Managing Death at the End of Life

Jim Hoefler, Ph.D., Dickinson College

Medical consensus groups

- American Medical Association (1996)
- American College of Physicians (2012)
- American Thoracic Society (2008)
- American Nurses Association (2010)
- Catholic Health Association (1993)

Legal consensus groups

- National Center for State Courts (1996)
- Uniform Law Commissioners (1989)
- NY State Task Force on Life & the Law (1992)
- U.S. Supreme Court (1990, 1997)

Ethics consensus groups

- Center for Medical Ethics, UPMC (1991)
- Hastings Center (2013)
- *President's Commission Report* (1983)
- *Clinical ethics* (Meisel, et al. 2010)

Decision making	Wishes of competent adults should always be heeded. If the patient is not competent to make medical decisions, legitimate surrogates may be deferred to without involvement of the courts. Surrogates should decide on the basis of: (a) *Substituted judgment*: Surrogates should make the decision the patient would make, if able. Failing that, surrogates should use . . . (b) *Best interests* standard: What would be in the *best interests* of the patient; the decision *most people* would make given the circumstances.
Forgoing life-sustaining treatment	Forgoing life-sustaining treatment or providing aggressive palliative care with the intent of relieving suffering are clinically, legally, and morally acceptable and do not constitute mercy killing, euthanasia, assisted suicide, or suicide.
Withholding & withdrawing treatment	While withdrawing life-sustaining treatment is often more difficult psychologically (both for caregivers and decision makers), withholding and withdrawing treatment are morally and ethically equivalent acts. Any treatment than can be withheld can be withdrawn after it is started.
Terminal illness	While *Living Wills* are not normally operative unless a patient is declared to be incompetent and terminally ill (or in a persistent vegetative state), a patient need not be declared terminally ill for that patient (or the patient's surrogate) to make medical decisions about life-sustaining treatment.
ANH (Artificial Nutrition & Hydration)	ANH is a medical intervention that can be withheld or withdrawn like any other medical intervention (including respiratory support and the use of antibiotics). The old *ordinary-extraordinary* distinction (introduced by the Vatican in 1957) is no longer helpful and causes more confusion than clarity. It is more appropriate to talk about treatments that are *proportionate* and *disproportionate*, given the patient's prognosis.
Palliative care	*-- It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death, if the medication is intended to alleviate pain and severe discomfort, not to cause death.* Vacco v. Quill (1997) *-- Palliative sedation to unconsciousness may be considered for those terminally ill patients whose clinical symptoms have been unresponsive to aggressive, symptom-specific treatments*. AMA, Opinion 2.201 (2008).

ETHICAL PRINCIPLE 1 -- Patient self-determination: Caregivers should provide patients & surrogates with all they need to make fully informed decisions about a range of legitimate treatment alternatives. Requires caregivers to carefully and sensitively work through patient and family denial to the degree it exists.

MD End-of-Life Conversations **(1)** Get permission. **(2)** *Tell me what you understand.* **(3)** *May I express my opinion?* **(4)** Stop talking. **(5)** *I **wish** there was more we could do...* **(6)** *What is important to you?* **(7)** *Tell me back what you understand.* **(8)** *I am with you.* **(9)** *There is still lots that we can do…*

ETHICAL PRINCIPLE 2 -- Beneficence: Caregivers should do whatever they legitimately can to optimize the degree of satisfaction patients experience.

ETHICAL PRINCIPLE 3 – Non-malfeasance: Caregivers should "Do no harm." Intent of caregivers is key; so long as the intent is beneficent (e.g., relief of suffering), actions taken that may hasten death are acceptable, and may even be morally obligatory if the care giver is to avoid doing harm (*double-effect*).

