

Ethical Decision Making in End of Life care

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Reference:

***Ethics in End-of-Life Decisions in
Social Work Practice***, by

Ellen L. Csikai and Elizabeth Chaitin

Lyceum books, Inc. 2006

OBJECTIVES

- Review the core principles of bioethics.
- Discuss areas of conflict between principles.
- Review case examples which have influenced current practice.
- Discuss: “Is there a right to die with physician assistance?”
- Review NASW Practice Standards in EOL and Palliative Care, and NASW Code of Ethics

The core Principles of Bioethics

- Autonomy
- Nonmaleficence
- Beneficence
- Justice

AUTONOMY

Aka: self-determination

I have the right to make
decisions about the care I
want or don't want.

NONMALEFICENCE

Professionals act in ways that do not intentionally cause harm to others.

“First of all, do no harm.”

BENEFICENCE

Acting in ways that promote the welfare of other people.

Associated duties: protect the rights of others; prevent harm; rescue the vulnerable and those in imminent danger

JUSTICE

Related to the distribution of benefits and burdens in society.

FAIRNESS

EQUAL ACCESS

NON-DISCRIMINATION

Sources of Ethics

- Religion
- Custom, Common Law
- Case Law
- Legislation
- Standards of Practice
- Professional Codes and Standards

NASW CODE OF ETHICS--CORE VALUES

Service

Social Justice

Dignity and worth of the person

Importance of human relationships

Integrity

Competence

NASW STANDARDS FOR PALLIATIVE AND END OF LIFE CARE (2004)

Standard 1. ETHICS AND VALUES-- SWs must be prepared to deal with ethical dilemmas. NASW does not take a position on morality, but affirms the rights of the individual.

Standard 2. KNOWLEDGE and ***Standard 10. CONTINUING EDUCATION*** -- SWs maintain up to date working knowledge of theoretical and biopsychosocial factors essential to practice.

NASW Standards (cont'd)

Standard 3. ASSESSMENT and Standard 9. CULTURAL COMPETENCE-- the client in context: psychological, social, spiritual, cultural.

Standard 4. INTERVENTION-- TREATMENT PLANNING-- adapting approaches to client; flexibility

Standard 5. ATTITUDE--SELF AWARENESS-- compassion, respect toward client, SW awareness of own biases, care of self.

NASW Standards (cont'd)

Standard 6. EMPOWERMENT AND ADVOCACY--

Advocate for client, participate in social and political action to ensure equal access.

Standard 7. DOCUMENTATION

Standard 8. INTERDISCIPLINARY TEAMWORK

Standard 11. SUPERVISION, LEADERSHIP, TRAINING.

EOL Care Decisions: Evolution Across Generations

2017--Six living generations in America

1901-1926-- **The GI (“Greatest”) Generation**

1927-1945-- **The Silent Generation**

1946-1964-- **Baby Boomers** (largest at 77 million)

1965-1980-- **Gen X**

1981-2000-- **Gen Y/ Millennials** (the 9/11 Generation)

