CASE BASED ETHICAL DILEMMAS

Ellen M. Robinson RN Ph.D.
Nurse Ethicist
Co-Chair, Optimum Care (Ethics) Committee
Massachusetts General Hospital

Nurse Practitioner Conference
May 2019
Objectives

- Describe and apply ethical principles and approaches, professional position statements, empirical evidence and hospital life sustaining treatment policy in complex case dilemmas.

- Explore strategies to mitigate conflict in complex cases with goal of enhancing beneficent care for patients, supporting surrogates during a difficult time and promoting clinicians’ professional-ethical practice.
Ms. S, 64 years, Irish-American

- End stage heart failure, EF <10%
- Full capacity, awake, aware, lying in bed
- Dyspnea managed by low dose Morphine
- Divorced, lives alone, adult children in 30s are not doing well in their lives. Ms. L endorses ‘a sad life’
- Pacemaker placed 12 years ago, post cardiac surgery; remains ‘totally dependent upon it’
- Requesting that pacemaker be ‘turned off’
- Cardiologist says: That would be ‘euthanasia’
Mr. A, 58 years, African-American

- Receiving hemodialysis for past 2 years
- Increasing dementia d/t long term effects syphilis, oriented only to self. He states ‘The dialysis cleans my blood, I’ll keep taking it’. Confined to a veil bed on unit and in dialysis
- Had been homeless; spouse, who is religious, took him back since he has been ill
- Difficult to complete an HD session, becomes agitated, needles dislodge, staff are concerned re: harm to him and themselves
- No discharge options
- Can/should dialysis be withdrawn? Who should decide?
Ms. L, 52 years, Asian Woman

- 52 year old Asian woman with metastatic NSCLC when she was age 46
- Received 6 years tx at major cancer center – when told she no longer qualified for tx, son brought her to hospital that also had a major cancer center
  - Disease advanced and unresponsive to tx
  - Patient has indicated to physicians and nurses that she understands she is at end of life
  - Patient oxygen dependent and pathological fx
  - In a great deal of pain
Mrs. S, age 67, Italian-American

- Metastatic breast cancer for 5 years, in end stages
- On comfort measures, with morphine gtt, finally appears ‘comfortable’ in a ‘deep sleep’, after 48 hours of pain crisis; respirations 18/min
- Husband, son and daughter in room. Daughter is 42, has young children, and has recently had a mastectomy for breast cancer
- Son calls nurse aside: “Can you please speed this up? My father is becoming so weary, we’ve been here for days.”
- Nurse calls Palliative Care for advice
Case Approach:

- Goals of care framework
- Ethics of care
- Ethical principles
- Empirical evidence
- Professional position statements
- Life sustaining treatment policy
Case Approach: Developing Goals of Care

- Prognosis
- Values, beliefs and preferences
- What is ethically and legally permissible
Care Ethic Operationalized

- Particulars:
  - Who is this person, living and dying with this disease?

- Context:
  - Where does this patient *(family)* find themselves at this time? What is confronting the patient?

- Relationships:
  - Significant family, friends, that the patient and family care about, and that care about them
  - Significant family, friends, that may be in conflict with the patient and family—*but are still important to the patient*
  - Health care providers in relationship with the patient and family
A right to refuse life-sustaining treatment exists in the US
This right extends to the competent, once competent and never competent person
The type of treatment is not determinative: analysis in terms of benefits and burdens to the patient
Withholding & withdrawing LST are ethically equivalent
Good palliative care is supported by US Supreme Court
Advance directives provide a mechanism for this right to be actualized
Nothing in this chapter shall preclude any medical procedure deemed necessary by the attending physician to provide comfort care or pain alleviation. Such procedures shall include but not be limited to treatment with sedatives and pain-killing drugs, non-artificial oral feedings, suction and hygienic care.

(Section 13, Pain Alleviation, comfort care procedures)
Type of Ethical Problem

- Ethical, or moral distress (barrier to doing what ought to be done)
- Ethical dilemma (two or more ‘roads’ could be taken, unclear which is the ‘right’ or ‘best’ road)
- Ethical uncertainty (is not yet clear)
- Locus of authority: Who should decide?
Strategies

- Ethical distress – identify obstacle and strategize how to remove
- Ethical dilemma – acknowledge the difficulty, clarify the options, support the decision
- Ethical uncertainty – gather more information, continue to listen
- Locus of authority – identify, and be transparent about decision-maker – who is responsible?
Principle-Based Ethics

