#### Ethical Issues at the End of Life

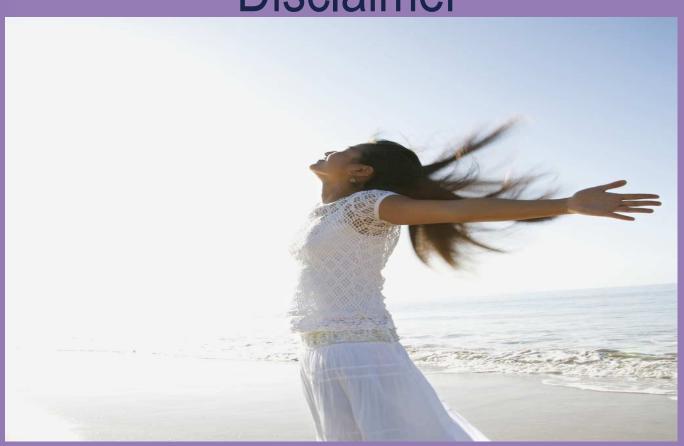
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### Disclaimer



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.

- 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.

- 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

- 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.

- 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.

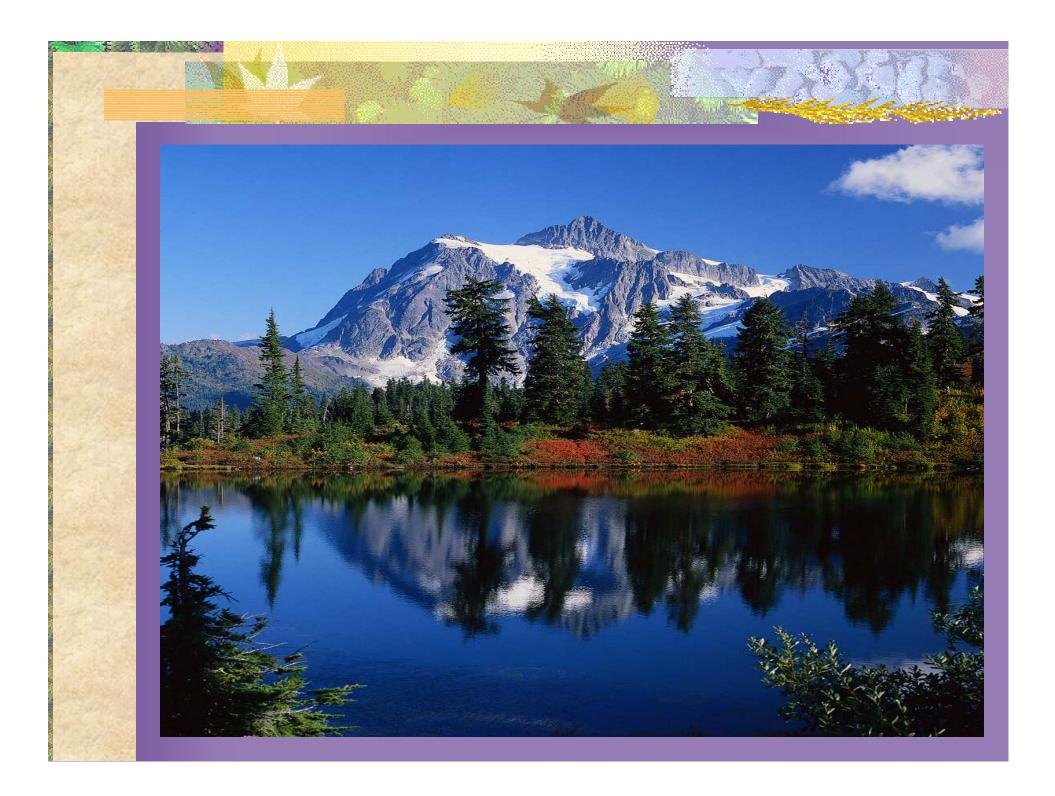
- If the patient lacks the capacity to make decisions, then we:
  - follow advance directives
  - find out patient's choices and follow them
  - act in patient's best interests
- Corollary Principle:
  - responsibility and accountability of both the physician and patient to each other and larger society.

- 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.

- 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.

- 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)

- 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.

