ADVANCE DIRECTIVES &
“DEATH PANELS”

AN ETHICS PERSPECTIVE

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Advance Directives

I. What advance directives are *not* . . .

II. Why *do* advance directives?

III. Why we *don’t* do advance directives...

IV. Why not do them anyway?
Learning Objectives:

1. To distinguish between "death panel" myths and appropriate advance care planning (ACP)
2. To give at least four ethical reasons for executing advance directives
3. To discuss at least one EOL case in which lack of advance care planning resulted in bad outcomes
4. To discuss at least one EOL case in which advance care planning resulted in better dying
5. To list several reasons why many Americans still hesitate to complete advance directives
6. To demonstrate knowledge of studies indicating that ACP with a physician is beneficial
Contextualizing . . .

Advance Directives
in relation to
Decisional Capacity
Patient has Capacity to Make Decisions?

Yes

Informed Consent Process

Right to Choose or Refuse Treatment

No

??????
Patient has Capacity to Make Decisions?

Yes

No

Advance Directive?
Advance Directives

I. What advance directives are not?

II. Why do advance directives?

III. Why we don’t do advance directives...

IV. Why not do them anyway?
Advance Directives are NOT a tool of Obama’s “Death Panel”
The “Death Panel” Myth...

Kaiser Health Tracking Poll (July 2010):
(of senior citizens polled)

Q: To the best of your knowledge, would you say the new [healthcare reform] law does or does not do each of the following?

- Allow a government panel to make decisions about end-of-life care for people on Medicare
  - 36% say ‘yes’
  - 17% don’t know

53% of seniors don’t know it’s mythical

http://www.kff.org/kaiserpolls/8084.cfm
Statement on the Current Health Care Debate
by Sarah Palin on Friday, August 7, 2009 at 3:53pm

As more Americans delve into the disturbing details of the nationalized health care plan that the current administration is rushing through Congress, our collective jaw is dropping, and we’re saying not just no, but hell no!

The Democrats promise that a government health care system will reduce the cost of health care, but as the economist Thomas Sowell has pointed out, government health care will not reduce the cost; it will simply refuse to pay the cost. And who will suffer the most when they ration care? The sick, the elderly, and the disabled, of course. The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care. Such a system is downright evil.

Health care by definition involves life and death decisions. Human rights and human dignity must be at the center of any health care discussion.

Rep. Michele Bachmann highlighted the Orwellian thinking of the president’s health care advisor, Dr. Ezekiel Emanuel, the brother of the White House chief of staff, in a floor speech to the House of Representatives. I commend her for being a voice for the most precious members of our society, our children and our seniors.

We must step up and engage in this most crucial debate. Nationalizing our health care system is a point of no return for government interference in the lives of its citizens. If we go down this path, there will be no turning back. Ronald Reagan once wrote, “Government programs, once launched, never disappear. Actually, a government bureau is the nearest thing to eternal life
Sarah Palin on FaceBook  (8/7/09)

Referring to HR 3200, Sec 1233: Advance Care Planning Consultation

- “The America I know and love is not one in which my parents or my baby with Down syndrome will have to stand in front of Obama’s ‘death panel’ so his bureaucrats can decide, based on a subjective judgment of their ‘level of productivity in society,’ whether they are worthy of health care. Such a system is downright evil.”
HR 3200, Sec 1233: Advance Care Planning Consultation

- (hhh)(1) Subject to paragraphs (3) and (4), the term 'advance care planning consultation' means a consultation between the individual and a practitioner described in paragraph (2) regarding advance care planning, if, subject to paragraph (3), the individual involved has not had such a consultation within the last 5 years. Such consultation shall include the following:
  (A) An explanation by the practitioner of advance care planning, including key questions and considerations, important steps, and suggested people to talk to.
  (B) An explanation by the practitioner of advance directives, including living wills and durable powers of attorney, and their uses.
  (C) An explanation by the practitioner of the role and responsibilities of a health care proxy.
The “Death Panel” Myth...

