Medical Ethics for Hospice Clinicians

Emmanuel Elueze MD. PhD. FACP. MPA (HCA).
Medical Director, Beacon Hospice, Longview.
Chairman, Supportive Care Committee,
Good Shepherd Medical Center, Longview.

Objectives

- Review the four cardinal medical ethical principles.
- Discuss the difficult ethical issues at the end of life.
- Discuss advanced care planning and surrogate decision making.
- Describe steps in ethical decision making for patients, families and care givers.

4 Cardinal Ethical Principles

- Autonomy
  - Respect patient’s choice about treatment/ self determination
- Beneficence
  - It is good to relieve suffering, cure a patient, save a life
- Nonmaleficence
  - It is good not to harm, cause suffering or prolong dying
- Justice
  - Fairness, equity

Other ethical principles

- Fidelity
  - Faithfulness to the patient first – being true or being there for the patient when they are most vulnerable
- Respect for persons
  - Attention to customs, beliefs and vulnerabilities of the patient.
- Trust
- Truth

Ethical issues in Palliative Care

- Conflicts in goals of care
- Refusal or withdrawal of Rx
- Artificial hydration and nutrition
- Under treatment of pain and other symptoms
- Physician assisted death and euthanasia
- Ineffective communication

Example of the Need for Ethics Consults (cont)

- Support needed by primary team
- Difficult/ complex communication: several family meetings already held by primary service
- Need for mediation
**Ethics Consult Addresses Issues of:**

- High levels of distress/suffering on the part of family and staff + moral distress
- Team is not united on goals of care
- Staff needs support for their medical judgment of what is best for the patient
- Family wanting their voice to be heard if there is disagreement in what they think is best for the patient and the medical point of view

**Advance Care Planning**

- Plan in place for future health care in the event you lack decisional capacity.
- Involves communicating your wishes for care and designates a proxy.
- Only goes into effect when you lose the ability to make decisions.

**Advanced Care Documents**

Advanced Directives include:
- Medical Power of Attorney/Proxy/Surrogate
- Living Will/Medical Directives

Others:
- Out of hospital DNR
- POLST / MOLST
- Inpatient DNR

**Physician Order for Life-Sustaining Treatment (POLST)**

- A physician order (like the Out-of-Hospital DNR)
- Valid for care across all settings
- Overcomes the problems of:
  - vague language
  - availability
  - utility across care settings
- Endorsed by The National Quality Forum as part of a health care system’s quality standards in end-of-life care

**Advantages of Advance Directives.**

- Extends patients autonomy
- Helps resolve conflicts and facilitate communication
- Reduce unnecessary/unwanted interventions
- Absolve physicians from liability if followed strictly
- May impact effective use of health care dollars

**Weakness of Advance Directives**

- 12th grade reading level
- Life sustaining treatments rarely defined
- Clinician confidence in these directives not high
- Majority of pts do not complete them
- Evidence they do not make a difference in health care costs for cancer pt at End of Life
Problems with use of Advance Directives

- Effective use of living wills requires patients to:
  - Fill them out;
  - “national conversation ready project”
  - Decide how they would want to be taken care of
  - “Accurately and lucidly” state that preference in clear but legally acceptable language
  - Be available to all concerned parties at the time when they are needed
  - Be implemented

Decision Making Capacity

- Communicate understanding of relevant information and the implications/consequences of treatment choices
- Decision is in accordance with personal values and goals/rational decision
- Demonstrates he/she is not delusional as a consequence of delirium or other psychiatric dx
- Express a static preference

Decision Making without Capacity

- Not the same as COMPETENCE

- Competence is legally determined

Hierarchy of Surrogates

- Spouse
- Adult children
- Parents
- Siblings
- Grandparent
- Grandchild age 18yrs or older
- Friend / Partner

Substituted Judgment vs Best Interest

- Substituted judgment attempts to mirror the decisions the patient would make

  - “If your loved one could wake up for 15 minutes and fully understand his/her circumstances, what would he/she tell us to do?”

  - Best interest standard applies when an advance directive is not available or a patient’s previously stated wishes and values are unknown. Consider the decisions a reasonable person would make under the patient’s circumstances.
Case of Mr. S

Mr. S is a 64 yo AAM dx 2002 w/ hemangioblastoma of the spinal cord. S/p resection of recurrent spinal tumor 2011 complicated by paraplegia, neurogenic bowel/bladder; s/p colostomy and has chronic indwelling foley. Recurrence at C6 w/ resection May 2012 complicated by postop hemorrhage and cervical cord ischemia. He is now quadriplegic and ven dependent. He is requesting removal of ventilator support and to allow him to die peacefully. Palliative care team is consulted for assistance with withdrawal of life support.

