

## SEVEN GUIDING PRINCIPLES

### Principle 1. Provide Structured Interaction

#### Communicating in the Chaos of Sudden Illness Situations

- Provide structured interactions in the otherwise chaotic environment by establishing regularly scheduled communications between specific identified parties from both the family and the health care team
- Much of the information covered in this module deals with ways to bring structure to a situation of stress and uncertainty. Often this is a confusing time, for many reasons:
  - The family is trying to cope with the shock of the situation
  - Things may be happening very quickly
  - There may be a need to involve multiple members of the family at a moment's notice
  - Most importantly, there will probably be multiple physicians and other members of the health care team providing different aspects of care to the patient
- In this atmosphere, coordinating information about the patient's condition and potential decisions can become a challenge
- A structured communication process can:
  - Help reduce confusion
  - Facilitate effective decision-making

#### Identifying Spokespersons

- Encourage one person on both sides (physician/team and patient/family) to act as the primary spokesperson and communicator
- The goal is not to cut off communication between the family and other physicians, but rather to minimize confusion
- Depending on the situation, the primary doctor who serves as spokesperson could be:
  - The primary care physician
  - The intensive care unit physician
  - Another physician
- The spokesperson for the family does not necessarily have to be the decision-maker

#### Coordinating Communication and Decision-Making Efforts

- Try to coordinate all information and decisions through the spokesperson
- Try to meet with the patient/family spokesperson and decision-maker at the same time, if both exist
- Restricting the number of meetings may be challenging when there are many family members visiting at various times throughout the day who all want information. The following suggestions may be helpful:
  - Ensure that everyone on the health care team understands the communication process that has been established
  - Tell all the family members and the members of the health care team about the communication plan
  - Identify regular times when you will communicate with everyone who wishes to be present

#### Incorporating Basic Communication Skills

- Using good communication skills can be more important than ever in situations of sudden illness, where emotions are likely to be prominent and fragile
- Follow these steps of good communication when conveying any information:
  - Get the setting right for the information
  - Find out what family members know before sharing new information
  - Respond to their feelings and finish with a concrete plan

### Principle 2. Communicate the Range of Possible Outcomes

#### Avoiding Common Mistakes in Situations of Uncertainty

- **Pitfall #1: Waiting Until More Is Known**
  - In situations of prognostic uncertainty, physicians sometimes wait until they have more information before they meet with the patient and family
  - Waiting actually heightens patient and family anxiety
  - It is better to identify what is known early, even if such information is incomplete and there is uncertainty
  - Even if the situation is very uncertain, you, as a physician, know more than the patient or family
  - The sooner family members have information, the sooner they will begin to understand what is happening
- **Pitfall #2: Communicating Only Extreme Outcomes**
  - At times physicians choose to provide information in terms of extreme outcomes, rather than discussing the full range of possibilities
  - As excessive optimism is common among physicians and health care workers, sometimes the discussion is limited to only one extreme outcome: the possibility of full recovery
  - In situations of prognostic uncertainty, it is important to communicate the full range of possible outcomes

### **Tips for Communicating the Full Range of Possible Outcomes**

- **Acknowledge Uncertainty and Discuss it Openly**
  - Discuss the current situation, the immediate future, and what is likely to happen next
  - Convey a range of possibilities, since the actual outcome is often somewhere in the middle
- **Be specific about all possible outcomes**
  - Use concrete examples to help the family understand
  - Acknowledge the limits of individual case experiences, both yours and the family's
  - Avoid saying vague things like, "It doesn't look good" or "I don't think the outcome will be good"
  - Be more specific by talking about the current information:
    - What you are looking for as positive signs or signs of a worsening condition
    - What outcomes are more likely or less likely
- **Use evidence-based information**
  - Where possible, use evidence-based information to support discussions
  - When the situation is particularly difficult consult with colleagues who have a broad experience (e.g., intensivists) and/or knowledge of the relevant, evidence-based literature
- **Check understanding**
  - Ask frequently what the patient and family understand in order to check what information they have heard
  - Remember, patients and families may need gentle repetition in order to take it all in
- **Involve Other Health Care Team Members**
  - Use other health care team members such as nurses, social workers, and chaplains to help:
    - Support the patient and family
    - Reinforce the information that has been given
  - Spend the time to tell appropriate caregivers the substance of what you have told the patient and family so that mixed messages and confusion are minimized
- **Respond to Emotions**
  - Anticipate that these discussions will result in strong emotions
  - Be prepared to respond to the emotions that are generated

### **Principle 3. Identify Decision Points in Advance**

#### **Importance of Patient & Family Involvement in Decision-Making**

- **Informed participation of the patient and family in health care and medical decisions is important for many reasons:**
  - It demonstrates respect for the individual, perhaps the most important of the ethical principles governing medical care
  - It maximizes the likelihood that health decisions will be made with the patient's best interests in mind