Harris Poll (July 2010):

Q: Does the Obama healthcare reform legislation establish “panels to decide what care very sick, older people should receive?”

- 33% say, yes, there will be ‘death panels’
- 44% aren’t sure if there will be “death panels”
- 23% understand that “death panels” are myth, not fact

The “Death Panel” Myth...

Report on Harris Poll (July 2010):

“. . . about one-third believed, incorrectly, that the legislation means there will be "panels to decide what care very sick, older people should receive," while 44 percent weren't sure if the bill would establish these panels. (So-called "death panels" were a rallying cry for those opposed to the legislation. The final law doesn't include such provision.)”

“Americans Still Confused About Health Reform”

Jenifer Goodwin, HealthDay News (7/29/10)

Advance Directives ARE...

- a mechanism for communicating and/or documenting “advance care planning”
- “a document in which you give instructions about your health care if, in the future, you cannot speak for yourself”

AMA website. 1995; AARP, ABA commission on legal problems of the elderly, and AMA
Definitions

- **Directives**
  
  = patient’s wishes/preferences
  ≠ “orders” (e.g., “doctor’s orders”)
  ≠ DNR/I (which is a doctor’s order)

- **Advanced**
  
  = pre-directives

Q: *In advance of what?*
A: decisional incapacity
An advance directive answers 2 questions:

1. **What** would you want done . . .?
   → *Healthcare Directive* form
   (or “living will” or ...)

2. **Who** would you want making healthcare decisions on your behalf?
   → *Durable Power of Attorney* form
   (or “proxy directive” or ...)

When does an advance directive become effective?

a) At the time of execution?
b) When a doctor says so? 
c) When the named proxy says so? 
d) When the ethics consult says so?
When does an advance directive become effective?

a) At the time of execution?
b) When a doctor says so?
c) When the named proxy says so?
d) When the ethics consult says so?
e) **When the patient loses decisional capacity for healthcare decisions and decisions need to be made**
Then... *proxy* decision-makers:

1. Respect the autonomy of the patient by decisions in keeping with written and/or oral directives

   *What did the pt tell us about this?*

2. Use “substituted judgment” for decisions not addressed in the pt’s directives, but consistent with relevant values of the pt

   *What would the pt have wanted done...?*

3. Act beneficently and nonmaleficiently in the “best interest” of the pt for decisions on which nothing is known of the pt’s preferences or values

   *What would a reasonable person decide...?*
Advance Directive documents come in many versions...

- *Caring Conversations* [& “for young adults”]
- *Courageous Conversations*
- *My Life: What I Want You to Know*
- *Five Wishes*
- *Respecting Choices*
- State forms
- Hospital forms

NONE of them looking anything like a “death panel” document...
Advance Directives

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III. Why we *don’t* do advance directives...

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Advance Directives

I. What *are* advance directives?

II. Why *do* advance directives?
   I. Because of American values
   II. Because it’s our legal right
   III. To avoid going to court
   IV. Dying is hard enough anyway
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   I. *Because of American values*
   
   II. Because it’s our legal right
   
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   IV. Dying is hard enough anyway
Advance Directives are grounded in what biomedical principle and American value?

a) Beneficence?
b) Nonmaleficence?
c) Respect for (patients’ ) autonomy?
d) Distributive justice?
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c) **Respect for (patients’ ) autonomy?**
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Healthcare providers are required:

“(A) to provide written information to each such individual concerning—

“(i) an individual’s rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives (as defined in paragraph (3)), and “(ii) the provider’s or organization’s written policies respecting the implementation of such rights;

“(B) to document in the individual’s medical record whether or not the individual has executed an advance directive;

http://www.fha.org/acrobat/Patient%20Self%20Determination%20Act%201990.pdf
It’s our (a patient’s) right to decide who will decide...

**CASE:** Pt Joan J has lost decisional capacity due to Alzheimer’s. Five years ago she completed an advance directive, naming her church friend Helen to be DPOA for healthcare decisions. A recent stroke has left Joan unable to swallow. It’s possible she eventually could regain function. A decision must be made whether or not to place a PEG tube for MANH.

