Learning Objectives

After reading this section, participants will be able to:

1. Describe three philosophical reasons for talking to surrogates about end of life care decisions.
2. Describe five purposes of a family conference.
3. Describe a five stage approach to facilitating a family meeting.
4. Describe how one might talk to a surrogate about forgoing life sustaining treatment.

Why This Topic?

Discussions about end-of-life issues take place with the family rather than the patient often because by the time the physicians think about “end-of-life” discussions, the patient is no longer competent. Conversations with family also take place when patients are incapacitated because they are the ones who operationalize the patient’s wishes. Also when the patient is beyond “physical harm (eg. the patient is comatose and does not feel physical symptoms),” physicians worry about the effect of treatment on those who survive the patient’s death. Regardless of the reason, physicians often talk to families about end-of-life issues. For the purposes of this discussion, we define “family” to mean the patient’s informally- or formally-chosen surrogate.

It is important to remember the justification for involving families in discussions of end-of-life decisions. These reasons include the fact that:

1. the family knows best what the patient would have wanted,
2. the family cares more about the patient’s well-being than anyone else,
3. the patient wanted the family to make this decision and trusted their judgment (this is particularly true in cases where there is a formal durable power of attorney for health care),
4. the family will live with the consequences of the decision more vividly than anyone else.

Most studies show that the most important information for families is about what is being done to their loved one and why. The need for this information is complicated by the fact that the family is under a great deal of stress, making retention of information difficult. The stress is also likely to exacerbate both the strengths and weaknesses of family dynamics.
Recommended Procedures

A. Prepare yourself
   Clarify conference goals in your own mind.

B. Choose a private location
   Ideally, you’ll have access to a comfortable room that is private with circular seating. It is important to allow all family members to “sit in the front row.” Also try to spread the health care providers out so all the health care providers are not sitting on one side and the family on the other. Remember to bring tissues and put them within easy reach of the family.

C. Think about who to invite
   1. Among family members, be sure to invite the legal decision maker/health care power of attorney (if one has been appointed) as well as any family members who are able to come. Ask if there are other people who provide social support for the patient and/or family.
   2. It is often important to invite the nurse who is caring for the patient. That way s/he will know what happened in the conference (as opposed to what people remember) and also because s/he can follow up on topics after the meeting.
   3. It is important to invite the social worker who often has been meeting with the family on a regular basis and knows the most about the family dynamics.
   4. Ask the family if they would like a chaplain present (this signals that the conference is likely to involve bad news).

D. How to organize/conduct the meeting
   1. The health care team should talk before the conference to make sure that they are in agreement about the medical facts and they know who is going to facilitate the meeting.
   2. When everyone is settled, have team members introduce themselves.
   3. Allow the family members to introduce themselves.
   4. Review meeting goals; clarify if specific decisions need to be made.
   5. Establish ground rules, i.e., each person will have a chance to ask questions and express views; ask that people be allowed to speak without interruption, etc.
   6. Sometimes it is important to identify legal/primary decision maker, and describe importance of supportive decision making. Other times one can allow the family to achieve a consensus.

E. Review medical status
   1. Determine what the patient/family already knows: “Tell me your understanding of the current medical condition”
   2. Review current status, plan & prognosis.
   3. Ask each family member in turn if they have any questions about current status, plan & prognosis (allow quiet members to be quiet if they wish)

F. Family discussions when the patient has lost decisional capacity
   1. Ask the family members, “What do you believe [your loved one] would choose if she could speak for herself?” or “If [your loved one] were sitting here now, what do you think she would say?”
   2. After one or two people have expressed their opinions, ask what others?
   3. Leave room to let family discuss alone.
   4. When you return, ask if the family has reached a consensus. If no, proceed to G; if yes, go to H.

G. When there is no consensus:
   1. Re-state goal: What would the patient say if she could speak for herself?
   2. Use time as ally: Schedule a follow-up conference the next day.
   3. Remember to attend to emotion and NURSE
   4. Try further discussion: “What values is your decision based upon? How will the decision affect you and other family members? What other concerns do you have?”
5. Identify and support the legal decision maker (if one has been appointed).
6. Identify resources: Minister/priest, other physicians, ethics committee.

H. Attend to family needs
1. Ask how they are doing.
2. Ask if there is anything that you can do to help support them.
3. Suggest they seek religious support if desired. Refer to chaplain if they do not have affiliations with a religious institution.
4. Offer to write work-release notes if necessary.
5. Reiterate that the social worker can help with financial issues.
6. Ask if there are children in the family and what you can do to help support the children (see Appendix X for “Fast Fact” on “What do I tell the children?”)

I. Wrap-up
1. Summarize consensus, disagreements, decisions, and the plan.
2. Caution against unexpected outcomes. Explain, in as much detail as possible, what is going to happen next to minimize surprises.
3. Identify family spokesperson for ongoing communication.
4. Document in the chart—who was present, what decisions were made, follow-up plan
5. Don’t turf discontinuation of treatment to nursing
6. Maintain continuity with the family and medical team. Schedule follow-up meetings as needed.

Pearls/Ideas to Facilitate Family Conferences
• Remember to talk to other health care providers to gain insight into the family dynamics. The social worker and nurses have often spent a great deal of time with the family and can give you information about the different relationships.
• Remember to talk about the positive things that you can do to help the patient/family accomplish their future goals.
• Allow the family to reminisce.
• Offer to shake hands going in and coming out.

Phrases That Might Be Helpful:
• “If [your loved one] were sitting here at the table, what would s/he say?”
• “Sometimes what you want is different than what your mom would want. I really respect your ability to focus on your mom’s wishes.”
• “I do not want you to feel like you’re making medical decisions. That is my job. You can help by telling me what your mom would have wanted if she were here.”
• “I want you to be able to look back on this six months from now and be sure that you did what your mom would have wanted.”
• “How are you doing? What can we do for you?”

Pitfalls/Common Barriers to Good Communication
• Trying to short-circuit the conversation and reach a decision quickly. Families often need to relive their loved one’s life and medical treatment. This life review is important to helping them put the current situation into perspective.
• Attending to only one family member. You may not know the family dynamics. Be polite and attend to everyone.
• Telling before you ask. If you say things that contradict others, you may lose face and trust.
REFERENCES

Included in this notebook

Additional references (not included)