

Ethical Issues in Advance Care Planning

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Why discuss advance care planning?

- A 75 yo woman with advanced dementia is admitted to the hospital from home with an aspiration pneumonia. Due to worsening function, the patient can no longer be cared for at home.
- The family and clinicians decide to place a G-tube prior to NH transfer.

■ About what percentage of patients say that they would be “very unwilling” or would “rather die” than be permanently fed through a tube?

1 - 100%

2 - 75%

3 - 50%

4 - 25%

5 - 0%

Willingness to Live Permanently Fed Through a Tube

(N=3828)

<u>Very Willing</u>	<u>Somewhat Willing</u>	<u>Somewhat Unwilling</u>	<u>Very Unwilling</u>	<u>Rather Die</u>
3%	14%	8%	24%	52%

-SUPPORT study data

Case – Questions to Consider

- Can the patient speak for himself?
- What is this patient's prognosis? What are the likely outcomes?
- Has the patient previously stated preferences that contradict likely outcomes?
- How to approach the incapable patient with no available surrogates?

The Goals of the Healthcare System

- Restoration of health, saving of life
- Restoration or preservation of function
- Relief of symptoms, provision of comfort
- *Steward scarce healthcare resources?*

Some Basic Principles

■ **Autonomy**

– An individual may choose a course of action in accordance with a plan chosen by him or herself. An autonomous person is self-governing; free from internal and external constraints.

» "Every human being of adult years and of sound mind has a right to determine what shall be done with his body"

(Schloendorff v. Society of New York Hospital.)

Some Basic Principles

■ **Beneficence**

- To promote the best interests of another

 - » Nonmaleficence is the related principle not to inflict harm

■ **Justice**

- Treat similar cases similarly

■ **Veracity**

- Always tell the truth

Fiduciary Duty of the Physician

- Strive to achieve the goals of the patient
- Underpinnings of the fiduciary duty
 - Relationship inherently imbalanced; physician holds knowledge, patient ill and vulnerable
 - Expectation of the patient on entering the relationship
 - Part of the responsibility of a self-governing profession
 - Training, practice and experience owed to society and its members

General Requirements of Informed Consent

- Decision-making capacity
- Necessary information
 - What a reasonable patient would want disclosed under similar circumstances
- Understand the information
- Alternatives to the procedure or treatment
 - Including the possibility of no treatment
- Risks and benefits
- Consent without coercion

Informed Consent: Unusual Treatment Choices

- Adult patients choosing a care plan different than recommended should have preferences followed taking into account:
 - Patient's decision making capacity and adequate informed consent
 - Patient's choices may be limited to the goals of medicine
 - Symmetric evaluation

Decision-Making Capacity

■ Capacity

- Clinical condition in which a patient is able to adequately participate in medical decision making to direct care

■ Requirements of capacity

- Able to communicate
- Able to understand relevant information
- Able to appreciate the situation and its consequences
- Able to rationally manipulate information

Decision-Making Capacity

- Capacity may be limited by internal and external factors.
- Clinical maneuvers may enhance capacity:
 - Depression -> pharmacologic or talk therapy
 - Delirium -> remove medications, treat disease, timing
 - Somnolence -> remove medications, treat disease
 - Psychosis -> pharmacologic therapy
 - Cultural misconnection -> recognize, consider match

Decision-Making Capacity

- Capacity may be gained or lost. May require re-evaluation
- Capacity may be decision-specific:
 - Sliding scale: Decisions with greater potential for harm may require a higher level of capacity
- Who may judge decision making capacity?
 - All physicians can judge a patient's capacity to make decisions
 - Psychiatric and neurologic consultation may be helpful
 - Evaluation for patients who speak a language other than English requires an interpreter

Capacity Cases

- Which patient provided informed consent (or refusal)?
 - A - Jehovah's Witness with decision making capacity refuses blood for religious reasons.
 - B - Patient delirious due to hypoxemia refuses intubation and mechanical ventilation.
 - C - Psychotic patient--oriented times zero--signs for an indicated cholecystectomy
 - D - Patient in septic shock refuses antibiotics because "All I have is the stomach flu and you can't treat a virus with antibiotics."

Efficient Testing of Decision Making Capacity

- Tell me what you understand to be the current situation...
- What are your treatment options?
- What will happen when you take this treatment? What makes you not want this treatment? Why do you want it?
- What other choices do you have?
- Tell me about the decision. How did you arrive at your choice?
- What questions do you have? What are you worried about?

