Ethical and Legal Issues in End-of-life Care

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No conflicts to disclose

Informed Consent
Communication
Right to Be Informed about Palliative Care

Treatment limitation
Voluntary Stopping Eating and Drinking (VSED)
Minimally Conscious State (MCS)
Ventricular Assist Devices (VADs)

Deciding for patients who have lost decision making capacity
Advance care planning, DNR orders, POLST
Recommendations, burden of decision making
Physician assisted death

Futility

Both set standards of conduct
Law = minimal consensus
Many areas of conduct not regulated by law
Ethical standards exceed legal obligations

Bioethics & the Law
Technology
Appropriate use or discontinuation of interventions
Landmark bioethics cases as benchmarks
Generally, legal precedent follows medical ethical principles

We still don’t do end-of-life well
We need:
- Palliative care
- Better communication
- Better education
- Better advance care planning
- Better alignment of financial incentives
- Greater transparency and accountability
- Better public engagement
- ([not necessarily better laws]
- advance directives, pre-hosp DNR, POLST have shout-outs;
- futility & PAS noted as issues
- Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. 2014

Dying in America: IOM Report 2014

Resolving Difficult Cases: Role of Law and Ethics

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Informed Consent

- Elements:
  - nature, risks, benefits, alternatives, no treatment
- Information (includes):
  - burdens of treatment
  - limitation of treatment if ineffective

Communication and Terminal Illness

- Communication
  - Terminally ill patients who knew they were terminally ill and talked with physicians about preferences were 3.5 times more likely to have preferences honored
  - 44% of patients who knew they were terminally ill had not had conversation with physician about preferences

- Communication re: Advanced Cancer
  - Most patients with advanced cancers of the lung or colon do not understand that chemotherapy was unlikely to cure them
    - 69% of those with Stage 4 lung cancer
    - 81% of those with Stage 4 colorectal cancer

Informed Consent & Palliative Care – “Right to Know” Laws

- California Right to Know End-of-Life Options Law (2008)
- New York Palliative Care Information Act (2010)

Right to Know End of Life Options Law - CA

- When a health care practitioner makes a diagnosis that a patient has a terminal condition, the health care provider shall, upon the patient’s request
  - provide comprehensive information and counseling regarding legal EOL options, including right to refuse unwanted treatment, or
  - provide referral or transfer, if practitioner does not wish to comply with provision of info

Palliative Care Info. Act – NY (1)

- Requires a health care practitioner to offer to provide palliative care information and end of life options to a patient diagnosed with a terminal illness or condition
  - including but not limited to:
    - the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and
    - the patient’s legal rights to comprehensive pain and symptom management at the end of life
- Where the patient lacks capacity to reasonably understand and make informed choices relating to palliative care:
  - the attending health care practitioner shall provide information and counseling under this section to a person with authority to make health care decisions for the patient
Palliative Care Info. Act – NY (2)
● Where the attending health care practitioner is not willing to provide the patient with information and counseling under this section,
  - he or she shall arrange for another physician or nurse practitioner to do so,
  - or shall refer or transfer the patient to another physician or nurse practitioner willing to do so
  • N.Y.S. Public Health Law Sec. 2997-C (2010)

Refusal of Medical Treatment
● Right to refuse medical treatment
● Grounded in
  - Law of Battery
  - Informed consent/refusal
  - Liberty Interest of 14th Amendment

Role of an ethics committee
● First cited in Quinlan (N.J. 1976)
  - For help in decision making
  - Description adapted from Baylor Law Review article by K. Teel, MD describing infant care review committee
● Exponential growth past decades
● Joint Commission requirement of mechanism to resolve ethical issues
● Now ubiquitous in medical centers
● Various degrees of expertise and experience

Limitation of Treatment: The Consensus
● Artificial nutrition and hydration (ANH) = medical treatment that may be refused
  - Majority decision reviewed state cases that equated ANH with medical treatment
  - O’Connor concurrence *artificial feeding cannot be distinguished from other forms of medical treatment
  • Cruzan (U.S. 1990)

