding the conference - - -
- Achieve a common understanding of the dx, prognosis and future treatment issues
- Make a recommendation regarding focus of tx, including agreement on beneficial and nonbeneficial treatments
- Agree to when the next follow-up meeting will occur and how to contact one another.
- Document the meeting on a family meeting summary form.





Ventilator Withdrawal Issues

- Discuss in context of the patient's current dx and response to treatments.
- Discuss in context of patient's choices/values.
- Discuss in context of whether this tx (the ventilator) is still offering benefit and the hope for recovery.
- Focus conversation on honoring what the patient would choose ...



Ventilator Withdrawal Issues

- Possibility of therapeutic trial with ventilator
- Educate the family on what the likely scenarios are after withdrawing the ventilator - -
 - Minutes to hours
 - Hours to days
 - Days to weeks
- Gain understanding and agreement on when to extubate from the patient, surrogate, or family members.



Compassionate Wean Protocol

- Facilitate a family conference in which family has time to share who the patient is as a person, their values, interests, accomplishments, etc.
- Allow the family to have time for family rituals, visits
- Allow time for spiritual or religious rituals.
- Based on the need of the patient, may start a morphine drip for pain and dyspnea relief.
- Based on plan made with family, may have family members present at time of extubation.



Compassionate Wean Protocol

- Start morphine drip about one hour prior to extubation.
- Remain available for support of family and patient while still in ICU
- Arrange for transfer to an IP Palliative or Hospice Unit, if patient survives longer than a few hours.



Summary

- Respect patient autonomy in the contexts of beneficial and nonbeneficial care and justice.
- Use known effective communication skills of active listening in family conferences.
- Communicate well with the ICU Team members regarding approaches to treatments and changes in treatments.
- Discussed the techniques for a successful family conference.
- Discussed my Compassionate Wean Protocol.



QUESTIONS?

