Ethical and Legal Issues in End-of-life Care

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Ethical and Legal Issues in End-of-life Care

- No conflicts to disclose

Ethical and Legal Issues in End-of-life Care

- 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

Resolving Difficult Cases: Role of Law and Ethics

- 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

Dying in America: IOM Report 2014

- 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
      - http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx

Informed Consent

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

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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
    - Mack JW, Weeks JC, Wright AA, Block SD, Pregerson HG. End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent With Preferences. J Clin Oncol 2010:1203-1208.

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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
    - Weeks JC, Catalano PJ, Cronin A, et al. Patients expectations about effects of chemotherapy for advanced cancer. N Engl J Med 2012; 367:1616-1625

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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)

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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
    - Chapter 683, California Statutes (2008)

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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

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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)

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Refusal of Medical Treatment

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

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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

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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)

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Limitation of Treatment: The Consensus

- Right to refuse any intervention
  - Ventilators, feeding tubes, blood products
    - Bartling (Cal.App. 1984), Bouvia (Cal.App. 1986)
    - Wons (Fla. 1989), Fosmire (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
    - Meisel A. The consensus about forgoing life-sustaining treatment: Its status and prospects. Kennedy Institute of Ethics Journal. 1993;2:309-345.

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Persistent Vegetative State

- = 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: Menomic 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
  - Junkerman C, Derse A. Schiedermayer D. Practical Ethics for Students, Interns and Residents 3rd ed. 2008.
  - Churchill LR, King NMP. End of Life Ethics: Some Common Definitions. Social Med. Reader 2nd Ed. 2005

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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.
  - Fins JJ, Schiff, ND, Foley KM. Late recovery from the minimally conscious state. Ethical and policy implications. Neurology. 2007;68:304-307.

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
  - to apply when the patient is no longer decisional (e.g. dementia)?
- 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
  - Span P. Complexities of choosing and end game. New York Times. Jan 20, 2015. pD1 col 3.
  - Pope TM, West A. Legal Briefing: Voluntarily stopping eating and drinking. J. Clin. Ethics 2014;25(1):68-80.

VSED

Table. Options to Potentially Hasten Death

Potential Last Resort Option	Current Legal or Ethical Status in United States and Canada
Medications such as opiates for severe pain/dyspnea used proportionately	Legal and ethically accepted
Stopping or not starting life-sustaining therapy	Legal and ethically accepted
Palliative sedation, potentially to unconsciousness	Legally accepted Ethically controversial if patient or physician's intention is to hasten death
Voluntarily stopping eating and drinking	Not illegal; legality not tested Ethically controversial
Physician-assisted death (aka physician-assisted suicide or medical aid in dying)	Legal in 6 US states; all of Canada Illegal in >30 states and uncertain in others[11] Ethically controversial
Voluntary active euthanasia	Illegal in all US states Legal in Canada Ethically controversial

Special Communication | Health Care Policy and Law

January 2018

Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects

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> Author Affiliations

JAMA Intern Med. 2018;178(1):123-127. doi:10.1001/jamainternmed.2017.6307

Nevada Advance Directive Authorizing VSED in Dementia 2019

2. The form for end-of-life decisions of a power of attorney for health care for an adult with any form of dementia may be substantially in the following form, and must be witnessed or executed in the same manner as the following form:

END-OF-LIFE DECISIONS ADDENDUM
STATEMENT OF DESIRES

Here are your choices. Please circle yes or no to each of the following statements and sign your name below:

1. I want to take all the medicine and receive any treatment I can to keep me alive regardless of how the medicine or treatment makes me feel.	*YES*	*NO*
2. I do not want to take medicine or receive treatment if my doctors think that the medicine or treatment will not help me.	*YES*	*NO*
3. I do not want to take medicine or receive treatment if I am very sick and suffering and the medicine or treatment will not help me get better.	*YES*	*NO*
4. I want to get food and water even if I do not want to take medicine or receive treatment.	*YES*	*NO*

(YOU MUST DATE AND SIGN THIS END-OF-LIFE DECISIONS ADDENDUM)

- Nev. S.B.121, Signed Jul. 1, 2019; Effective Oct. 1, 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
  - Bailey M. Kaiser Health News/ USA Today. Jun. 17. 2019

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

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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

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Limitation of Treatment: Advance Directives

- Initially, no evidence that completion changed care
  - Teno JM, Lynn J, Wegner N et al. Advance directives for seriously ill hospitalized patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention. J. Am. Geriatr. Soc. 1997;45:500-507.
- Subsequently, patients who had prepared advance directives received care that was strongly associated with their preferences
  - 83.2% of subjects who requested limited care and 97.1% who requested comfort care received care consistent with their preferences
    - Silveira MJ, Kim SYH, Langa KM. N Engl J Med 2010;362:1211-1218.

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Advance Directives ~ 1/3 of US Adults

- 36.7% had completed an advance directive,
  - including 29.3% with living wills.
  - Proportions were similar across the years reviewed.
  - Review of studies published in the period 2011–16
    - proportion of US adults with a completed living will, health care power of attorney, or both.
  - 795,909 people in 150 studies analyzed
    - Similar proportions - chronic illnesses (38.2%) and healthy adults (32.7%) had completed ADs.
      - Yadav KN, Gabler NB, Cooney E, Kent S, Kim J, Herbst N, Mante A, Halpern SD Courtwright KR. Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care Health Aff July 2017 vol. 36 no. 7 1244-1251.

