Mastering Difficult Family Conversations in Surgical Care

End of Life Modules

Care Goals and Treatment Options

Welcome to the fourth module on the topic of End of Life Family Care Conferences.

In previous modules, we’ve discussed a 7-step model for framing end of life conversations. In this module, we address the process of revising care goals for patients with a terminal prognosis. Your goal is to engage the family in decision making. To do that, you have to first educate them on the realities of continuing treatment and life support. You need to explain “comfort care,” clarify code status options, and answer questions about the dying process.

A powerful article by Ken Murray contrasts the choices that doctors tend to make when faced with death, with how patients usually die. The differences are stark and due, in part, to doctors’ greater awareness of the end of life experience. Because they can anticipate what’s coming, doctors are more proactive in planning for it: 64% of doctors have advanced directives vs. 20% of the public. Doctors are more likely to resist “heroic measures” such as CPR, because they know how little they benefit the patient. In contrast, the public thinks “heroic measures” “work.” TV shows may reinforce this perception. In one study, 75% of CPR cases shown on television were “successful.” In reality, a research study of more than 95,000 CPR cases found that only 8% of patients survived for more than a month, and only 3% were leading mostly normal lives.

Physicians know what patients fear the most: and that is dying in pain, and dying alone. They fear being caught in a medical system they cannot control. Research by Heyland, et al., found that the second “most important element” of quality care for both patients and families was not being kept alive on life support when there is little hope of a meaningful recovery.

Doctors, patients, and families agree on what constitutes a “good death:” feeling comfortable, safe, in control of one’s surroundings. Being able to achieve a sense of closure, usually by spending time with family, dying at home, and dying with grace and dignity. The difficulty for patients and families is that can’t always see the point in the road at which they need to actively choose that path. As a result, they may find themselves on a path they never imagined being on.

If asked by doctors, “Do you want us to continue to do everything we can?” patients and families will say “Yes, of course!” How does one say “no” to that? Some families really do mean “everything,” but often they mean “everything reasonable.” However, it is hard for them to know what is reasonable; they may not fully understand the emotional, physical, and financial costs of “futile” care.
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To engage the family in informed decision making, you need to educate them on the difference between active interventions to sustain life, and “comfort care,” which allows death to come naturally and peacefully in a supportive environment. Here are some effective words for changing the goals of care to “comfort care.” Check the Moodle website for others.

Here is an example of how one provider explained the difference in care goals and the meaning of comfort care.

You also need to explain the myriad of options for them with regard to code status. Even if they have a living will or set of advanced directives, you need to walk them through options that are relevant for the patient. Here is a sample of some effective ways to explain DNR / DNI and a few comfort care options. Check the Moodle website for others.

Here is an example of how one provider explained DNR and related comfort care options.

Families need to be part of the decision making process when comfort care is being discussed. For patients without a living will or advanced directives, your goal is to help the family focus on what they think their loved one would want, and to enlist the support of other people who can help them with this decision.

Here is an example of how one provider engaged the family in deciding whether or not to change the goals of care to comfort care.

Patients and families often turn to the doctor for advice. They may ask, “What would you do if you were in my place, or if this was your father / mother / child, etc.” Physicians vary in how they handle this question. Some prefer to let the family own the decision entirely – to not influence them in any way. Some feel it is appropriate to offer an opinion, but also assure the family that the decision is theirs alone. Others provide advice, based on what they think is best for the patient.

Some providers take the approach that their job is to support the family’s decision, no matter what it is. Others will reinforce or “approve” a decision if they think it is right. Some doctors (such as Ken Murray, referenced in Module 3) feel it is unethical to agree to unreasonable family wishes that cannot benefit the patient and only add further harm.

Multiple factors in the larger health system can contribute to excessive treatment at the end of life: fear of litigation; fee-for-service reimbursement; and, in the case of ER traumas, lack of opportunity to build a trusting relationship with families. As you develop your own practice, take time to discuss these ethical dilemmas with mentors.
Ok, time to go! Here is a simple checklist to add to your mental tool box.

Death and dying have been removed from many of us in the U.S. Your goal is to support families as they consider what it means for their loved one to have a “good death.” In our fifth and last module, we will talk about how to close an end-of-life family conference.