Limitation of Treatment: The Consensus
● Right to refuse any intervention
  - Ventilators, feeding tubes, blood products
  • Bartling (Cal.App. 1984), Bouvia (Cal.App. 1988)
  • Wons (Fla. 1989), Foxmore (N.Y.1990)
● All patients have right, even incapacitated
  • Quinlan (N.J. 1976), Cruzan (U.S. 1990)
● Withholding / withdrawing
  - not homicide or suicide
  • Barber (Cal.App. 1983), Cruzan (U.S. 1990)
  - orders to do so are valid Dinnerstein (Mass. 1978)
  - Courts need not be involved

Persistent Vegetative State
● Persistent Unresponsive Wakefulness Syndrome (UWS)
  - Irreversible loss of cortical activity without loss of autonomic (brain stem) functioning
  - Lack consciousness, awareness
  - Retain reflexes, sleep wake cycles
  - Eyes open
  - Mnemonic for neuro exam "Lights on, nobody home"
  - Note: Mnemonic is not an evaluation of the personhood of the patient. Patients in PVS/UWS, even though they lack cortical activity, are still persons
  - Prognosis after 6 months = any recovery extremely unlikely
  • Jupiterman C, Denver A. Schidermeyer D. Practical Ethics for Students, Interns and Residents 3rd ed. 2006
Minimally Conscious State (MCS)

- MCS = severe and persistent alterations in consciousness
  - Inconsistent but discernible evidence of consciousness, such as the ability to localize sound and tactile stimuli
  - May have sustained visual fixation and pursuit
  - Prognosis for recovery - extremely poor
- Defined 2002
- Still needs epidemiology, elucidation of mechanisms of recovery, identification of clinically useful diagnostic and prognostic markers for decision making.

Voluntary Stopping Eating and Drinking (VSED)

- Right to refuse life-sustaining measures
  - does it extend to oral fluid and nutrition?
- Can a patient who is decisional put a similar refusal of oral feeding in an advance directive
  - What if the now demented patient appears to take offered nutrition and hydration voluntarily?
- Meaning of oral feeding as care (vs. artificial nutrition and hydration)
- Some advance directive legislation does not allow refusal of oral nutrition and hydration
- Long term care issues
  - Regulatory sanctions & elder abuse allegations

VSED

<table>
<thead>
<tr>
<th>Table: Options to Potentially Hasten Death</th>
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<tr>
<td>End-of-Life Option</td>
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<tr>
<td>Voluntary Stopping Eating and Drinking</td>
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<td>Physician-assisted Death (i.e., physician-assisted suicide or medical aid in dying)</td>
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Nevada Advance Directive Authorizing VSED in Dementia 2019


ECMO

- Extra Corporeal Membrane Oxygenation
- ECMO = Priority in Queue for Organ Transplantation OPTN Oct. 2019
- ~50% = bridge;
- ~50% = final destination (die in ICU)
- Median Charges = $550K/pt

Decision Making Capacity

- Vs. Competence
- Elements:
  - understand the information
  - evaluate the consequences and to make a decision
  - communicate the decision
- Assess for each decision
Decision Making for the Incapacitated

- Who should decide?
  - Guardian, health care agent, surrogate

- What standard should be used?
  - Substituted judgment, best interest

- How sure must the decision maker be?
  - Clear evidence, preponderance

Advance Directives

- Living Will - direction to physician
  - Terminal condition or PVS

- Power of Attorney for Health Care - appointment of agent often with direction
  - Any incapacity

Greater % of patients dying Out of Hospital

- Lower likelihood of dying in an acute care hospital, an increase and then stabilization of intensive care unit use during the last month of life, and an increase and then decline in health care transitions during the last 3 days of life
  - 33.5% Home
  - 24.6% Hospice