- **Beneficence** – do good for patients
- **Non-maleficence** – do no harm to patients
- **Autonomy** – seek to learn the patient’s values and goals
- **Justice** – treat patients fairly
Ethical Principles Can Guide

- **Principle of Autonomy:**
  - decisions must be informed to be ‘autonomous’
  - a surrogate ought to provide the best substituted judgment possible
  - most families want guidance, rather than ‘stand alone options’
  - alternatives must be known, for patient to be ‘well informed to make an authentic choice’
  - Bear in mind the ‘goals of one’s profession’, and be knowledgeable about ethical-legal practice parameters
Principles: A Critique

- **Beneficence** – doing good became paternalistic
- **Autonomy** – does not mean consumerism or carte blanche – preserve your professional obligation to guide
- **Justice** – societal allocation questions don’t belong at the bedside, but keep in mind, for all patients, regardless of socioeconomic status, responsible stewardship of resources remains an obligation AND each patient deserves ‘fair opportunity’ for good end of life care
- **Non-maleficence** – more is not always better – prolonging death may be a harm
What About the Patient?

- Doing no harm becomes paramount – must insure relief of pain and troublesome symptoms

- **Rule of Double Effect** allows clinicians a way to analyze their interventions for patients who are approaching death

- Principle recognizes that an action can have ‘two effects – a good and a bad effect’

- Derived from the principle of ‘non-maleficence’
Rule of Double Effect

- **Nature of Act** *(must be good, or at least morally neutral)*
- **Agent’s Intention** *(intent of good effect, bad effect foreseen, but not intended)*
- **Distinction Between Means and Effects** *(bad effect not a means to good effect)*
- **Proportionality Between Good and Bad Effects** *(bad effect only permissible if proportionate reason is present to tolerate the bad effect)*
Rule of Double Effect Applied

- Use of morphine is not in itself immoral
- Intention is to relieve the patient’s pain / symptoms – intention is **NOT** to kill patient
- Killing the patient is not required in order to relieve pain
- The relief of pain / symptoms is a compelling reason to accept the risk of hastening death
Empirical Data Can Guide:

- Cardiopulmonary Resuscitation
- Tube Feedings
- Dialysis
- Patient Experiences at End of Life
CPR: A Proposed Model for Decision-making

Cardiopulmonary Resuscitation

Beneficent for Well Person

Consider Prognosis & Pt. Values & Beliefs for Chronically Ill Shared Decision

Medical Decision At End of Life: Nonmaleficence
Position Statements


- Responding to Requests for Potentially Inappropriate Treatments in ICUs. *ATS, AACN, ACCP, ESICM, SCCM* (2015)

Recommendation #6 - Consider forgoing dialysis for AKI, CKD or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely

- Those whose medical condition precludes the technical process of dialysis d/t inability to cooperate, or d/t physiological instability

Renal Physicians’ Association, Clinical Practice Guideline, 2010
HRS Expert Consensus Statement on Management of CIEDs (Lampert et al., 2010)

- Ethically-Legally, no difference between refusing CIED therapy or requesting withdrawal of CIED therapy

- Carrying out request to withdraw is neither PAS or euthanasia—intent to ‘allow’ patient to die, not to ‘intentionally terminate’ life

- Clinician can ‘conscientiously object’ to carry out this ‘legally and ethically permissible procedure’, but must not abandon the patient & thus obligated to find a clinician who can do it for the patient
MGH recognizes that cardiac implantable electronic devices (CIEDS) are a form of life-sustaining therapy and that a competent patient, or the patient’s Health Care Agent if the patient lacks capacity, has the right to request deactivation of these devices once continued device therapy is no longer compatible with the patient’s goals of care.

When deactivation of a CIED is requested, the Responsible Physician or designee should place a note in the medical record documenting the patient’s goals of care, the specifics of the request (e.g., implantable cardiac defibrillator deactivation, pacer deactivation), and the identity of the person who has made the request (i.e., the patient or the patient’s Health Care Agent). In the rare case in which urgent CIED deactivation is necessary, a verbal request may be made with written documentation placed in the record as soon as feasible.
No clinician will be required to deactivate a CIED when he or she is not comfortable doing so. If a situation arises where a clinician is asked to deactivate a device and does not feel comfortable doing so, rapid consultation between the patient’s Responsible Physician and an electrophysiology (EP) attending physician should take place. If a resolution cannot be reached that is satisfying to the Responsible Physician, the EP attending physician and the patient or the patient’s health care proxy, an Optimum Care Committee consult should be urgently obtained.
Additional issues may arise when deactivation of a CIED will likely lead to immediate death (e.g., in a patient who is pacer dependent). The following guidelines apply in such cases:

- Requests for deactivation should be initiated by direct discussion between the Responsible Physician and the EP attending.
This deactivation should typically be performed by an EP physician (attending or fellow) and not by device clinic staff, advance care practitioners or industry representatives, although exceptions to this may be necessary for patient sites outside of MGH, such as hospice facilities.