Decisions for Patients who Cannot Decide for themselves

- Best: Patient's preferences.
- Second best: Substituted judgment
- Third best: Best interests judgment

Decision makers for Patients who Cannot Decide for themselves

- An appointed healthcare proxy
- If no appointed proxy, family members
- Whether or not they know the patient's preferences, many patients simply want their family members to make decisions for them after they lose decision making capacity

Decision makers for Patients who Cannot Decide for Themselves (*cont.*)

- Studies show that surrogates often do not know what treatments patients want and rate a patient's quality of life worse than the patient's own rating.
 - However surrogates know patients' preferences better than caretaking physicians.
- Unrelated friends may be *ethically* appropriate surrogate decision makers
- If there is no surrogate decision maker for a patient who has lost decision making capacity, an ethics committee may facilitate decision making or consider legal designation of a guardian

Decisions for Patients Without Decision Making Capacity

- Best: to know patient's preferences
 - Advance directives preserve patient preferences to be employed after patient has lost decision making ability
- Second best: "substituted judgment"
 - Surrogate makes decisions based on patient's preferences and values previously discussed
- Third best: "best interests" judgment
 - Best if surrogate able to apply some knowledge of patient. Less good: judgments based on objective estimates of QOL.

Surrogates need decision
making capacity too

How to Approach End-of-Life Decisions?

- A 42 yo man sustained a serious brain injury in an MVA. He is resuscitated and receives extensive aggressive care. Years later, he is conscious yet severely disabled, both mentally and physically, and dependent on artificial nutrition and hydration. The wife and daughter disagree with the patient's mother about whether to continue tube feeding.

Wendland Decision

- Conservator may not withhold artificial nutrition and hydration from a conscious conservatee who is not terminally ill, comatose, or in PVS, and who has not left formal instructions for health care or appointed a surrogate for health care decisions, absent "clear and convincing evidence that the conservator's decision is in accordance with either the conservatee's own wishes or his or her best interest."
 - California Supreme Court, August 2001

Wendland Decision (*cont.*)

- Applies only to a case with *all* of the following:
 - Court appointed a conservator in the absence of a patient-designated health care surrogate and;
 - The conservator proposes to withhold or withdraw life-sustaining treatment and;
 - The patient is conscious and;
 - The patient has not left formal instructions for health care and;
 - The patient is not terminally ill.

What Guides Care at the End of Life?

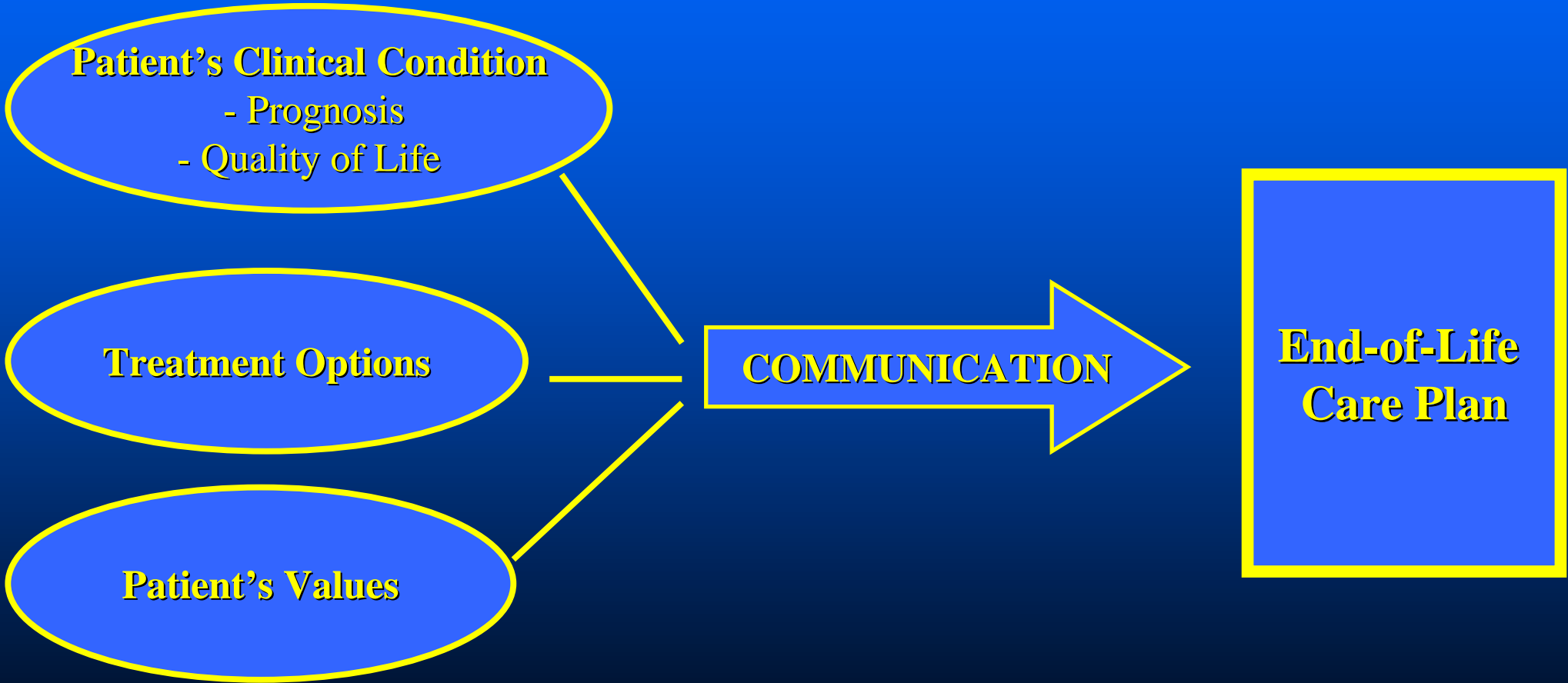
Patient's Clinical Condition
- Prognosis
- Quality of Life

