Life and Death Decisions: Beyond Advance Directives

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Overview

- Case for discussion
  - Should we override a patient’s DNR?
- Advance care planning
  - Understand the utility of advance directives
  - A process that should focus on patient’s goals and values
- Explore how to effectively communicate with patients about goals of care and values
- Identify common pitfalls in communication and how to avoid them

Case for Discussion

87 year old woman presented to the ED with c/o shaking chills, right arm pain and swelling. Her history is remarkable for HTN, CHF, CAD, and breast cancer. She is on Lisinopril, Lasix, Metoprolol, Zocor. She noted some chest discomfort while washing dishes.

On exam she was awake, alert, and in no distress. Temperature is 101.4, BP 135/70, pulse 70, respirations 18, RRR, normal S1, S2, II/VI systolic murmur at LUSB. Lungs CTA. Abdomen is soft. Skin exam reveals right upper extremity erythema and warmth consistent with cellulitis.

Labs: WBC 14.7; CK 254, 697, 595, CK MB 14.7, 39.2, 27.1, Troponin 4.2 EKG 1 mm ST depression in V4-V6, unchanged from prior EKG.

While in the ED she became hypotensive and is admitted to the CCU for further management.

Ethical Questions

- Should the patient be intubated and taken to the cath lab?
  - Who should make this decision?
- Would taking the patient for catheterization be inconsistent with her advance directive?
- Is it ever ethically justified to override a patient’s DNR/DNI order?
What is Advance Care Planning (ACP)?

- Advance care planning is a process that involves making decisions about the care patients would want to receive if they become unable to speak for themselves
  - An advance directive is one outcome of process
- The decisions should be based on their personal values, preferences, and discussions with their loved ones and doctors

Clinical Indications for ACP

- Urgent indications
  - Imminent death
  - Patient talks about wanting to die
  - Recently hospitalized for severe progressive illness
  - Severe suffering and poor prognosis
- Routine indications
  - Discussing poor prognosis
  - Discussing treatment with low probability of success
  - MD would not be surprised if the patient died in 6-12 months
  - Reviewing health care maintenance with patient

Benefits of ACP

- Promotes patient autonomy
  - Gives voice to patients’ preferences even when they cannot speak
  - Gives patients peace of mind that their preferences will be respected
- Associated with improved clinical outcomes
  - Decreased hospitalization, improved QOL, increased hospice
- Avoids future confusion and conflict
  - Decreases family angst about end-of-life decisions

Outline for Successful ACP

1. Solicit patient’s understanding of their illness
2. Assess if the patient has a health care agent
   - Encourage communication between patient and health care agent/proxy
3. Elicit patient’s goals and values
4. Offer a prognosis
   - Share information on outcomes
5. Make a recommendation
6. Summarize
7. Document goals and values
8. Apply the directives when indication arises

Opening the Discussion

- Adopt a patient/family-centered approach
  - Primary goal is to establish trust and dialogue
- Access the patient’s understanding
  - What do you understand about your illness?
- Gently fill in the gaps and correct any misunderstandings

Health Care Agent/Proxy: The Voice of the Patient

- If you were ever to become so sick that you could not talk to me directly, who should I talk with to help make decisions about your medical care?
  - What led you to choose that person?
  - What have you told that person about the kind of care you would want?
  - Encourage communication between patient and health care agent

National Hospice and Palliative Care Organization (NHPCO)

T Quill, JAMA 2000;284(19): 2502-7
Beyond Advance Directives: Discussing Patient Goals & Values

- Goals of Care
  - Cure
  - Aggressive treatment aimed at life prolongation at all costs
  - Treatment aimed at restoring prior level of function
  - Symptom control or comfort care

- Values
  - Hopes and worries about the future
  - Most important life goals
  - What is ‘acceptable’ quality of life?
  - Tradeoffs: Preferences for quality or quantity of life

Eliciting Patient Values

- I’ve been wondering if there are things that you want me to know about your beliefs or wishes that would help me be sure you get the care you want…
- When you think about the future, what do you hope for? Is there anything you want to avoid?
- When you think about the possibility that you may get sicker, what worries you the most?
- If your health gets worse, what are the most important things to you?
- What sort of life would you find unacceptable?
  - Unable to talk and be understood, fed through feeding tube, unable to care for yourself, etc.

Prognosis: Survival to Hospital Discharge after CPR in the Elderly

- Medicare data on 433,985 patients who underwent in-hospital CPR
- Overall survival 18.3%

Prognosis: Survival in Cancer Patients Undergoing CPR

- National Registry of CPR
- 14,720 resuscitation attempts (2000-2002) in adults
- 14% had diminished neurological function
- 25% decline in overall functional performance

Beyond Survival: Functional Outcomes after CPR

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Make a Recommendation

- As with other treatment decisions, it is appropriate to offer your recommendations
- Base on clinical situation and goals of care
- Offers guidance and relieves patients & families of some of the burden of decision-making
- Does not undermine patient autonomy
Summary Statements

- From what we’ve talked about, it sounds like if your heart and lungs were to stop suddenly, that you would want to be allowed to die peacefully.
- Tell me if I have this right. If we thought you might get better quickly, to the point where you could return home and live by yourself, you would want to be in the ICU. But if we thought that it would only prolong your suffering, we should take away machines, make you comfortable and let you die peacefully. Did I get that right?
- Sounds like you need more time think about these things and discuss them with your family. How about we talk about it again at your next visit?