- It improves the likelihood that the therapeutic goals of care will actually be achieved

### Identifying Future Decision Points

- It is particularly helpful to identify decision points in advance
  - For Example... A patient may have need for immediate respiratory support and vasopressors for stabilization, but the possibility of hemodialysis may or may not become an issue. Let the family know how you will determine whether or not dialysis will need to be considered. For instance, you may need time to determine the metabolic gap after respiratory stabilization. Let the family know what kind of information you will be giving them about dialysis if it becomes relevant.
- Clarify which decisions need to be made immediately and those that will need to be made in the near future
- Even when things are uncertain, the physician should be very clear that there would be decisions to be made
- All options for care are open for discussion, from aggressive attempts to reverse the disease to purely comfort measures

### Structuring Discussions with Family Members

- Begin preparing the family early for decisions to be made in the future
  - **For example...** "We've talked about what we know at this point. Now let's talk about the future and what we can expect to happen."
- The earlier the family knows what discussions will be needed, the better they can organize themselves psychologically and logistically for the decisions they will need to make
- At each meeting, set expectations about when you will meet again, and what information you will need to discuss, e.g.: "I'll talk to you again in the morning. At that point we should have more information from the tests and can talk better about whether dialysis is a good choice"

### Involving Other Team Members

- Use other members of the health care team to:
  - Support the patient and family
  - Reinforce the plan that has been determined
- Be sure to let them know the details and rationale for the plan you have established

## Principle 4. Use the General Goals of Care to Guide Decision-Making

### Reassessing Goals of Care

- As prognosis changes and decisions come up, use the general goals of care to guide decision-making about:
  - Treatment priorities
  - The use of technology
- Assessing or reassessing the general goals of care is an important step in all medical decision-making, since the overall goals of care provide the basis for further decisions about specific treatment priorities
- In situations of sudden critical illness, radical readjustment of goals of care is often appropriate
- The physician, patient and family need to work together to assess and re-prioritize the goals of care in light of:
  - Recent developments
  - Patient values
  - Advance directives
  - The range of possible outcomes

### Informed Consent

- The goal of informed consent is to enable patients (or parents if the patient is a child) to make choices consistent with their own personal goals, beliefs, and values
- Achieving informed consent can be a special challenge at times of sudden life-threatening illness because of the uncertainty and changing nature of the situation
- Four conditions need to be met for informed consent to occur:

- The patient (parents) must have the capacity to make an informed decision
- Pertinent information must be provided to the patient (parents)
- The patient (parents) must comprehend the information well enough to make a rational choice
- The decision itself must be voluntary, not coerced

### When the Patient Lacks Capacity

- If the patient does not have the capacity to make an informed decision, then the physician's next step is to work closely with the proxy decision-maker
- Focus on what the patient would want if the patient were able to speak for himself or herself
- Avoid asking the proxy, "What do you want us to do?"
- Instead, use words like
  - "Can you help me identify what he would want in this situation?"
  - "What would she say?"

**Steps in Decision-Making** In order to make informed decisions, patients, parents, and proxies need to know:

- The nature of the illness
  - Clarifying the nature of the illness serves to verify that the patient, parent, or proxy has an accurate understanding of the situation
- The recommended treatment
  - Discussing the recommended treatment includes a description of:
    - What is recommended
    - How it will be done
  - This information could also include the rationale for the treatment based on the patient's current medical condition
- The reasonable alternatives:
  - Provide information about reasonable alternatives and the chance of each alternative achieving its intended goal
  - Give information about:
    - What the most likely outcomes of each alternative are
    - The evidence on which the statements are based
- The burdens and benefits of each option
- For each option being considered, list the most common and the most significant burdens and benefits

### Focus on the Degree of Recovery

- Focusing on the degree of recovery that would be acceptable to the patient (or parent if the patient is a child) can help families cope with confusion and guilt in situations of prognostic uncertainty
- By identifying the desired and acceptable degree of recovery, and comparing this with the markers of recovery, it is possible to outline decision points
  - **For example...** "If it becomes clear that the goal of complete recovery of mental function is not possible, then we will withdraw mechanical ventilation". "If we don't see an improvement in x, y, and z in 1 week, then I would recommend that we discontinue the medications maintaining blood pressure."