Treatment Options

Patient's Values

COMMUNICATION

**End-of-Life
Care Plan**



Advance Care Planning: Theory

- Principle of autonomy dictates that patients have the right to direct care.
- Physicians have a beneficent duty to tailor care to clinical circumstances and preferences (and steward resources).
- Toward the end of life this may require
 - specification of a surrogate
 - documentation of values or preferences to inform care when patients lack capacity.

Advance Care Planning Practice

Four steps for successful Advance Care
Planning:

1. Recognize need
2. Discuss
3. Document
4. Review and update

Advance Care Planning:

1. Recognize need

- Three types of patients should be especially targeted for ACP:
 - Patients with no family or with family members who do not have decision making capacity
 - Patients for whom there is likely to be disagreements among potential surrogates
 - Patients for whom the likely surrogate would make different decisions than what the patient would want

Advance Care Planning: Recognize need (*cont.*)

■ Integrate questions into “History”

– **HPI:**

- » Does patient know diagnosis and prognosis?
- » Is patient likely to lose decision making ability?
- » Is patient likely to need life-sustaining treatments?

– **Social History:**

- » Is there a family? Which members would help make decisions?
- » Is family able to make decisions? At risk of losing capacity?
- » Would surrogates make different decisions than patient?

Factors associated with deteriorated function post-CPR

	<u>Odds Ratio (95% CI)</u>
Age <u><</u> 55 years	1.00
56 - 65 years	1.13 (0.33, 3.89)
66 - 75 years	1.21 (0.38, 3.86)
>75 years	5.25 (1.45, 19.1)
Acute physiology score (per point)	1.02 (1.00, 1.05)
CPR hosp day <u>></u> 4	8.30 (3.14, 23.3)

Advance Care Planning:

2. Engage in Discussions

- Determine patient familiarity, comfort level
- Use an iterative process
- Elicit patient's/family's values, goals
- Describe scenarios, options for care
- Multidisciplinary approach
- It is appropriate to make *recommendations*

Eliciting Preferences for End-of-life Decisions

- Define key medical terms
- Ask about past experiences
- Describe possible situations
- Explain benefits, burdens, outcomes of treatments
 - Life support can be used as a short-term trial
 - Any intervention can be refused

Why Don't Physicians Engage in End-of-Life Discussions?

- Physician believes the pt will not die during the hospital admission
- PCP should discuss DNR instead
- Not knowing the patient well enough or too little time to get to know the patient.

-Eliasson et al. *Arch Intern Med.* 1999;159:2213-8.

Advance Care Planning:

3. Document information

- The California Advance Health Care Directive
 - A Durable Power of Attorney for Health Care
 - NOT a financial instrument
 - May be revoked orally at any time until patient loses decision making capacity
 - **USUALLY** becomes effective when patient loses capacity
 - Provides physician with legal immunity for following DPAHC specified wishes
 - Physician with objections of conscience should transfer care

Oral Appointment of a Surrogate

- A person may appoint a surrogate by telling the primary physician.
- The physician must document in the medical record that the patient has capacity and who the surrogate is to be.
- The appointment lasts through the course of the hospitalization and supercedes any prior directive, oral or written.

Physician Duties

- To request a copy of the directive to be placed in the medical record.
- To document the existence or revocation of a written or oral directive.
- To document the loss and the recovery of decision-making capacity.
- To inform the patient of decisions made by the surrogate before implementing those decisions.
- To comply with the instructions of the patient or surrogate (with limited exceptions).