Common Pitfalls

- Physician:
  - Talks too much
  - Uses jargon
  - Misses opportunities for empathic connection
  - Fails to elicit patient’s values and goals
  - Jumping straight to code status and treatment preferences
  - Offering forms and reading material without discussion

Questions to Guide Conversation

- What is your understanding of your illness?
- How much information do you want about what is likely to happen in the future with your illness?
- Who would you want to make decisions for you if you cannot communicate?
- What are your most important goals?
- What are your biggest fears and worries?
- If you become sicker, how much are you willing to go through in order to have the possibility of more time?
- Are there certain health situations you would find unacceptable? E.g. feeding tube, unable to care for self, etc.
- Have you discussed your preferences with your family?

Advance Care Planning Summary Points

- ACP is more than just filling out an advance directive form
- It is a process of understanding the patient’s values and goals
- Begin with what the patient understands
- Listen more and talk less
- Share prognostic information & data on CPR outcomes
- Make a recommendation & document

Case Revisited

- Patient hypotensive and confused
- Staff initially unable to contact health care agent
- DNR/DNI order rescinded
  - High mortality of untreated CAD
  - Belief that aggressive treatment would provide her with a good outcome
- Patient intubated and taken to cardiac catheterization lab
- HCP agent contacted during procedure and informed of patient’s current status
  - She seemed to agree with current course of treatment

Case Continued

- Cardiac cath revealed significant left main coronary disease, for which she underwent PTCA and two stents were placed
- Pt. transferred to the CCU ventilated on an IABP
- She awoke from the sedation, angry and requested removal of IABP and ventilator
- She understood the consequences might be death
- Attending physician was called and came in at 1 AM to meet with the patient and family
Case Continued
- Physician explained that it was likely that the balloon pump and ventilator could be removed by 5 pm that day
- Patient expressed her willingness to continue with aggressive treatment only until 5 pm
- Should it not be possible for her to be weaned from the ventilator by 5 pm, she wished withdrawal of treatment regardless of the consequences
- Patient’s family felt that the patient had been pressured into that decision, that the patient’s true preferences were being ignored

Case Continued
- Patient extubated without difficulty
- Patient clarified her goals of care and treatment preferences
  - Limited care with medications
  - DNR/DNI, no shocking
  - Patient ready to die
- Preferences clarified with medical staff and documented in chart
- Patient discharged to rehabilitation one week later
- Able to resume independent living

Patient Quotes From Post Discharge Discussion
- “I don’t think I have to live to 87 or 100.”
- “No matter what I said, no one could find the form and they had to start all over.”
- “I thought I was dying and was waiting for death and all of the sudden I realized that I am not dead. It was disappointing in a way.”
- “I knocked myself out to get back to where I am…It has not been easy.”

Ethical Questions Revisited
- Should the patient have been intubated and taken to the cath lab?
  - No. When a patient lacks capacity, medical decisions should be consistent with the patient’s prior stated preferences and goals.
- Was taking the patient for catheterization inconsistent with her advance directive?
  - Yes, she clearly stated a preference to be DNR/DNI.
  - She preferred death to risk of disability.
- Is it ever ethically justified to override a patient’s DNR/DNI order?
  - Yes, e.g. patient with DNR who choked on his eggs.
  - What are the patient’s goals?
    - Death—need for an exit strategy
    - Avoidance of prolonged suffering or poor quality of life

Summary
- Advance care planning is a process that should focus on patient’s goals and values
- Have a script of questions to guide difficult conversations
- Use “Ask, Tell, Ask” to clarify and reinforce
- Respond to patient and family emotions

Question 1
You have a patient with severe advanced multiple sclerosis who has developed renal failure secondary to diabetes. The patient is DNR. She presents to the ED unconscious with a K of 8 meq/L.

Which is the most appropriate next step?
- a. No intervention because she is DNR
- b. Discuss a reversal of the DNR order and dialyze
- c. Proceed with dialysis and ignore the DNR order
- d. Give kayexelate until you can find the health care agent to discuss dialysis
Question 1

Correct answer is proceed with dialysis.
“Do-Not-Resuscitate” (DNR) is specifically defined as refraining from cardiopulmonary resuscitative efforts.
A DNR order should prompt a conversation about the patient’s goals of care and raise the question of whether she intended comfort care only.
DNR does not mean do not treat.
Hyperkalemia is life threatening. Kayexalate is an inferior therapy for the long-term management of renal failure.

Question 2

A 29 year old man sustained a C1 and C2 spinal fracture during a boxing champering championship 3 months ago. He is paralyzed from the neck down and is ventilator dependent.
He is fully alert and understands his condition. He requests removal from the ventilator and understands that he will die as a result.
The most appropriate next step is:
a. Assess for depression and if no evidence remove the ventilator as requested
b. Obtain a court order to continue the ventilator
c. Seek family consensus on removing the ventilator
d. Seek approval of the health care agent

Correct answer is assess for depression and remove the ventilator.
Any adult patient with the mental capacity to understand his medical condition and the implications of withdrawal of treatment has the right to do what he wants to his own body. There is no ethical distinction between withholding and withdrawing life sustaining treatment.
Patients are frequently depressed following a high c-spine injury.
The patient is alert so no consent of the family or health care agent is necessary.

Advance Directive Decision Aid

♦ Making Your Wishes Known
– Online decision aid
– Generates a personalized advance directive that can be saved as a pdf file

References

Disclosures
None