Prior to deactivation, a discussion should take place between the EP attending physician or fellow and the patient or Health Care Agent to ensure that the requestor understand the implications of what he or she is requesting prior to deactivation.
Not Offering CPR—Study Results

- Retrospective ethics consult case review 2007-2013 (N=339 consults)
- 134 cases—disagreement about whether to provide CPR
- In 45 cases, ethics consult led to agreement for DNR
- In 67/89 (75%) of remaining cases, ethics consult recommended NOT OFFERING CPR
  - DNR ordered for 61 of the 67
  - 72% of 61 died during hospitalization—0 rec’d CPR
  - N=15 alive transferred to SNF/LTAC
  - 90% of 61 had 90 day mortality
    - 5 remaining alive after 90 days (2 PVS; 3 residents of LTC)
Not Offering CPR—Study Results

- In 22/89 (25%) cases, ethics consult recommended OFFERING CPR—
  - None of the 22 died during hospitalization; none rec’d CPR
  - 90 day mortality was 27%

A.Courtwright et al., 2015 Journal of Critical Care
Case Analysis

- Prognosis, Values/Beliefs—Who is this person?
- How do ethical principles and rules clarify and inform?
- Type of ‘ethical problem’
- What is ethically and legally permissible?
- Consider empirical data, professional position statement, law and policy
- Who will decide? (locus of authority)
Ms. SL

- Nurses concerned that SL is ‘full code’
  - Inhibits ability to medicate
  - Concerned that she will die within days, and ‘resuscitation attempt’ would not be right
- Patient at end of life – her son having difficulty accepting it
- Ethics consult requested by attending MD – DNR needed to protect SL from harm
Oncologist and nurse informed the son, with compassion, that his mother would be a DNR/DNI.

Son resisted, initially angry, stating, “I’ll take my mother to another hospital.”

MD and RN did not engage his anger, rather, stated, “We know this is hard for you. We want to take care of your mother here. We want to take care of you, too.

Son, over the next few hours, quieted, and remained at his mother’s bedside.
Ms. SL

This chaplain was paged by nursing staff stating that patient is actively dying and that family requested chaplain to offer a religious service according to the Pureland tradition, very common among Asian Buddhist practices. Patient was sedated and had labored breathing, sister, niece and nephew were around as well as pt's son and daughter. Son in particular was quite emotionally distressed. I advised family regarding a few Buddhist practices related to end of life preparation. Son told me that yesterday patient was shortly awake and joined family members chanting "Namu Amitabha" together and that patient looked happy. I told son that it was very comforting that patient still followed her practice and that family was supporting her spiritually. After that, I did a long traditional Pureland service and together with family evoking "Namu Amitabha" by patient bedside. I also talked directly to patient reminding her practice and offered well-wishes for a peaceful transition into Pureland. Son and family members were very appreciative of spiritual support and service. May patient have a peaceful transition and all her family members be well.
Ms. SL-Nurse’s Note

- Patient’s son is the point of contact for patient and making all healthcare decisions. Patient’s son and daughter very emotional this shift, requiring continuous emotional support and reassurance. After patient passed away, the son reported to nurse that he was so happy that she passed peacefully and that he now understands and appreciates what the staff who had cared for his mother had tried to say to him, because he now realizes how much she was suffering for all these months. Empathic listening provided.
Complex Cases...

- It is actually easier not to raise end-of-life issues...

- Conflict and/or difficult ethical questions can be ignored, glossed over, or taken up with a fight

- But, to not engage the conflict, or speak of the elephant in the room, to not try to assist patients and families in transitioning from curative care to palliative care, when appropriate, is to deprive them of the opportunity to bring closure to that which has been important to them in their lives, and may assist them in their grief

*So, must continue to ask the question:

When does gravely ill become dying?

*(Finucane, 2002)*
CPR: A Proposed Model for Decision-making

Cardiopulmonary Resuscitation

Beneficent for Well Person

Consider Prognosis & Pt. Values & Beliefs for Chronically Ill Shared Decision

Medical Decision At End of Life: Nonmaleficence