- 2015 compared with 2000

- Among Medicare fee-for-service beneficiaries who died
Cardiopulmonary Resuscitation

- Indication: Reversible arrhythmia from cardiac or other cause
- Everyone (with few exceptions) assumed to be “full code” unless ordered otherwise.
- Some rhythms better than others: VF vs. PEA
- The sooner the response the better (EMS, Bystander CPR, AEDs) – BUT
- Not indicated for everyone in cardiac arrest
- Not wanted by everyone in cardiac arrest
- Overall CPR survival rates are WAY lower than most people think
  - Survival to discharge thought >75%
  - vs. actual 10.6%
- Crist C. CPR survival rates are lower than most people think. Reuters Feb. 23, 2018
- Solution in hospital = DNR orders

Do-Not-Resuscitate Orders (1)

- Initially, CPR used for almost all arrests, but
- CPR appropriate for those with reversible cardiac arrhythmias or arrest
- DNR orders
  - Originally verbal, now written
  - Also called Do-Not-Attempt-Resuscitation (DNAR) orders, (or Allow Natural Death =AND orders)

Do-Not-Resuscitate Orders (2)

- Now 89% of in-hospital deaths DNR
- Based on patient preference and medical condition
- DNR ≠ Do not treat
- No “slow codes, show codes”
- Special settings
  - Anesthesia for procedures
  - Emergency medical services
  - Nursing homes

POLST Paradigm

- Physician Orders on Life-sustaining Treatment
  - Translation of patient wishes into portable pre-hospital physician orders
    - Resuscitation, Intubation, Artificial nutrition and hydration, Antibiotics, Dialysis
  - Widespread adoption
    - Also known by different acronyms depending upon the state in which it has been adopted: New York Medical Orders for Life Sustaining Treatment (MOLST), North Carolina Medical Orders for Scope of Treatment (MOST), West Virginia and Idaho Physicians Orders for Scope of Treatment (POST), and Vermont Clinician Orders for Life-Sustaining Treatment (COLST).

Advance Directives vs. POLST

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<tr>
<th>Advance Directives</th>
<th>POLST Paradigm</th>
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<tr>
<td>Population:</td>
<td>Advanced illness or frailty</td>
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<tr>
<td>Timeframe:</td>
<td>Future care/ future conditions</td>
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<tr>
<td>Who completes:</td>
<td>Patient/ Doctor</td>
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<tr>
<td>Resulting product:</td>
<td>Surrogate appointment &amp; statement of preferences/ Medical orders based on shared decision-making</td>
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<tr>
<td>Guide Actions by EMS &amp; EPs</td>
<td>Usually not/ Yes</td>
</tr>
<tr>
<td>Guide treatment decisions in the hospital</td>
<td>Yes/ Yes</td>
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LaPOST

- The Louisiana Physician Orders for Scope of Treatment (LaPOST) document
- Quality initiative of the Louisiana Health Care Quality Forum, a private, not-for-profit organization dedicated to reshaping health care in Louisiana.
- Approved as Act 954 in the 2010 regular session of the State Legislature, LaPOST is an evidence-based model designed to improve end-of-life care for those with serious, advanced illnesses.
POLST & Outpatient EOL wishes
- Out-of-hospital & ED care generally concordant with patient wishes
  - 94% POLST DNR orders honored
  - 84% POLST Resuscitate orders honored
- Vs. 60% If no POLST


Failure to honor DNR
- Florida Agency for Health Care Administration fined Jacaranda Manor, St. Petersburg, FL, $16,000
- 75 yo. man w; COPD, Ky dz and dementia had DNR order.
  - Had resp. arrest in dining hall and was resuscitated
  - LPN discovered DNR order after CPR & paramedic transport
- State fines St. Petersburg Nursing Home for violating residents do-not-resuscitate order