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Default Surrogate Consent

e.g. Illinois Surrogate Consent Act

- Hierarchy of surrogates able to make medical decisions for non-decisional patients
  - Priority of surrogates = Spouse • Adult child • Parent • Adult Sibling • Adult grandchild • Close friend • Guardian of the estate
    - If dispute, majority rule for children, siblings and grandchildren
  - If decision concerns forgoing life-sustaining treatment, patient must be in terminal condition, permanently unconscious, or incurable or irreversible condition
  - Standards § 40/20(b)
    - N/A to admission to mental health facility, psychotropic medication or ECT (see 405 ILCS 5/1-121.5; 5/2-102; 5/3-601.2, amended 1997)
      - 755 ILCS 40/1 to 40/65, at 40/25 (Smith-Hurd 2007)

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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% Hospital
  - 24% Hospice
- 2015 compared with 2000
- Among Medicare fee-for-service beneficiaries who died
  - Teno JM, Gozalo P, Trivedi AN, Bunker J, Lima J, Ogarek J, Mor V. Site of Death, Place of Care, and Health Care Transitions Among US Medicare Beneficiaries, 2000-2015. JAMA 2018;320(3):264-271.

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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%
  - Ouellette L, Puro A, Weatherhead J, Shaheen M, Chassee T, Whalen D, Jones J. Public knowledge and perceptions about cardiopulmonary resuscitation (CPR): Results of a multicenter survey. Am J Emerg Med. 2018. Online February 3, 2018. DOI: https://doi.org/10.1016/j.ajem.2018.01.103
  - Crist C. CPR survival rates are lower than most people think. Reuters Feb. 23, 2018
    - https://www.reuters.com/article/us-health-cpr-expectations/cpr-survival-rates-are-lower-than-most-people-think-idUSKCN1G72SW
- Solution in-hospital = DNR orders

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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)

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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

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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).
    - Schmidt TA, Hickman SE, Tolle SW, Brooks HS. The physician orders for life-sustaining treatment (POLST) program: Oregon emergency medical technicians' practical experiences and attitudes. *J Am Geriatrics Soc.* 2004; 52:1430-1434.

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Advance Directives vs. POLST

	Advance Directives	POLST Paradigm
Population:	All adults	Advanced illness or frailty
Timeframe:	Future care/ future conditions	Current critical care/current condition
Who completes:	Patient	Doctor
Resulting product:	Surrogate appointment & statement of preferences	Medical orders based on shared decision-making
Guide Actions by EMS & EPs	Usually not	Yes
Guide treatment decisions in the hospital	Yes	Yes

From Sabatino CP. Advance Directives vs. POLST 2018.

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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.

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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
      - Richardson DK, Fromme E, Zive D, Fu R, Newgard CD. Concordance of out-of-hospital and emergency department cardiac arrest resuscitation with documented end-of-life choices in Oregon. Ann. Emerg. Med. 2014;63:375-383.

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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
  - Tampa Bay Times Jun. 4, 2014. http://www.tampabay.com/news/state-fines-st-petersburg-nursing-home-for-violating-residents/2182898

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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
  - Kingston Nurse Charged With Failure To Give Life-saving Care To Nursing Home Resident; Patricia Smithmyer Charged With Falsifying Records; Faces Jail Time. NY Atty. Gen. Press Release. http://www.ag.ny.gov/press-release/kingston-nurse-charged-failure-give-life-saving-care-nursing-home-resident

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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
  - Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: A systematic review. Arch Intern Med. 2006;166(5):493-497.
  - 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.

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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.
      - White DB, Malvar G, Karr J, Lo B, Curtis JR. Expanding the paradigm of the physician's role in surrogate decision-making: An empirically derived framework. Crit Care Med. 2010;38:743-750.
  - 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 mere menu choices

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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 patients want to be treated – and how the physicians themselves would want to be treated?
  - Periyakoil VS, Neri E, Fong A, Kraemer H. Do unto others: doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives. PLoS One. 2014 May 28;9(5):e98246.

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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)**
    - **Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Ann Intern Med.** 2011;154(5):336-46
    - **Data Synthesis: 40 studies, 29 qualitative and 11 quantitative methods, data on 2,854 surrogates, > ½ of whom were family members of the patient**

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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**

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Physician Assisted Death: Oregon DWDA Experience

- **21 year experience (1998-2019)**
  - **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**
    - **Oregon Death with Dignity Act. Data Summary 2019. Oregon DHS. February 15, 2019**
- https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

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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**

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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**

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"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**
    - **http://www.bbc.co.uk/news/world-us-canada-15251734**

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"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

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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)

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"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
    - Quill TE, Arnold R, Back AL. Discussing treatment preferences with patients who want "everything." Ann Intern Med. 2009;151:345-349

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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
    - Quill TE, Arnold R, Back AL. Discussing treatment preferences with patients who want "everything." Ann Intern Med. 2009;151:345-349

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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)

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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%
  - Huynh TN, Kleerup EC, Wiley JF, Savitsky TD, Guse D, Barber BJ, Wenger NS. The frequency and cost of treatment perceived to be futile in critical care. JAMA Intern Med 2013;E1-E8.

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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

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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

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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 Physicians Ethics, Professionalism and Human Rights Committee. ACP Ethics Manual 6th ed. Ann intern Med. 2012;156;73-104.

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"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"?

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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
  - ACEP Non Beneficial ("Futile") Emergency Medical Interventions Policy (Approved 1998; Reaffirmed 2002; Reaffirmed 2008)

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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.
        - Pope TM. Legal briefing: Futile or non-beneficial treatment. Journal of Clinical Ethics. 2011;22(3)277-296.
- 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.
    - Luce JM. A history of resolving conflicts in end-of-life care in ICUs in the US. Crit Care Med. 2010;38(8):1623-1629.

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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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Ethical and Legal Issues in End-of-life Care

- 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

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