Cultural Competence

Presenting Advance Directive Concept and Difficult Diagnosis Successfully
Patient Safety Issues created by Culturally Inappropriate Presentation

- **Advance Directive**
  - Patient declines to write an Advance Directive, creating the possibility of painful, extended, and expensive interventions beyond what patient would prefer.
  - Family and/or patient may enter care phase in conflict with each other or with care team

- **Notification of Serious Diagnosis**
  - Family or patient may enter care phase in conflict with each other or with care team.
  - HIPAA violations may occur if assumption is made that family should share info and decisions.
  - Patient’s right to knowledge about his care and options may be infringed upon if provider follows family demands to withhold diagnosis.
Be pro-active: Present concept, solicit preferences in advance of crunch.

Respect the patient’s privacy: When asking about needs, goals, and preferences, clear the room to ask.

Put yourself in the patient’s shoes: Hear her voice: What are her goals for herself, based on what values?
Advance Directive
Advance Directive Solicitation--How we (often) do it now

- We wait until the patient is going to be admitted or have a procedure, or until he is very sick.

- The patient is asked about whether he has an Advance Directive during his Admitting interview or during his Pre-Anesthesia check-off by a nurse.
Advance Directive--
Results of last-minute, hurried presentation in preparation for admission or surgery:

- Patient gets very worried about a possible bad outcome
- Patient suspects that care team is hiding a bad diagnosis from him
- Patient feels alienated from care at moment that he needs to be concentrating on getting well
- Family tensions can arise immediately
Concept of Advance Directive elicits one of several possible reactions:

- Shrug—what happens will happen, don’t bother me with this.
- Shrug—my family will make the right decisions, don’t bother me with this.
- Oh, oh, they want to cut corners on my care. I better not sign anything like this.
- Shhh, Quiet! Don’t tempt fate! Talking about bad things happening will make them happen! You have jinxed me!
- This sounds like a useful tool, tell me more.
We can do Advance Directives better.
Best Practices in Soliciting an Advance Directive

- Start the discussion before test results are in, before treatment is planned, when emotions are stable.
- Primary care is the best location to have the discussion.
- Specialty care is fine, too.
- The person who speaks to the patient about an AD should be trained to do so and able to answer technical questions. The provider, the nurse, the care coordinator, and the social worker are credible in this role.
Cultural Competence in Soliciting an Advance Directive--Concepts

- Cultural competence ALWAYS begins with putting oneself in the patient’s shoes:
  - Only include other people as directed by patient.
  - Preserve the patient’s dignity by choosing a time and place that gives her time to think, react, tell her story, work through the concept. This is her mortality we are talking about.
  - Meet the patient at her level of understanding, and provide more information from there.
  - Assure the patient that her goals for herself and her values are the foundation for the care that will be provided.
Preparation of the patient to discuss the topic, use the script.

“Across the United States, doctors ask their patients to guide them in how to care for them. It is customary for patients to think about their values and their goals for themselves, and to create a document that directs their care team to make certain interventions, and to not make other interventions, in the case that the patient is not able to speak for himself. I would like to give you some background information on the topic of an Advance Directive, and ask that you and anyone that you wish to include from your support circle, think about what you would include in your instructions to us. We are not in a hurry, and we will discuss this more next time we see each other.”
Logistics, cont.

- Give examples of interventions, describe them carefully and completely. Most non-health workers do not understand how painful and invasive CPR, intubation, ventilation, feeding tubes, etc. can be.
- Give example of an Advance Directive created by a patient.
- Reassure pt. that it is best to create an AD when not sick or facing surgery.
- Reiterate patient’s ability to change AD at any time.
Notifying Patient of Serious Diagnosis
How we (often) do it now

- We do not discuss the patient’s preferences for managing his care or for information sharing.
- We get results from tests back, or we complete an examination. The condition is serious. We now have to inform the patient of the results.
- We assume that anyone in the room with the patient is someone that the patient wants involved in his care. (Elderly, ethnic, immigrant, big family…)
- We start to tell the patient what we think his condition is.
- If the family intervenes and insists that the patient not be told, the provider has to decide whether to keep going anyway or to not tell the patient what his diagnosis is.
Results

The provider is now in a bind. The family may be telling her that the patient will give up and die quickly if he knows how serious his condition is. The provider is now worried about:

- the family’s influence and judgment
- the provider’s legal and ethical responsibilities
- the patient’s state of mind and whether he will truly stop trying if he know how sick he is.
Reactions

The family is all upset. They are worried that the doctor will sneak in the diagnosis when they are not watching, so they become hyper-vigilant and do not allow any staff access to the patient without their supervision. It becomes difficult to talk to the patient even by phone. If the patient does not speak English, the family particularly mistrusts the interpreters, because they can communicate with the patient.

Often, different factions of the family have different opinions about how to conduct the information-sharing. This raises tensions at every interaction, just at the time that the care team needs to get the patient’s consent for treatment.
Reactions, cont.

The patient himself, a compos mentis adult, knows that he has come to the doctor to find out how he is doing. He is aware that his family is trying to control communication efforts by his provider. He usually figures out that if the results were benign no one would be making a fuss. This creates tension for him and worry about his medical condition.

Unless the patient is very dominant in the family group, he is unlikely to be able to unilaterally direct both the provider and the family members in what he wants to happen, now that the drama is unfolding.
We can do notification of serious diagnosis better.
Best Practices in Notifying Patient of Serious Diagnosis—concepts

- Talk to the patient **early** and **privately** about
  - who he wants to be included in information about his condition;
  - who he wants included as a decision-maker in his care;
  - whether he, the patient, wants to know the results of his tests or his medical status;
  - whether he, the patient, wants to participate in the treatment plan in its iterations.

- Talk to the patient about what his goals are for himself. (Quality of life, functionality, longevity)

- Talk to the patient about his foundation values. (Harmony with family, submitting to God’s will, sanctity of life regardless of functionality, usefulness as a measure of worth, not being a burden to family, …)

- Document and share this info with the care team members.
Best Practices in Notifying Patient of Serious Diagnosis-- logistics

- Build the discussion into your first encounter with the patient.
- Clear the room. Use a script if that makes it easier.
- Ask the patient about his goals for his health, and about his preferences for information sharing and decision-making.
- Document clearly in record. Share this info with entire care team.
- Now you are ready to do tests and exams, get results, notify of diagnosis and prognosis.
- Always do the heavy lifting from here on out, direct who will participate in each aspect of care according to patient’s wishes. Do NOT make the patient defend his choices against family or visitors who want to intrude on care.
Prepare the patient to discuss the topic as far before a crunch point as possible, ask him to think about how he prefers to manage care decisions and information.

Discuss the patient’s values and goals for himself (and document them), as well as his preferences for social support and information management.

Have other people present only as the patient has directed in private.

Consistently reiterate your commitment to providing care consistent with patient goals.