**Q:** Who should decide for Joan?
It’s our (a patient’s) right to decide who will decide...

Q: Who should decide for Joan, per accepted ethical principles and by law?

a) Her partner, Lee, of 20 years
b) Her brother, whom she sees infrequently
c) Her mother, 95 y/o but alert and attentive
d) Her church friend and named DPOA, Helen
e) A legal guardian to be appointed by a judge
It's our (a patient's) right to decide who will decide...

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However, in some states, a court appointed guardian may amend or revoke the DPOA, if necessary...
It’s our (a patient’s) right to decide who will decide...

**CASE:** Pt John K, 73 y/o, has lost decisional capacity, on vent, and in multi-organ failure. Two weeks ago, while still capacitated, he consented to ICU dialysis, despite having written in advance directives that he wouldn’t ever want dialysis. He named his spouse as DPOA. She now says, no dialysis, and comfort measures only. But what about 2 weeks ago??

**Q:** Should doctors do dialysis or heed DPOA?
It’s our (a patient’s) right to decide who will decide...

... DPOA says, no dialysis, and comfort measures only. But what about 2 weeks ago??

Q: Should doctors do dialysis or heed DPOA?

a) Dialyze, vent, etc on grounds that AD is overridden by prior consent to aggressive care?
b) Heed DPOA, don’t dialyze, comfort measures?
c) Comfort measures only, on grounds of medical futility—further vent, dialysis, CPR is nonbenefical and potentially harmful to pt?
It’s our (a patient’s) right to decide who will decide...

... DPOA says, no dialysis, and comfort measures only. But what about 2 weeks ago??

**Q: Should doctors do dialysis or heed DPOA?**

a) Dialyze, vent, etc on grounds that AD is over-ridden by prior consent to aggressive care?

b) **Heed DPOA, don’t dialyze, comfort measures**

c) **Comfort measures only, on grounds of medical futility—**further vent, dialysis, CPR is nonbenefical and potentially harmful to pt
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Terri Schiavo...

- Collapses in cardiac arrest Feb 1990 (26 y)
- Resuscitation “successful”--but brain damage due to lack of oxygen
- Sustained via “tube-feeding” (artificial [or “medically administered”] nutrition and hydration = ANH)
- Various treatments/therapies/placements, with no significant improvement
- Diagnosis: PVS--persistent vegetative state
- *No written Advance Directive* . . .
- *No clear or undisputed family or caregiver conversation regarding end of life issues* . . .
The Terri Schiavo “Case”...

Schiavo v. Schindlers . . .
NANCY BETH CRUZAN
MOST LOVED
DAUGHTER — SISTER — AUNT

BORN JULY 20, 1957
DEPARTED JAN. 11, 1983
AT PEACE DEC. 26, 1990
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Dying in America Today:

- 70%+ of us prefer to die at home
  Only ~25% of us do so
- 50%+ of deaths occur in hospitals
  - Not all offer palliative care programs
- 20% Medicare deaths are in ICU
- Only 12%-26% deaths involve hospice

- Means to a Better End: A Report on Dying in America Today, 11/18/02
- 2006 American Hospital Association Annual Survey of Hospitals
Dying in America Today:

✓ 25% of nursing home residents were in pain for at least 2 months, without appropriate pain management.

Means to a Better End: A Report on Dying in America Today, 11/18/02
“The United States is a cold and uncaring place to die, offering little relief from pain or even sympathy to people in their last weeks and months.”

(Reuters, reporting the release of *Means to a Better End: A Report on Dying in America Today*, 11/18/02)
>50% of us will die in hospitals, many of us on life-support

80% of those who die in hospitals are without decisional capacity

Q. Will you be able to make your own EOL health care decisions?

(Flip a coin...
3 more reasons for ADs:

1. To prevent avoidable suffering . . .
   - For dying patients
   - For their survivors
     - Spouses 2X more likely to die soon if partner’s EOL was not good

2. To protect providers . . .
   - “Doctors don’t want to be flying in the dark, but they are so scared of being sued that they over-treat.”

