Talking About Advance Care Plans and Do Not Resuscitate Orders

Learning Objectives

After reading this section, participants will be able to:

1. List five reasons why one should talk to patients in the ambulatory or hospital setting about the goals of therapy.
2. Describe four myths regarding advance care planning/DNR orders.
3. Describe a six step approach to discussing the goals of therapy in either the inpatient or outpatient setting.

Why This topic?

Oncological therapy is designed to help promote certain patient-centered goals - the prolongation of life, decreasing symptoms, or promoting quality of life. As the patient becomes sicker, prolongation of life may become a less important goal while promoting the quality of life becomes more important. Physicians are urged to talk to patients with life-limiting illnesses about the goals of treatment on an ongoing basis because goals of care may vary from patient to patient, and how a patient balances these competing goals may change. These discussions may occur early on in the illness so patients can express their views about the future and their concerns, whenever the illness becomes worse or treatment “fails,” prompting a discussion of new treatments in light of current goals, or when a patient has a high probability of requiring life prolonging treatments such as CPR or intubation.

The purpose of conversations about the goals of care also will vary depending on where patients are in their disease process. Various reasons for talking to patients about the goals of care include:

- Giving the person a sense of control in the dying process. Many patients want to avoid “being stuck on machines” in the dying process. Advance care planning ensures that the patients goals will be followed should the patient become incompetent.
- Reflecting clearly the patient’s personal values and goals for terminal care. This is particularly important in conversations at the end of life that focus on specific treatments (e.g., DNR orders).
- Enabling patients to anticipate and consider aspects of the dying process that they might not have considered previously. This may help patients think about goals that they otherwise might not have considered.
• Facilitating communication with significant others. For many patients with a terminal illness, a top priority is to make sure their family is taken care of. Talking about end-of-life issues ahead of time may make it easier for surrogates to act in keeping with patients’ goal should they need to make decisions for them.
• Allow the identification of the patient’s preferred spokesperson (health care proxy).

Some Myths Regarding Advance Care Planning

Myth 1: There is only one type of power of attorney.
Myth 2: If one does not have an advance directive then the doctors must do everything.
Myth 3: An advance directive or DNR order means “don’t treat.”
Myth 4: Once a person names a proxy in an advance directive they lose control of their own care.
Myth 5: A lawyer is required to complete an advance directive.
Myth 6: If a patient fills out an advance directive you don’t ever have to talk to them again about end-of-life care.
Myth 7: The doctor can be the durable power of attorney for health care.

Critical Theoretical Considerations in DNR Conversations

1. Patients do not WANT CPR. They want the outcomes they think are likely to result from CPR. Decisions on CPR are made around:
   a. What the patient’s pre-CPR quality of life is like
   b. What the patient’s post-CPR quality of life is like
   c. What the probability of the CPR working is

2. You do not need to ask patients about every component of CPR or ACLS. The purpose of the discussion is to make sure the decisions about treatments reflects and tries to promote the patient's goals. There is little reason to think that the patient cares about whether they get vasopressors or anti-arrhythmics (from their point of view these are merely medicines that go through their vein.) The problem is that when you ask about them, the patient is likely to perceive them as real options and give you real answers. These answers may lead to “irrational” medical decisions which you will then try to “talk to patient out of”. This likely to lead to conflict and problems.

3. It may be more helpful to think of the discussion as an attempt to understand the patient's goals -eg. What is an acceptable quality of life for the patient and what is she willing to go thru to get to that point. Your job is then to make recommendations to the patient about what is likely to accomplish these goals.

4. Check lists of different interventions that may be available at your institution are for communication among health care providers...not for you to ask the patient about.

5. If the conversation is about goals rather than treatments, yes and no answers to specific treatments are less important than the “Why’s”. Ways to get at the whys include:
   a. What do you think will happen if we do X?
   b. If the patient says they want CPR in their current health status, ask...“What if something horrible happened and you had a stroke and I never thought you were going to wake up? Would you still want X?” (Most patients will say no). Then you can ask about this (“Tell me why not” Or “Tell me about that”) which will then lead to a discussion of quality of life considerations
   c. If they patient says they don’t want to be a ventilator ask “Even if I thought it was only going to be for a week and then I thought you would be pretty much back to how you are now”. If the patient then says they might be willing to consider the ventilator again talk about the whys

6. Therapeutic decisions are typically viewed in a hierarchical fashion — aggressive (CPR or mechanical ventilation) to less aggressive (iv meds in the hospital) to even less aggressive (oral meds at home).
   a. If a pt. does not want to be readmitted to the hospital you probably do not have to ask about CPR. (It almost surely does not make sense). I would assume they do not want cpr and tell them that given their goals that it does not make sense and we would not do it.
7. Conversations about “code status” are really broader conversations about the pt's goals and what we can (and can’t) do to accomplish them
   a. Make sure the focus is on how we can achieve their goals rather than just about what we are not going to do.