### Time-Limited Trials: General Principles

- In situations of prognostic uncertainty, all treatment can be thought of as a time-limited trial
- Use terms like, "We're doing everything we can, but in 48 hours we may find that it's not working."
- The use of time-limited trials in situations of prognostic uncertainty should be given careful consideration to assure that the trial is consistent with the general goals of care and goals of recovery
- Informed consent is necessary, as there are both benefits and burdens associated with time-limited trials

### Benefits of Time-Limited Trials

- Plan can be used while more information is gathered

- Often in situations of prognostic uncertainty, there is the perception that the choice is limited to either initiating a treatment or not
- Characterizing treatment in terms of a time-limited trial offers another option that allows treatment to continue while time allows the prognosis to become clearer
- Provides structure to situations of uncertainty
  - May help families to cope with the uncertainty of the situation
  - Life-sustaining treatment can always be stopped at a later time

### **Burdens of Time-Limited Trials**

- May result in a poor or undesired outcome
- Decision to stop treatment may become more difficult
  - Once treatments have begun, a variety of powerful forces tend to perpetuate them
  - It is important to establish clear guideposts or criteria for decision-making in advance to prevent a difficult future decision-making process

### **Consider the Role of Palliative Care**

- When considering reasonable alternatives, aggressive palliative care should always be discussed
- Physicians often inadvertently leave the impression that they will either "do everything" or "do nothing"
- Aggressive relief of suffering is not an alternative to medical care, or the opposite of medical care, or what we do when we decide we "don't want to do anything"
- It can be included in curative approaches to sudden illness as well as in chronic and incurable conditions
- When aggressive attempts to maintain comfort are included in the care plan from the beginning, it permits these aspects to be continued when other treatments are discontinued

### **Principle 5. Take Sociocultural Differences into Account**

#### **Sociocultural Perspectives: Patients, Families, and Providers**

- Identify, acknowledge, and address differences in values and beliefs with care and sensitivity
- Each patient, family member, and member of the health care team will:
  - Hold a unique set of values, beliefs, and experiences related to the health care system
  - Make unique choices about the type of health care that is appropriate for him or her
  - Experience a given situation from his or her social, cultural, and spiritual perspective
- When discussing important medical decisions with patients and/or families, it is important for everyone to:
- Potential differences in perspectives between patients, families, and members of the health care team are discussed in Module 9: Medical Futility, and Module 11: Withholding/Withdrawing Treatment
- In the end, the final decision about treatment remains with the patient and family
  - Be sensitive to these differences
  - Acknowledge and address them openly

#### **Values and Beliefs that May Impact Reactions to Sudden Illness**

Examples of values and beliefs that could potentially impact discussions about prognostic uncertainty and life-threatening illness include:

- Distrust of the medical system or physicians
- Unrealistic expectations of the medical system or physicians
- Any life, no matter how compromised, is worth living
- Belief in miracles
- Death is "the enemy"
- Death should not be discussed openly

#### **When Language is an Issue**

- When language is an issue, ensure that information is communicated through a medically trained translator or an interpreter who is sensitive to the cultural nuances of the patient and family members. For additional information on using medical translators and interpreters, see Module 13: Cultural Issues
- Subtleties in language can lead to significant differences in understanding
- Try to avoid using a family member to translate, as family members may be:
  - Wrapped up in the drama of the situation
  - Unable to convey information accurately, particularly when emotions are heightened

### **Principle 6. Manage Symptoms Effectively**

- Stress that the provision of comfort and relief of symptoms is part of the management plan
- Practice good symptom management in order to maximize quality of life even during periods of maximum effort to restore full function and health
- Many patients, parents, and family members unnecessarily remember their periods of acute health crisis as miserable
- Approaching the relief of suffering in this way permits the physician to convey accurately to the family what aspects of the plan are going to continue, even if other treatments will be stopped

### **Principle 7. Consider the Impact of Stress on Caregivers**

#### **Caregiver Responses to Stress**

- Although this module has focused on the skills of the physician in dealing with patients and families during sudden illness, it is worth considering the stress that may be experienced by caregivers
- Physicians and other health care professionals have their own responses to sudden illness in the patients they are caring for
- The impact of stress on caregivers can be significant, and debilitating
- All members of the health care team may feel stress, loss, and grief in relation to their needs, values, and hopes for patients
- Unrecognized, these responses may lead to occupational stress and burnout

#### **Minimizing Caregiver Burnout**

- Particularly when the outcome is not what was initially hoped for, physicians may:
  - Experience unrealistic feelings of guilt and fear of rejection (by patients, families, or colleagues)
  - Project these feelings in unhealthy ways
- Careful negotiation of goals of care with patients and families in light of the situation, the prognosis, and the likely outcomes will:
  - Make these distressing reactions less likely
  - Enhance the possibility of meaningful human interactions that can sustain rather than stress the clinician

#### **When Additional Support is Needed**

- Many clinicians find additional support necessary in order to continue functioning effectively
- Support may come in the form of:
  - Professional counseling
  - Informally from family members
  - Religious advisors
  - Supportive colleagues, some of whom may meet regularly in small groups to discuss their feelings
- Physicians and other professionals should learn to recognize their own need for care and set up supports that allow them to continue to function throughout these stressful situations

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