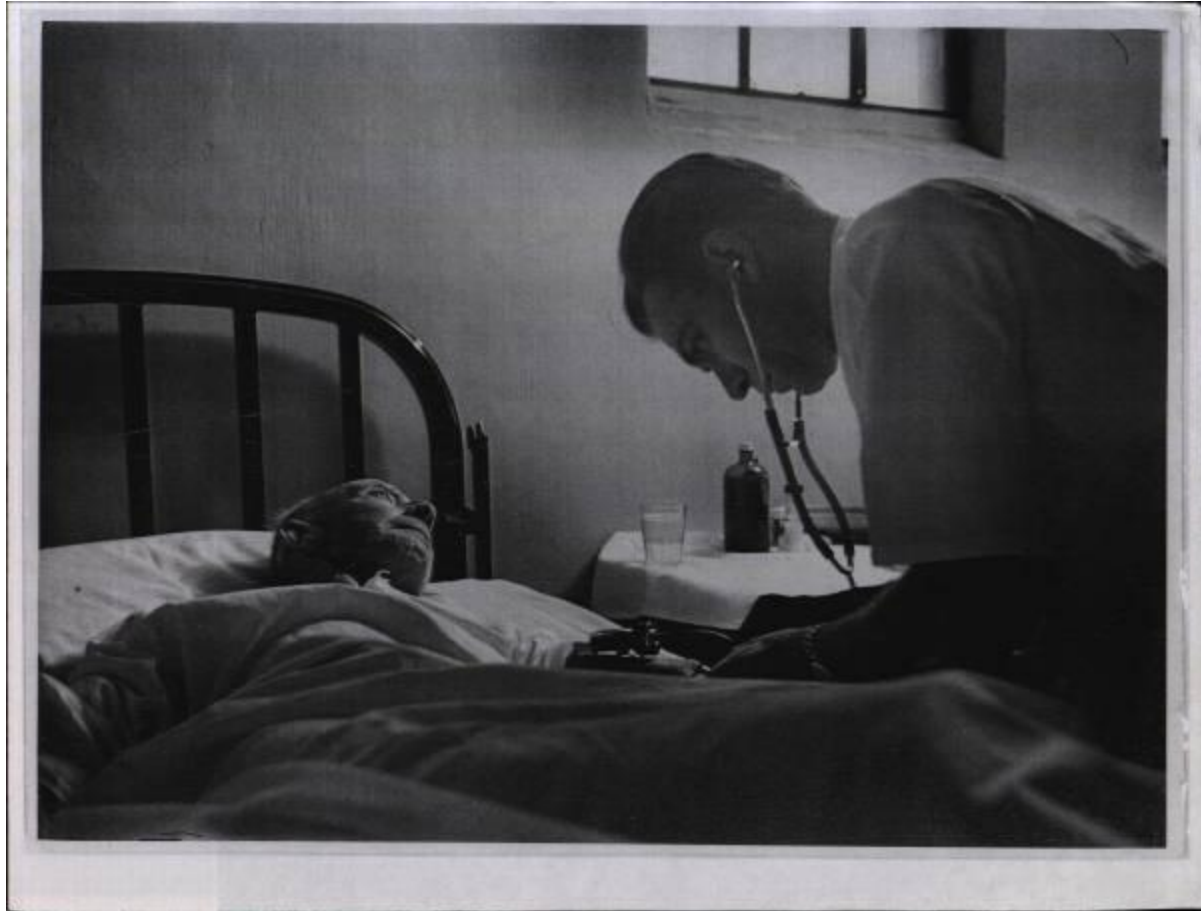
2001-- **Gen Z/ Boomlets**

EOL Care Decisions: A Contemporary Problem

The Case of President F.D. Roosevelt
April 12, 1945

What care choices were available at that time?

What ethical principle(s) was/were practiced?



The Standard of Care 1940s--50s . Photo: LIFE magazine, undated.

Advances in Life Saving Care

*1940s --Antibiotics

*1950s-- Experiments with Defibrillation

*1960-- Rescue Breathing

*1965-- White House Report-- **better chance of surviving an injury in combat than in a car crash in the USA**

*1969--first EMS Curriculum developed.

The Case of Karen Ann Quinlan, April 15, 1975

- 21 y/o single woman--unconscious after gin and valium.
- EMS resuscitates, hospital puts on life support.
- DX: Persistent Vegetative State (PVS), sustained by ventilator and feeding tube.
- Father: remove ventilator--is causing her pain.
- Local authorities: **removing ventilator to be charged as homicide.** Local court: ventilator to remain.

Karen Ann Quinlan Decision--1976

New Jersey Supreme Court Overrules Local court:

Precedent-- every competent person has the right to refuse any and all medical treatment, even if such refusal could result in death.

Distinction is made between “passive” and “active” actions leading to death.

The Case of Nancy Cruzan, 1988

- In 1983, this 25 y/o single woman crashes car.
- Prolonged anoxia at scene, EMS restores heartbeat.
- Comatose, feeding tube inserted, moved to rehab.
- No progress. Diagnosed PVS.
- Parents request removal of feeding tube, a “death prolonging procedure.”

Cruzan--*Missouri Supreme Court* decides: 1988

It would be wrong for the state to allow a feeding tube to be removed from a non-terminally ill patient without clear and convincing evidence of her wishes.

- Although in PVS, she is neither dead nor terminally ill.
- Her right to refuse treatment did not outweigh the state's policy favoring preservation of life.

Cruzan, ***US Supreme Court***, 1990

Recognized competent person's right to refuse life prolonging treatments, including nutrition and hydration.

In the case of an incompetent person, a state could adopt a standard of clear and convincing proof of a person's preferences.

Nancy Cruzan Inspires

Patient Self Determination Act of 1990

Sponsored by Senator John Danforth of Missouri--becomes law Dec. 1, 1991

Institutions receiving Medicare and Medicaid must inform patients about their right to accept or refuse treatment, and about existing State laws.

The Case of Terri Schiavo --1990

27 y/o married woman--sudden cardiac arrest.

EMS resuscitates--intubated and ventilated.

