# **Learning Objectives**

### **Attitudes**

• Understand the importance of compassionate communication by fostering a supportive and respectful environment that helps families navigate difficult discussions about their loved one's condition.

### Knowledge

• Effectively convey medical information in a clear, accessible manner, ensuring families understand the patient's prognosis, treatment options, and current state without feeling overwhelmed by medical jargon. Prognostic certainty is not required to have a family meeting.

### **Skills**

• Foster Collaborative Decision-Making through the shared decision-making process, ensuring that the patient's values, preferences, and goals of care are central to the discussion.

### **Teaching Outline**

Often, a clinician caring for patients with serious illnesses or in critical conditions will need to help patients and their families navigate difficult decision points in a patient's care. A family conference is indicated when lack of clinical improvement, acute changes, or a prognosis discussion is needed. It is important to communicate directly and clearly during a family conference or care conference, as this is a key time for families to receive information during transition points, serious news and updates on prognostic factors. Many times, these updates lead to further discussion of goals of care (GoC). Initially, not all family conferences will result in discussions of goals of care as people may need time to comprehend the complex information provided, and multiple discussions may be appropriate. Although this section refers to family conferences, a patient's family may consist of their support system that consists of close friends or designated surrogate decision makers. This section's purpose is to gain a strategy on how to conduct a successful family conference.

# **Approaches**

Family conferences are a critical part of caring for patients in critical conditions or with serious illnesses. These conversations are difficult and sometimes are avoided due to lack of training, failure to recognize when a conversation is needed, discomfort with discussing end-of-life issues, and desire to avoid conflict. These conferences allow for all important clinical parties to be present to provide families with updates. For the families, these conferences provide time for processing information regarding declining health status, asking questions regarding their loved one's condition, and developing insight into the patient's values and goals that can help aid a goals of care conversation. It is critical for the relevant specialties that are part of the care team to be a part of these conversations: i.e. neurosurgery for patients with traumatic brain injuries; pulmonologists for patients with severe ARDS. Other members of the care team should also be included: nursing, social work, chaplaincy, etc. Family conferences also can help mitigate burn out in the health care team by humanizing their patients. Learning more about your patient and what they value can help to explore caring for the patient rather than just treating their diagnoses. Patients and families who have an opportunity to speak to their physicians about the nature of their illness and serious illness care preferences have been shown to experience less psychological distress, report better quality of life, and receive care at the end of life that is more consistent with their values.

Physicians with training on formal mechanisms to assess a patient's wishes and goals are more likely to value the importance of these conferences and feel they are more rewarding. A family conference should be viewed similarly to a procedure and physicians should expect to develop proficiency in difficult conversations. The next section will review several ways to conduct a family conference. Multiple frameworks and training programs for leading these conversations are available online. By familiarizing yourself with themes that commonly arise in these discussions, a clinician can better build a tool set to better conduct a family conference.

### **Preparation**

It is critical to adequately prepare for a family conference. One should first thoroughly review the patient's medical history, recent events, current conditions, expected outcome and prognosis. Reviewing an Advance

Care Directive, if available, can be helpful to understand what the patient valued prior to this hospitalization. Understanding the patient's overall health trajectory, prognosis, and potential outcomes will help ensure that one is equipped to answer questions accurately and offer clear guidance. Clinical certainty and prognostic outcome are not required for having a family meeting and conveying information. Conversations with specialty teams may be necessary to further elicit prognosis, and, depending on the situation, these specialty teams should be a part of the conference. Other health care team members such as bedside nurses and social workers may have additional insight and help ensure that the conversation reflects a comprehensive view of the patient's situation and allows for coordinated communication across the medical team.

Prior to entering the care conference, the multidisciplinary team should meet to discuss goals for the discussion and what key pieces of updates need to be communicated to the family. This meeting creates an opportunity for team members to familiarize themselves with the patients' care and each discipline's contributions to that care. A leader for the conversation, which is often the primary team or ICU team, should be designated. In preparation, anticipating questions or difficult points in the conversation and how to mitigate them should be discussed in advance. In some cases, specific specialties should deliver certain updates, while the leader can synthesize all the information into an overall clinical picture. For example, if there is concern for brain herniation it may be necessary for the family to hear this update from the neurosurgery team. By discussing these updates prior to entering the room, the conversation with the family may run smoother. This preparation also gives the opportunity to compare prognostic factors and ideas to ensure consensus regarding treatment options, prognosis, and recommendations. Clinical and prognostic certainty is not required to have a family meeting.