3. To avoid families’ financial ruin . . .
   - “If everyone had an advance directive, it would save $1.7 billion a year in health care expenses.”
   - >30% families of pts dying in ICU are financially devastated (SUPPORT study findings, JAMA 1995)

Stephen Kiernan, *Last Rights* (St Martin’s Press, 2006)
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Why we (most) DON’T complete Advance Directives:

1. Apathy
2. Procrastination
   - Task not perceived as urgent
   - More highly valued with urgent medical need
3. Discomfort with the topic
4. Uncertainty on how to express preferences
5. Fear of irrevocability
6. Belief that family will/should decide
   - Many (30-65%) would rather trust a proxy than express a preference

Why we (most) DON’T complete Advance Directives:

7. Because “they don’t work” . . .

Really?
HEALTH CARE DIRECTIVES:

Donna Mae Rosell

I am not afraid to die; I just don’t want to hurt.
Do everything possible for pain and symptom management.
I desire a D.N.R. (Do Not Resuscitate) order. If doctors are quite sure that I will not “get better,” I do not wish to be kept alive by artificial or mechanical means. If a ventilator or a feeding tube might be used short term only for getting through an ‘episode’ from which I have good possibility of getting better, it may be considered and tried. Do not continue if I won’t get better. Listen to my husband and to my children where I am not sure what I want in a given situation.
Do not prolong life where there is no quality of life and where it prolongs pain and suffering.
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AD documents and especially conversation
Does (just) **talking** about end of life actually help?
LETTING GO

What should medicine do when it can’t save your life?

by Atul Gawande

AUGUST 2, 2010

Modern medicine is good at staving off death with aggressive interventions—and bad at knowing when to focus, instead, on improving the days that terminal patients have left.

Sara Thomas Monopoli was pregnant with her first child when her doctors learned that she was going to die. It started with a cough and a pain in her back. Then a chest X-ray showed that her left lung had collapsed, and her chest was filled with fluid. A sample of the fluid was drawn off with a long needle and sent for testing. Instead of an
Does talking about EOL help?

Aetna study of terminally ill pts provided phone calls and visits from nurses

- Hospice use went from 26% to 70%
- ICU use fell 67-85%, ERs by 50%
- Costs decreased by 25%

“Somehow that was enough—just talking.”
Coping with Cancer study of terminal pts

Of the 33% who had an EOL discussion with their doctor:

- “far less likely” to have CPR, vent, ICU
- 2/3 used hospice
- “suffered less, were physically more capable...to interact with others”
- Less depression in family members
This doesn’t sound much like a “death panel…”

“In other words, people who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation, and to spare their family anguish.”
CASE of LaCrosse, WI . . .

1991-present:
  collaborative emphasis on advance directives ("Respecting Choices") and discussion (using a list of 4 questions)
  - after 5 yrs, >85% deaths had completed ADs
  - EOL costs = 50% of national average
CASE of LaCrosse, WI . . .

1991-present:

- collaborative emphasis on advance directives ("Respecting Choices") and discussion (using a list of 4 questions)

Gawande: “The discussion, not the list, was what mattered most.... It was that simple—and that complicated.”
Letter-Writing
(or video or audio taping)
as yet another means to a better end...
(preparatory to conversation)
Why not me? I’ve had a good journey.

I’m not afraid to die; I just don’t want to hurt...

It isn’t what we wanted, but there are many good things happening, too.... Everyone is being so kind. I’m just so thankful.

Donna Mae Rosell, September 2008

(quoted with permission)
“Making Our Wishes Known”
Terry Schraeder, MD
Boston Globe 12/5/06

“Many people in my generation are watching and worrying as our parents get further and further into their senior years....

Baby boomers like me are truly unprepared for these issues.... We will no doubt overwhelm our current system....

It is imperative that we talk about a plan with our loved ones now....”