Recommended Procedures

ADVANCE DIRECTIVE CONVERSATIONS

A. Introduction
   1. Make sure the setting is appropriate and that other significant people are present.
   2. Explain why you are raising the topic of goals now (e.g., may relate to prognosis of illness, recent hospitalization, the fact that you always do this, etc.).
   3. Use the discussion as a way to emphasize your support of the patient and that you will be there to help them achieve their goals

B. Setting the stage
   1. Reassure the patient that death is not believed to be imminent (if true), but avoid false reassurance.
   2. Make sure the patient understands the course of illness and prognosis at this time. It is important to begin with a shared understanding of what the current medical situation is and what the future is likely to bring.
   3. Explain any treatments that are discussed in terms of the patient's experience and probable outcome.

C. Elicit Preferences
   1. Ask patients to explain their goals for treatment, probing for an understanding of what makes their life worth living or if they have personal goals they want to achieve. You can ask about general goals or more specific treatment preferences. (“Do you want more chemotherapy at this point?” or “If you get sicker, would you want to come back to the hospital or be put on machines?). When patients state specific preferences about treatments, always ask “why?” The underlying principle is that the discussion should move back and forth among preferences for specific treatments, information about the treatment implications and the patient's values, ensuring that the patient understands the implications of his decisions regarding specific treatments and the physician understands the patient's values. Identify what life situations the patient would find unacceptable (e.g. “being a vegetable on a machine”).

2. Discuss probabilities inherent in medical treatment and ask how the patient would manage uncertainty: The decision making data suggests that one should frame the information in both positive and negative terms. “Sometimes you can not tell what is going to happen with treatment. Some people would want to keep trying even with a very low chance — say 5% — that the treatment will work, while others say that if 95% of the time the treatment will not help, they do not want to go through it. What do you think about this?”

3. Give a clear description of what you will do to meet patient's goals. Emphasize that you will be there and remain actively involved regardless of what goals the patient wants to pursue.

D. Identifying a Proxy
   1. Identify who is to be the proxy should the patient not be able to convey her preferences.
   2. Stress the need for the patient to communicate with her proxy both that she wants that person to be her proxy and about her goals of care and preferences for treatment.
   3. If the proxy choice is likely to be controversial, advise the patient to complete a legal durable power of attorney for health care form.

E. Documentation
   1. Be sure to document your conversation. If the patient is an in-patient, follow hospital policy. If an outpatient, make notes for the chart. Clearly state the context for the discussion, goals discussed and any decisions made or still pending.
   2. Follow state legal policy if the patient completes a living will or a durable power of attorney for health care.
   3. Advise the patient to have a copy of the form(s) at home and to give copies to all of her health care providers (in both outpatient and inpatient settings).

F. Closing the Conversation
   1. Express your appreciation for their willingness to talk about the topic.
   2. Emphasize non-abandonment.
   3. Stress that this is an on-going conversation.
Pearls/Ideas to Facilitate Conversations about Goals of Care

- Attend to affect and provide opportunities for patients to talk.
- Avoid vague terms — or define them.
- Ask for questions.
- Remind patients that they don’t need to make an immediate decision and can always change their mind.
- Ensure shared understanding of conversation by asking “why” when patients ask for specific treatments or express their goals. Restate your understanding and ask patients to confirm that you’ve got it right.
- Remember that you are offering to let people talk about this issue, not forcing them to “give up.”
- Remember to talk about the positive things that you can do to help the patient accomplish their future goals.
- It might help to conceptualize these conversations like going to AAA for travel-guides (at least it helps us). You want to find out where they want to go and what they want to avoid. Also find out what they might be willing to go through to get to these destinations and how to handle probabilities. Knowing this, you can then make recommendations about the best treatments to help them accomplish this plan.

PHRASES THAT MIGHT BE HELPFUL

A. To start the conversation

If early in disease:
- “I try to talk to all my patients about what they would want — if god forbid — they become sicker. Have you ever thought about this?”
- “I try to talk to all my patients about living wills. Have you ever heard about these?”

When taking a history, if either or both of the patient’s parents have died, ask about the care they received at the end of life and use this to lead into a discussion of what they would want.

B. To inquire about values

- “As you think about the illness, what is the best and the worst that might happen?”
- “What makes live worth living for you?”
- “Would there be any circumstances under which you would find life not worth living?”
- “Have you seen or been with someone who had a particularly good death or a particularly bad death?”
- “How do you think about balancing quality of life with length of life in terms of your treatment?”