As the clinician, which of the following is the next best step?

1. Withdraw all life sustaining treatment
2. Ask Mr. S to clarify his reasons for wanting to discontinue the ventilator
3. Request a psych consult
4. Continue all treatments against pt wishes

First step Gather all relevant information about the decision to be made

4 Box Model: Practical approach to ethical decision making at the bedside

<table>
<thead>
<tr>
<th>Clinical Facts</th>
<th>Biographical Facts</th>
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<td>Cultural Facts</td>
<td>Quality of Life</td>
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Clinical Facts

- Recurrent hemangioblastoma
- Progression of disease on Thalidomide
- Per SCI (spinal cord injury) and Pulmonary attending, pt will remain vent dependent the remainder of his life
- He is having recurrent pulmonary, urinary infx’s, decubiti
- Dependent for all adl’s and will need long term placement

Biographical Facts

- Based on respect for personhood
  - Preference for care/values/wishes...including family
  - Does pt have capacity to make health care decisions?
  - Is there an advanced directive/MPOA?
  - Is pt informed of risks, harms, burdens, benefits?
  - What do the other clinicians recommend?
Biographical Facts

- 30 yr marriage to an RN; well informed of consequences of treatment
- Told his wife on numerous occasions if ever in his current state, he would not want Life sustaining treatment (LST). No previous executed advanced directive.
- Wife and daughters are supportive of pt’s decision based on previous expressed values.
- SCI attending, pulmonary attending, Primary Care, psychologist and ethics team assess pt to have decisional capacity.

Cultural Facts

- Pt is a proud man and lead a very active life.
- Enjoys walking his dogs and doing crossword puzzles.
- Wife reports financial concerns as she has had to stop working to take care of pt and has used some of her 401K to cover expenses. Pt will need long-term care.

Quality of Life

- Sees future quality of life as poor.
- Burden to his family.
- He is not depressed/no spiritual/emotional pain; not delirious based on psychological testing.
- He is not in pain.

Quality of Life

- How does pt describe his quality of life?
- Will pt return to a normal life vs undesirable life?
- Does it make sense to forego treatment?
- What treatments would provide a satisfactory outcome for the pt?
- Symptoms well controlled? Unrelieved suffering?

What ethic principles would you apply in making a sound decision?

1. Beneficence
2. Nonmaleficence
3. Autonomy
4. Justice
5. All of the above
**Autonomy and Nonmaleficence**

Recognizes the right of a pt with decision making capacity to make decisions about treatments according to his/her beliefs, cultural and personal values and life plan.

When physicians initiate a life prolonging treatment, they have an ethical obligation to discontinue treatment when it is no longer effective or desired by a patient with decisional making capacity.

**Conclusion of Case**

After substantial deliberation among pt, family and health care team, plus documentation by attending staff, palliative and ethics team, the decision is made to withdraw ventilator support. Appropriately titrated doses of opioid and benzo are available to treat and relieve any symptoms. After removing ventilator, pt died within thirty minutes with chaplain at bedside for bereavement support.

**Withholding and Withdrawal of Life Sustaining Treatment**

- Court recognition of right of adult w/ mental capacity to reject LST
- Legally/ethically equivalent
- Burden of treatment outweighs benefit
- Time limited trials of treatment
- Withdraw in the most humane way

**AAHPM Statement on Artificial Nutrition and Hydration (ANH) Near End of Life (EOL)**

- ANH is a medical intervention; can be ethically withhold/withdrawn
- Evaluate benefit and burden in light of the pt's clinical circumstances
- Presumed benefit of relief of thirst/starvation may be alleviated w/ less invasive measures
- Symbolic importance for pts/families

**Withdrawing Artificial Nutrition and Hydration**

When feeding tubes may help:
- ALS patients with swallowing problems
- Oro-pharyngeal or esophageal ca treatment
- Brain injury until prognosis is known

When feeding tubes probably don't help:
- Cancer cachexia
- Advanced dementia

**ANH CAUSES DISCOMFORT AT EOL**

- ANH and IV hydration in dying patients associated with increased:
  - Nausea and emesis
  - Bronchial secretions and respiratory distress
  - Peripheral and pulmonary edema
  - Need for more intervention with catheters, other treatments, and medications
ANH OF NO BENEFIT IN DEMENTIA

- Compared to hand feeding, ANH not shown to
  - Promote healing of pressure ulcers
  - Lower the risk of aspiration pneumonia
  - Increase patient comfort
  - Increase survival
  - Prevent weight loss

ANH INTERFERES WITH THE WISDOM OF THE BODY AT LIFE’S END

- Most dying patients do not experience hunger or thirst
- “Terminal” dehydration and caloric deprivation lead to electrolyte imbalances and ketosis that promote sedation and comfort.
- On a 0 (very bad) to 9 (very good) quality of dying scale, patients who die without ANH have a median score of 8.