1990-1993--Rehab attempted, PVS diagnosed.

With no advance directives, husband, as guardian, authorizes DNR.

1998--husband petitions to have feeding tube removed.

Schaivo Case continued--

Feb. 2000--Florida court agrees with husband: remove feeding tube.

Parents disagree, file counter motion, courts debate.

Oct. 2003--feeding tube removed by order of Fla. court.

Florida legislature passes “Terri’s Law” , Gov. Jeb Bush orders feeding tube reinserted.

May 2004--Fla. Supreme Court--Terri’s Law is unconstitutional.

Schaivo Case goes to Washington-- March 2005

Republicans in US Congress vote to transfer case to Federal Courts.

President G.W. Bush signs legislation.

“Pro Life” and Disability Rights groups agree: continue tube feedings.

Federal Courts agree with Florida Courts: remove feeding tube. Terri dies on March 31, 2005.

Public Reaction to Legislative Intervention

Time Poll--70% disapprove of President and Congressional involvement.

“Keep Government out” of End of Life decisions.

Congressional opposition to “Right to Die” Legislation diminishes.

WV ADVANCE DIRECTIVES

- Medical Power of Attorney
- Living Will
- Do Not Resuscitate (DNR)
- Physician Order for Scope of Treatment (POST)
- Five Wishes

WV CENTER FOR END OF LIFE CARE

- www.wvendoflife.org
 - Forms and Resources
 - Upload Your Forms
 - For Patients
 - For Providers

AUTONOMY-- the core issue

Consent:

Informed

Implied

Substitute

THE LIMITS OF AUTONOMY

- **Does not cover**: immature, mentally incapacitated; coerced; impaired; intent on harming self or others.
- **State rights overrule individual rights to**:

Preserve life

Prevent suicide

Protect interest of innocent 3rd parties

Cultural Awareness Caveat

- Some cultural groups do not practice or endorse individual/ autonomous decision making.
- Collective decision making is the norm.
- The family is the source of support/strength.

Assessing Decision-Making Capacity

- If no Advance Directive, an assessment that the patient lacks DMC means that others will make decisions.
- *Incompetency is determined by a Court,*
- **Decision Making Capacity is a clinical judgment** made by authorized persons.
- *See handout*

BENEFACTENCE vs. NONMALEFACTENCE

Benefit

- *Therapeutic effect**
- *Prolong life**
- *Relieve pain**

Cost

- *Side effect**
- *Continue suffering**
- *Hasten death**

JUSTICE

- **Is access to care equal?**
- **Do we have a free market, or a controlled market?**
- **Are there limits to free choice?**
- **How are we to allocate scarce resources, such as organs for transplant?**

Access to Healthcare??

“ I have to tell you, it’s an unbelievably complex subject.

Nobody knew that healthcare could be so complicated.” Donald J. Trump-- February 27, 2017

Physician Assistance in hastening death

euthanasia

Is it legal?

Is it moral?

Is it ethical?

Dr. Kevorkian Makes House Calls--1990



Oregon “Death with Dignity” Law--1994 and 1997

- Allows some terminally ill to choose the time of own death.
- Requires terminal prognosis (<6 months) by two physicians.
- No mental or mood disorder that impairs judgment.
- No coercion.
- Must receive counseling about hospice and palliative care.
- No obligation to fill the Rx for life ending drugs.

Bush Administration Opposes DWDA

- **2001 Attorney General Ashcroft:** Rx. under Federal controlled Substances Act for the purpose of hastening death of terminally ill person was “**not medically legitimate**” action and would be sanctioned.
- **Jan. 2006-- US Supreme Court (6 to 3) in Gonzalez v. Oregon:** Federal authority over controlled substances did not give government power to determine medically legitimate purposes.

The Case of Brittany Maynard 2014



Oregon Death With Dignity Act

- Three Pillars
 - **Patient self-determination**
 - **Professional immunity and integrity**
 - **Public accountability--website, data available online**

Critics of “Death with Dignity”

The Disability Rights Education and Defense Fund

- Could let insurance companies coerce vulnerable into “cheap and quick” death.
- Delaying approval for treatment could steer persons to choose death to end suffering.
- Depressed persons could “doctor shop”.
- Errors in determining prognosis

The Case of John R

Case Review and Discussion

What is our ethical duty?

RESOURCES

The WV Center for End of Life Care www.wvendoflife.org

National Hospice and Palliative Care Organization www.nhpco.org

Compassion and Choices (supports aid in dying)

www.compassionandchoices.org

Disability Rights Education and Defense Fund (opposes aid in dying)

www.dredf.org