C. To close

- “I want to thank you for helping me understand your values and goals. Have you talked to anyone else about these issues?”
- “If something should happen to you and I could not talk to you about these in more detail, who would you want to help me make these decisions? Have you ever spoken to them?”
- “I want to thank you for helping me understand your position if you should get sicker. It has been very helpful to me. I know that in the past, you have not given this very much thought. Would you be willing to think a bit more about what we spoke about today so we can talk some more at your next visit?”

TALKING TO SERIOUSLY ILL PATIENTS ABOUT DNR ORDERS

A. Setting the stage

1. Assess the patient’s understanding of their illness - it is unlikely that a patient who thinks she is going to live forever is going to come to the same decision about their code status as one who knows she is dying. Knowing what the patient knows about their illness is thus really important to knowing how to proceed in the conversation. A patient who not aware (or willing to be aware) of their prognosis is unlikely to be willing to consider a DNR order.
2. On the other hand remember that not knowing one’s prognosis is different from hoping that it will not occur.
3. One can try to see if patient is willing to talk about these issues even if they are hopeful they will get better by gently asking “What if (God forbid) something happens and things do not go as well as we would help. Have you thought about some of the decisions we might have to make then?”

B. Ways to get into the conversation

1. If late in the disease (and/or for hospitalized patients):
2. “Do you have any particular concerns about what’s happening to you now?” (often this will lead to issues of fear of dying).
3. “We are working hard to help you get better. While I hope for the best, some of my patents want to also prepare for what happens if the treatment does not work. I wonder if you have ever thought about this?”
4. “I try to talk to all my patients in the hospital about what they would want — if god forbid — they become sicker. Have you ever thought about this?”
C. Talking about Code statues
1. “Suppose you were to become suddenly very sick and the doctors think you only have a 5% chance of getting better enough to leave the hospital, and it would require you to be on machines and have a tough time for a week or so. Some people would want to try and see if they could get well enough to go home, while others would say that it is not worth it if there is a 95% chance they would not survive to go home? What do you think?”
2. “What if something happened and you could not breathe. Typically in these cases, we have to put people on a respirator — a tube that goes down their throat and then is connected to a machine that breathes for them. What would you think if you needed this?”
3. If they say they would not want this, ask: “What about if I told you that you might only need it for a week or two and then you would get better enough to go home? Would that change how you feel?” Probe for reasons and rationale.
4. If the patient says they would want to be on the machine, ask: “What if the reason you needed the machine is that you had a large stroke and I thought you never were going to wake up. Would you still want to be on a breathing machine?” Probe for reasons and rationale. The key is to focus on the “why.”

D. Identifying a Proxy
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2. Stress the need for the patient to communicate with her proxy both that she wants that person to be her proxy and about her goals of care and preferences for treatment.
3. If the proxy choice is likely to be controversial, advise the patient to complete a legal durable power of attorney for health care form.

E. Documentation
1. Be sure to document your conversation. If the patient is an in-patient, follow hospital policy. If an out-patient, make notes for the chart. Clearly state the context for the discussion, goals discussed and any decisions made or still pending.

F. Closing the Conversation
1. Express your appreciation for their willingness to talk about the topic.
2. Emphasize non-abandonment.

Pitfalls
• Focusing on interventions without trying to understand the patient's rationale for the preferences of the decisions. Patients often feel that if they are offered an intervention the doctor must think it will help and will therefore “want” things you think are unreasonable. Conversely patients may say “I do not want machines” because they think they will be “stuck on machines.” If one explores the reason for the decision, these patients are often want to ‘try’ the machine, but forgo treatment if it is not working.
• Trying to explore goals and future decisions at the same time that you are giving bad news. It is hard to think/ make plans about the future when you are trying to deal with the “here and now.” If at all possible, try to separate giving bad news and asking patients to make large decisions about their future care.
• Expecting patients to make a decision on the first discussion. Often discussions about goals are helpful because they get the patient thinking about the future and show that you are interested in their values. It may be unrealistic to expect that the patient will reach a decision the first time you bring up the subject.
• Ignoring emotions. These often are difficult conversations and may cause sadness and other emotions. Be empathic (see Module #1).
• Forcing patients to talk about the future or DNR orders. Some patients — up to 25% in some studies — do not want to talk about these issues or make decisions about the future. Do not force them. Ask them if they want to be talking about these issues. You might say “Some people want to be very involved in making medical decisions, while others would rather I talk to their surrogate/family about these kinds of issues. What would you like? Who should I talk to?”
REFERENCES

Included in this notebook

Additional References (not included)