Denominational Positions on End-of-Life Care

Roman Catholic (21%)
True compassion . . . encourages every reasonable effort for the patient's recovery. At the same time, it helps draw the line when it is clear that no further treatment will serve this purpose. Pope John Paul II: *Statement on Palliative Care*, National Catholic Bioethics Quarterly; 5, no. 1 (2005): 153-155.
Palliative care is an expression of the properly human attitude of taking care of one another, especially of those who suffer. It bears witness that the human person is always precious, even if marked by age and sickness. . . . For this reason, when life becomes very fragile and the end of earthly existence approaches, we feel the responsibility to assist and accompany the person in the best way. Pope Francis' address to the Pontifical Academy for Life, 3/5/15

Methodist (4%)
There is no moral or religious obligation to use [medical technologies] *when the burdens they impose outweigh the benefits they offer, or when the use of medical technology only extends the process of dying.*
-- *Faithful Care for Persons Suffering and Dying*, Book of Resolutions (2004).

Lutheran (4%)
Health care professionals are not required to use all available medical treatment in all circumstances. Medical treatment [including artificially-administered nutrition and hydration] *may be limited in some instances, and death allowed to occur. Patients have a right to refuse unduly burdensome treatments which are disproportionate to the expected benefits.*
-- *End-of-Life Decisions*, ELCA Message (1992)

Presbyterian (3%)
*The Christian moral tradition allows for the possibility of withholding or withdrawing treatment when it can no longer restore life. People should not have to fear that others will unnecessarily prolong their dying .. . . Such caring may require the Christian community to take initiative in developing and supporting new models of care, such as hospice. Euthanasia, Assisted Suicide and End-of-Life Issue*s, Study Guide (1995).

Assemblies of God (2%)
There are times when a debilitating accident, a life-threatening illness at an advanced age, or prolonged terminal illness without any natural hope of recovery makes it appropriate for a patient to say, "Do not perform any extraordinary measures to resuscitate me or maintain my body on life support machines, for I am ready to go home to be with my Lord" (2 Corinthians 5:1-10). *Euthanasia, & Extraordinary Support to Sustain Life,* AoG statement (undated)

Churches of God (2%); **Brethren in Christ** (1%)
The National Association of Evangelicals acknowledges that the withdrawal of life-support systems is an emotional and difficult issue. However, we believe that medical treatment that serves only to prolong the dying process has little value. It is better that the dying process be allowed to continue and the patient permitted to die. Termination of Medical Treatment, National Assoc. of Evangelicals (1994)

Episcopal (1%)
There is no moral obligation to prolong the act of dying by extraordinary means and at all costs if such dying person is ill and has no reasonable expectation of recovery. . . . The decision to withhold or withdraw life-sustaining treatment should ultimately rest with the patient, or with the patient's surrogate decision-makers in the case of a mentally incapacitated patient. Established Principles Re: the Prolongation of Life, Church Resolution (1991)

United Church of Christ (1%)
We can legitimately refuse certain medical treatments when 1) their purpose is solely to extend life without attendant quality of life, 2) they bring greater hardship than comfort, and 3) they provide no significant medical value. What might be ordinary and ethically mandated treatment for a healthy adult or child (for example, antibiotics for the treatment of pneumonia) may be excessive or extraordinary treatment for an elderly resident of a nursing home (pneumonia is often described as the "old person's friend") or a person is already in the final stages of the dying process. . . . Further, the utilization of pain relievers is not considered killing the patient even though morphine and other pain relief will likely shorten a person's lifespan. End-of-Life Care, UNC Science & Technology Taskforce (undated)

Jewish (2%)
Jewish law is compatible with the principles of palliative medicine and end-of-life care as they are currently practiced. Kinzbruner, BM. *Jewish Medical Ethics and End-of-Life Care*, J of Palliative Medicine, 7:4, 2004.

Jewish (Reform): *The Cessation of Medical Treatment for Terminal Patients. Jewish tradition teaches that we achieve this compassion through two means: measures aimed at the relief of pain, and the cessation of unnecessary medical treatment for the terminally ill. On the Treatment of the Terminally Ill,* CCAR RESPONSA, 5754.14

Figure 1:
Religious affiliation
in the U.S. (2014)

Pew Research Center