The care team should also anticipate the emotional dynamics that may arise during the family conference. Recognizing that family members may experience grief, confusion, or distress, one should prepare to approach the conversation with empathy and patience. Planning involves how to present difficult information in a compassionate manner, allowing time for the family to absorb the information, ask questions, and express concerns. The surgeon may also benefit from identifying key family members or decision-makers ahead of time, ensuring that they are aware of the patient's condition and prepared to discuss potential care decisions.

Additionally, the team should outline key goals for the meeting, ensuring clarity around what needs to be discussed (i.e., code status, possible withdrawal of life-sustaining therapies, no further medical interventions, or escalation of treatment, etc). This discussion may include reviewing the patient's prognosis, clarifying any recent clinical changes, exploring the family's understanding of the patient's condition, and revisiting any previously expressed goals of care (GoC). The surgeon should prepare to guide the family toward making informed decisions that align with the patient's values and medical realities. If complex decisions such as withdrawing life-sustaining treatment need to be considered, the surgeon should be prepared to offer clear recommendations while respecting the family's autonomy and ensuring the patient's wishes are honored to the greatest extent possible.

Finally, an appropriate meeting space with no interruptions should be identified and an in-person interpreter present if needed. Ideally all care team members should limit distractions for their pager/phone if able. The patient should be in attendance, however, when patients are in critical condition, medical necessity often

prohibits their participation. If there is a large family/support system, it is helpful to identify a representative to be present at all meetings and disseminate key updates and outcomes of the conference to other members.

### **Introductions and Agenda Setting**

Every family conference should start in a similar fashion with introductions by the family and their relationship to the patient and then with the care team and their role. These introductions are also suitable time to learn from the family or the patient where they find joy, what they enjoy doing, what they value in life and their goals and expectations from medical treatment. The lead team member can follow this introduction by having the family outline any questions they want addressed in the meeting. Setting an agenda of discussing update, then addressing their questions/concerns helps the family have structure in the meeting. Depending on the group, ground rules for the discussion to respect all members in the meeting may be needed. Sometimes there are differences in opinions within the family that lead to disagreement, but it is key to keep a welcoming and safe environment during the conference.

## **Assessing Understanding**

After getting to know who is involved in the conference, the next step is to assess everyone's understanding of the patient's medical condition. Asking open-ended questions such as "what is your understanding of the condition of your loved one?" starts the conversation. Asking the family to describe their loved one's overall health and trajectory over the past year helps them see the preceding decline prior to this current hospitalization. The goal initially is to elicit as much understanding as possible. These inaccuracies in family perceptions may be more reflective of the families' hopes and anticipatory grief and not necessarily a lack of understanding. Prognosis awareness, coping styles and preparedness may be extracted from this section of the conversation, which gives the health care team an understanding of what the family is hearing.

### **Delivery of Updates and Prognostic Information**

At this stage, summarizing the previous section of the families' understanding of the situation helps them feel heard and provides an opportunity for the team leader to address any inconsistencies and to fill in any gaps in understanding. Once this information is shared, new updates can be shared. Asking for permission to share information gives the family control and builds trust in the health care team during this challenging time. There are many ways to share updates and prognostic information which will be discussed in detail in the following sections. By finding a technique with which you are most comfortable, you will be able to best connect with families. There are many techniques such as SPIKES, discussed in previous sections. In addition to the SPIKES protocol, one can utilize several other techniques such as the Ask-Tell-Ask method or Best Case/Worst Case. These techniques foster a two-way conversation, ensuring patients and families are active participants in the discussion. Surgeons can also use chunk-and-check, where information is broken into small, manageable "chunks" to avoid overwhelming the patient. After each piece of information, the surgeon "checks" for understanding before moving forward. Another technique after updates are given are NURSE (Name, Understand, Respect, Support, Explore) statements, which focus on addressing the emotional aspects of receiving bad news. NURSE statements encourage the health care team to name the emotions they observe in the patient, express understanding, show respect for their feelings, offer support, and explore further concerns. This technique allows for deeper emotional connection and validation of the patient's experience. Most family meetings are a combination of many communication

tools. All the techniques involve asking the patient or family what they understand about the situation, providing information clearly and compassionately, and then asking again to ensure comprehension and address any concerns. The key is to remain empathetic, patient, and responsive to the emotional needs of the patient and family.