Advance Care Planning:

4. Review and update

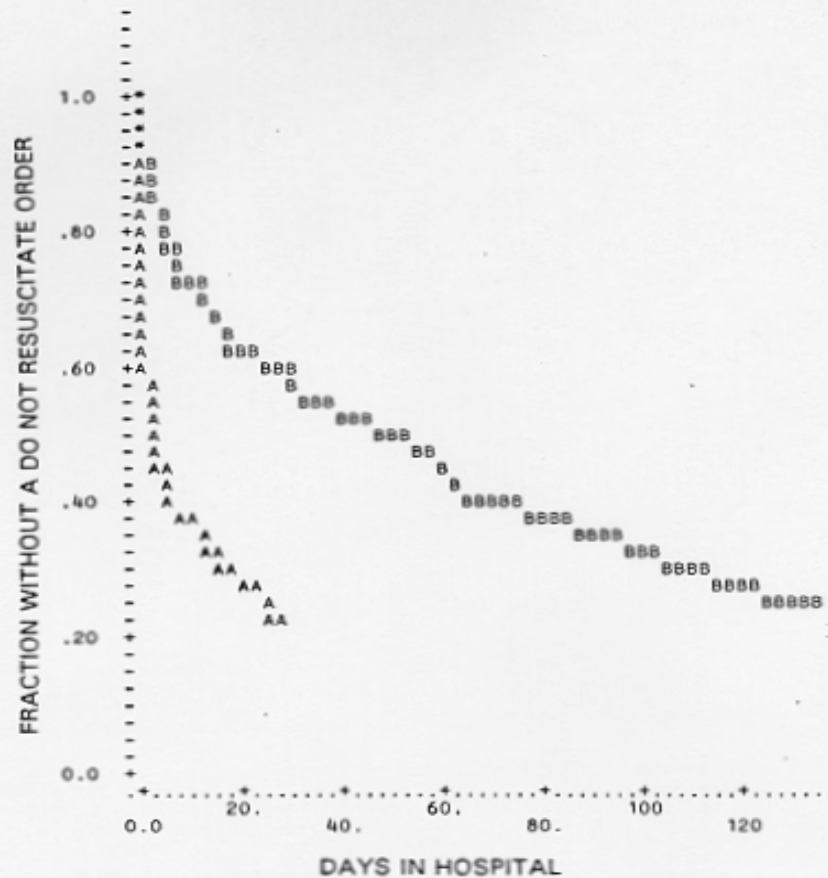
- Review and re-discuss if prognosis changes
- Advance directive and decisions should be followed patient to outpatient setting or transfer to another facility

Do Not Resuscitate (DNR) Orders

- The relationship of DNR orders to advance directives
 - Having an advance directive does not mean that a patient prefers not to be resuscitated
 - DNR does not mean "do not treat"
 - Informed consent for DNR orders is similar to other procedures with implications for survival except that for a DNR order, a patient must consent NOT to receive the treatment
 - » Some people believe that a "resuscitation not indicated" order may be written
 - DNR orders in the operating room
 - Outpatient DNR orders

MD Understanding of Patient CPR Preferences

PT MD	Receive CPR (N=3238)	Forgo DNR (N=1817)	
Receive CPR	2783	990	PPV= .74
Forgo DNR	455	827	NPV= .65
	Sens= .86	Spec= .46	



Time in hospital before receiving a do not resuscitate (DNR) order among patients who prefer to be DNR. Patients ($n=334$) whose physicians understood their preference to be DNR (indicated by AAA) received DNR orders earlier than patients ($n=416$) whose physicians misunderstood their preference to be DNR (indicated by BBB). Patients with a DNR order prior to study entry are excluded.

Decisions to Withhold and Withdraw Life-Sustaining Therapy

- Ethical equality of withholding and withdrawing
- Food and fluids can *legally* and *ethically* be withheld and withdrawn
- Adjuncts to ethical withholding and withdrawing
 - Meticulous attention to maintaining comfort and dignity is mandatory
- Assisted suicide
 - Probably does not meet any of the goals of medicine. It should not be practiced by physicians and is currently illegal in 49/50 states. Requests should trigger a search for depression, uncontrolled pain, suffering.

Decisions for Patients without Surrogates

- Diligent search for surrogates
- Specification of prognosis and quality of life
- Making a best interests decision
- Checks and balances

Follow-up on Case

For the 75 yo woman with advanced dementia s/p aspiration pneumonia who cannot eat or be cared for at home:

- Focus decision making on what patient would want. Offer various options.
- Trial of G-tube is possible.
- Other aggressiveness of care decisions can be made.
- Missed opportunity for ACP

How to Approach End-of-Life Decisions?

- A 50 yo intoxicated man sustains an open femur fracture in a MVA. In the ER he refuses surgery, indicating he will be “just fine” if his pain is controlled and he is left alone.

How to Approach End-of-Life Decisions?

- An 85 yo man with advanced dementia yells “No” and pulls out his feeding tube. Son, the advance directive agent, feels the feeding tube response is “just a reflex” and desires continued feeding. No preferences ever discussed.

How to Approach End-of-Life Decisions?

- The 3 daughters of a 65 yo man with end-stage lung cancer disagree about his care. He is admitted to the hospital with pneumonia, hypovolemic and somnolent. One daughter, who wants palliative care, supports her father's hand as he signs a DPAHC appointing her to be the agent. The other 2 daughters are livid.