Allegation: Failure to give CPR
- Patricia Smithmyer, RN charged in NY with misdemeanor wilfull violation of health laws and felony falsifying business records
  - Possible 4 year imprisonment
- Resident w/ COPD, Alzheimer’s, full code
- Alleged: Patient has resp arrest while defendant (supervising RN) in room, did not provide or direct others to provide; patient died
- Alleged: false written statement that did not witness resp. arrest

Accuracy of Surrogate Decision Makers for the Incapacitated
- Patient-designated and next-of-kin surrogates incorrectly predict treatment preferences in 32% of cases
- Neither patient designation of surrogates nor prior discussion of patients' treatment preferences improved surrogates' predictive accuracy
  - Literature search re: studies on how accurately surrogates predict treatment preferences and efficacy of commonly proposed methods to improve surrogate accuracy.
  - 16 studies, 151 hypothetical scenarios and 2595 surrogate-patient pairs.

From Paternalism to Abdication?
- Early benchmark cases in bioethics
  - Physicians paternalistically overriding patients’ wishes to forgo life-sustaining medical treatment
- Now
  - In life support discussions with surrogates, for approximately half of the decisions that arise, physicians do not provide a recommendation
  - Even when families explicitly ask for a recommendation, only about half of physicians give one.
  - Struggle in training physicians
  - Not tamping down a burgeoning paternalism, but helping them understand their professional role to provide recommendations
  - rather than offering treatment and non-treatment options as menu choices

What Would Doctors Do?
- 88.3% of doctors wish to forego high-intensity treatments for themselves at the end-of-life
  - Opt for DNR
- Terminally ill patients are subjected to ineffective high-intensity treatments & die expected deaths from known chronic illnesses, BUT
  - Seriously ill patients prefer to die at home
  - Why do doctors treat their patients differently from how they themselves would want to be treated – and how the physicians themselves would want to be treated?
Burden of Surrogate Decision Making for the Incapacitated

- Making treatment decisions has a negative emotional effect on at least 1/3 of surrogates
  - Stress
  - Guilt over the decisions made
  - Doubt regarding whether made the right decisions
- Often substantial; typically lasts months (sometimes, years)
  - • Data Synthesis: 40 studies, 29 qualitative and 11 quantitative methods, data on 2,854 surrogates, > ½ of whom were family members of the patient

Aid in Dying/Physician Assisted Suicide [AID/PAS]

- Physician Assisted Death
- Physician Assisted Aid-in-Dying [AID]
- Medical Assistance in Dying [MAID]
- Death with Dignity [DWD] Acts

Physician Assisted Death: Oregon DWDA Experience

  - 1,459 deaths (0.4% of deaths)
- Top reasons
  - Loss of autonomy (91%)
  - Loss of activities enjoyed (89%)
  - Loss of dignity (75%)
  - Loss of bodily functions (44%)
  - Burden for family, friends, caregivers (45%)
  - Pain (26%), finances (4%), not out of state
- Physician Response to Requests for PAD (1)
  - Clarify the request
  - Determine the root causes
    - Fear of psychosocial, mental suffering, future suffering, loss of control, indignity, being a burden
    - Depression
    - Physical Suffering
- Physician Response to Requests for PAD (2)
  - Affirm your commitment to care for the patient
  - Address the root causes of the request
  - Affirm the patient’s control over treatment decisions and legal alternatives for control and comfort
  - Seek counsel from colleagues
    - Education on Palliative and End of Life Care (EPEC) Curriculum, 1999, 2003
- “Jobs died of respiratory arrest”
  - “Steve Jobs’ immediate cause of death was respiratory arrest, as cancer spread to other organs in his body, his death certificate reveals”
    - BBC News
      - Monday Oct. 10, 2011
“Futile”
- Useless, vain, ineffectual.
- [From Latin - futilis = leaky, that easily pours out]
- The gods condemned daughters of Danaus to carry water in leaky buckets, never achieving their goal
  - Hamilton E. Classical Mythology

Physician-Patient Relationship
- Whether to offer and perform medical treatment or procedure in a given situation is a professional medical determination
- Patient (or surrogate decision maker) may choose whether to accept or refuse that offer (autonomy)