# Discussing Treatment Options and Making a Recommendation

Shared decision making should be utilized to help guide the conversation of treatment options. In very critical conditions, sometimes there are minimal options, but treatment options can be framed in the context of burdens, possible benefits and the likelihood of success. Relating treatment options to a patient's values and the things that they enjoy in life helps ground these options. As a support system deliberates, the care team should remain engaged and add information as needed. At this time, best-case/worst-case scenario conversations can be used to personalize the treatment options. (See Best Case/Worst Case section). The family may ask for or appear to need a recommendation. By outlining previously agreed upon recommendations by the care team, this may help make decisions easier for the family. Emphasizing the family is speaking for the patient and reflecting their wishes, rather than "making the decision themselves" is often helpful- this is the principle of substituted judgment. Again, recommendations by the care team are encouraged, but personal biases should be avoided.

## **Review and Finalizing the Treatment Plan**

A simple summarization of the updates that were discussed helps recenter the conversation. The last step, although intimidating, is to finalize a treatment plan with the knowledge that it is malleable, and to remember that not all care conferences will end with a decision. If this is the case, scheduling a care conference for the following day is helpful to give emotions time to settle and families additional time to discuss. During this time, it is important to touch on code status, surrogate decision maker, treatment route, and conflicts. All members in the conversation should leave with a clear understanding of which treatment is being pursued, timeframe on expected changes in patient's conditions, and the timeline on reevaluation of treatment plan if relevant.

### **Pre/Post Test**

### **Questions**

- 1. What is the primary goal when leading a family care conference?
  - a) Convincing the family to agree with the surgeon's recommended treatment
  - b) Providing the family with detailed medical terminology to explain the situation
  - c) Facilitating a collaborative discussion that respects the patient's values and the family's emotional needs
  - d) Focusing solely on delivering the prognosis
- 2. Which of the following is the best approach to conveying medical information during a family care conference?
  - a) Using detailed medical terms and expecting the family to ask for clarification
  - b) Presenting information in small, manageable chunks and checking for understanding frequently
  - c) Providing as much information as possible at once to cover all details
  - d) Focusing only on positive aspects of the patient's condition to reassure the family

#### **Answers**

- 1. C) Facilitating a collaborative discussion that respects the patient's values and the family's emotional needs
- 2. B) Presenting information in small, manageable chunks and checking for understanding frequently

## **Bibliography**

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### **Case Scenario**

Dr. Smith is preparing to lead a family care conference for Mrs. Maria Gonzalez, a 47-year-old woman admitted to the ICU after suffering a fall from 20-foot ladder. Mrs. Gonzalez is currently intubated, on mechanical ventilation, and has shown minimal neurological recovery in the past 24 hours. The ICU team has performed multiple imaging studies that reveal extensive brain damage, making meaningful recovery unlikely, per neurosurgery. Her family, including her husband, daughter, and two sons, are understandably anxious and hopeful for improvement, but they have yet to fully grasp the severity of her condition.

Before the conference, Dr. Smith reviews Mrs. Gonzalez's medical history and prognosis with the ICU team, ensuring she has all the necessary information to provide a complete update. Dr Smith speaks with Neurosurgery and invites them to the family meeting. She gathers the family in a private room and begins the conference by expressing her sympathy for the stress they are experiencing. She starts by asking the family what they understand about Mrs. Gonzalez's condition, giving them space to express their perceptions and concerns. When it becomes clear that the family is holding onto hope for a full recovery, Dr. Smith gently provides updated medical information, explaining the imaging results and what they mean in terms of prognosis. She uses simple language and pauses frequently to check for understanding, inviting questions and clarifications.

As emotions begin to surface, with some family members expressing grief and frustration, Dr. Smith validates their feelings, acknowledging the difficulty of the situation. She reassures them that the care team will continue to support them, whether they choose to pursue further life-sustaining treatments or consider palliative options. Dr. Smith emphasizes that the family's input on Mrs. Gonzalez's values and wishes is critical in guiding the next steps. Together, they explore the options, including continuing mechanical ventilation or transitioning to comfort care, ensuring the family feels involved in the decision-making process while respecting Mrs. Gonzalez's dignity and their emotional needs. At the end of the meeting, discussion regarding pending decisions and time for the next family meeting are determined.