FEEDING GUIDELINES AT LIFE’S END

- Eliminate diet restrictions
- The Hagen-Daz Diet – comfort foods
- Teach family the love of hand feeding
- Fluids: sips, ice chips, popsicles, favorite liquids
- Provide a pleasant environment for meals
- Control pain, constipation, nausea, vomiting and other symptoms with proper medication
- Practice good mouth care

Issues Related to CPR for Dying Patients

- 3.9% of ICU patients resuscitated on pressors survived to leave the hospital
- Misconceptions:
  - CPR is a benign procedure
  - CPR always restores quality life
  - DNR order somehow causes death to become more imminent
  - Patient is ignored, curative treatments w/ held
  - Pain/comfort measures will stop

DO NOT ATTEMPT RESUSCITATION

DNAR is more accurate; no effort will be made to do an intervention that has a low rate of success for patients at end of life

Medically Futility
AMA, 1992

Physicians:
- Obligated to offer patients “medically sound” options to “Cure or prevent a medical disorder” or “relieve distressing symptoms”
- Not obligated to offer or provide non-beneficial treatments

Patients:
- Do not have right to demand treatments contrary to medical judgment
FUTILITY (Potentially Inappropriate Treatment)

• Empathic listening

• Compassion / Honest communication

• Respect for death related fears, grief, guilt and uncertainties

• Time limited trial of treatment

• Ethic and palliative consultation; do not make decisions in isolation

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Pearls for Discussing Goals of Care

1) Each conversation is part of a process, not an end-point
2) Autonomy may be about the family rather than the individual
3) Patients are universally under-informed. Never assume that an unreasonable request represents real understanding of the options
4) Do not be discouraged if the next time you see the patient or family they deny all memory of the previous conversation
5) Always remain humble about possible outcomes. Death and dying are spiritual, rather than scientific, events to many patients and family members.
6) Try to act with the correct intention.

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Useful Information in Determining Goals

• Data that patients find useful when defining goals of care:
  • information about invasiveness and duration of therapy
  • chance of recovery
  • chance to remain cognitively intact
  • Prognosis
  • risk of pain

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Offer a Recommendation

• Offers a recommendation based on clinical experience and tailored to the patient’s real interests
  • “Given what you have told me about your mother, here’s what I would recommend that we do moving forward.”
  • Making a recommendation does NOT infringe on a patient’s autonomy – quite the opposite

• Do not “abandon people to their autonomy.”

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Documentation

• Two most important elements are
  • PHILOSOPHY and GOALS of care
  • name and contact information for the surrogate

• Summarize in a way that clarifies all participants are on the same page

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Legal Myths

• Forgoing LST for an incapacitated pt requires knowledge of his or her actual wishes
• Risk management must be consulted before artificial hydration and nutrition are stopped
• If clinicians order high doses of opioids and/or sedatives to treat intractable suffering, they are at risk for legal prosecution
• No legally available options are available to address intractable suffering outside of Montana, Washington, Oregon
Legal and Ethical Truths

- Because of legal fears, patients are at higher risk of under treatment for them suffering than over treatment.
- Ethics and legal consultation is highly advisable if treatment withdrawal decisions are being contemplated in pts who have never had capacity.
- Your best defense against legal intrusion is to discuss difficult cases w/ your colleagues, get ethics consultation in uncertain cases and carefully document what you are doing.

COMMUNICATION PEARLS AND CONCLUDING THOUGHTS

- Sooner or later, death is no longer a medical problem to be solved, it is a spiritual problem to be faced.
- Nursing, social work, and clergy must be partners with physicians; works as interdisciplinary team.
- Avoid medical debates and dialogues.
- Focus on how patients want (or would have wanted) to live.
- Focus on things that work and that we can do.
- Acknowledge emotions (love, loss, sadness, hope, anger) and spiritual concerns.

Conclusions: Knowledge of Medical Ethics and Team Work

Will help provide ethical guidance for, clinicians patients and family members when they:

Make decisions about goals of care
Make decisions about cardiopulmonary resuscitation
Make decisions about withdrawal of artificial hydration and nutrition
Make decision about futile treatment

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Questions?