“Do Everything”
- Everything that might:
  - Prolong life?
  - Relieve suffering?
  - What if can’t maximize both? How balance?
- “Everything”
  - Cognitive: Incomplete understanding/ Reassurance best medical care/ reassurance all life-prolonging treatment
  - Affective: Abandonment/ Fear/ Anxiety/ Depression
  - Spiritual: Vitalism/ Faith in God’s will
  - Family: Differing Perceptions/ Conflict/ Dependents

Discussion re: Everything
1. Understand what “everything” means to patient
2. Propose a philosophy of treatment
   - E.g. Balance of burdens and benefits
3. Recommend a plan of treatment
4. Support emotional responses
5. Negotiate disagreements
6. Use harm-reduction strategy for continued requests for burdensome treatments that are unlikely to work
   - Clinicians should still exercise clinical judgment

Doing Everything is not always Doing the Right Thing
- When the physician has the expertise (and professional responsibility) to determine whether proposed treatment would be effective, and
- When patient and/or family preference would result in:
  - No benefit (beneficence)
  - +/- significant harms to the patient (non-maleficence)

Intensivists’ Perception of Futility
11% of ICU patients “futile”
8.6% ICU “probably futile”
- 68% of “futile” died in hospital
  - 51% of remaining died with 6 months of ICU care
- Total 6 month mortality of “futile” = 86%

Futility Definitions (Translated)

1. “It won’t work (or won’t achieve the goals of the patient)” [quantitative]
   - General support by medical society ethics codes
2. “It may work, but if it does, it’s only going to work for a while, and will prolong the dying process [quantitative/qualitative]
   - Less consensus
3. “It’s not worth it (because of cost or quality of life)” [qualitative]
   - Most controversial

Futility -
AMA Code of Ethics

- All health care institutions should adopt a policy on medical futility
- Due process approach
  - Negotiate disagreements
  - 2nd opinion by consultant if appropriate
  - Ethics consultation
  - Seek transfer of care
  - No obligation to provide futile treatment
    - AMA Code of Ethics § 2.037

Futility
American College of Physicians

“[When] no evidence shows that a specific treatment desired by the patient will provide any medical benefit

The physician is not ethically obligated to provide such treatment (although the physician should be aware of any relevant state law).”

- “The physician need not provide an effort at resuscitation that cannot conceivably restore circulation and breathing…”

American College of Emergency Physicians (ACEP) Futility Policy

- Physicians are under no ethical obligation to render treatments that they judge have no realistic likelihood of medical benefit to the patient
- Emergency physicians’ judgments in these matters should be unbiased, and should be based on available scientific evidence, and societal and professional standards...
- [For] patients in cardiac arrest who have no realistic likelihood of survival...emergency physicians should consider withholding or discontinuing resuscitative efforts, in both the prehospital and hospital settings

“Not a Resuscitation Candidate”?

- Surgeons’ judgment resulting in a refusal to operate if a very high likelihood of mortality
  - “Not a surgical candidate”
  - “Do not want this patient to die on my operating table”
- Corresponding emergency medicine judgment, “Not a resuscitation candidate”?

Litigation Experience

Stopping life-sustaining treatment without consent

Several comprehensive studies of reported court cases
- Healthcare providers are overwhelmingly successful in lawsuits brought against them
- Study of unreported cases concludes the same
  - More success with suits for intentional infliction of emotional distress
    - When unilateral, no consent, no consultation, and especially deceptive and insensitive manner.
- Physicians who act unilaterally against family wishes run the risk of malpractice suits
  - Although suits usually unsuccessful because physicians are not shown to have violated standards of care.
**Futility & Professionalism**
- Determination of ineffectiveness is within the professional judgment of the physician
- Importance of careful determination, second opinion
- Multidisciplinary ethics committee can help with issues, communication, but not determination
- Professional determination of futility has burdens

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