

EPEC

Education for Physicians on End-of-life Care

Participant's Handbook

Module 8

Sudden Illness

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Abstract

Sudden illness, particularly when it is severe and unexpected and has an uncertain prognosis, challenges everyone. As in other aspects of medicine, there are features and skills that can be learned. Structured communication is especially important when the prognosis is uncertain. Goals for care may need to change rapidly as the prognosis changes. Discussions should include the possibility of time-limited trials. Sociocultural differences may need rapid and sensitive appreciation to keep urgent care consistent with the patient's values.

Key words

acute symptom management, chaotic environment, clinician burnout, continuous reassessment, goals for care, informed consent, patient and family support, prognostic uncertainty, sociocultural difference, stress, sudden illness

Objectives

The objectives of this module are to:

- describe the features of sudden illness that require special skills
- know how to communicate effectively in the face of sudden illness
- know how to guide decision making in the face of sudden illness
- explain the benefits and risks of using a time-limited trial approach

Clinical Case on Trigger Tape

Kevin Robinson is a 15-year-old bicyclist who has been struck by a car. He sustained major traumatic injury and has been in a coma since yesterday. He has minimal brain activity. His prognosis for survival is poor; the chance of regaining consciousness is small.

Introduction

Situations of sudden illness are often caused by an unexpected event, such as an accident or a sudden change in the patient's health status. Frequently, the patient and family members find themselves in a turbulent environment—such as the emergency room or intensive care unit—where there are many people involved in the care of the patient, the situation is constantly changing, and critical decisions need to be made rapidly.

During these times, physicians and other members of the health care team are simultaneously working to save the patient's life, manage symptoms, and prepare the patient and/or family for the possible outcomes and the hard decisions they will need to make. The un-

certainty and chaotic nature of these situations can make it difficult for patient, families, and the health care team alike.

The goal of this module is to enable physicians to effectively facilitate decision making in situations of sudden illness where a patient's condition is changing quickly and there is prognostic uncertainty. The module discusses guiding principles and steps the physician should take to optimize communication, provide structure in an atmosphere of uncertainty, and ensure that decisions are based on informed consent and identified goals of care.

Overview

An understanding of the characteristics common to stressful situations involving sudden illness will help the physician to guide care more effectively. Although each situation will differ, there are 7 guiding principles that are likely to aid decision making during intense situations. They are outlined here and discussed in detail in the sections that follow.

1. Provide structured interaction. Establish regularly scheduled communications between 1 person from the family and one from the health care team. This reduces confusion and avoids misunderstandings. It helps to keep things on track. It breaks activities down into steps that can be taken one at a time:

- Use good communication skills. Get the setting right, ask the family what they understand before giving them information, respond to their emotions, and establish a follow-up plan, even if it's just for the next few hours (see Module 2: Communicating Bad News).
- Expect emotions to be prominent and fragile.

2. Communicate the range of possible outcomes. In situations of prognostic uncertainty, do not wait to communicate, even if there is little known information. Tell what you do know as soon as possible. Provide the relevant information to help the patient and family make informed choices. Discuss all possible outcomes. Be as clear and direct as possible.

3. Identify decision points in advance. Identify the points in the future when additional information will be available that will help with decision making. Be clear about when you think decisions will be needed. It is important to begin to prepare the family early in the process.

4. Use the general goals of care to guide decision making. Discussion of goals of care should be ongoing. Decisions about treatment priorities should be based on the patient's goals and beliefs. It cannot be stressed enough how important this step is. Have a plan but keep it flexible (see Module 7: Goals of Care).

5. Take sociocultural differences into account. If necessary, try to involve a colleague to help transcend sociocultural differences that may impede supportive decisions. Explain concepts in clear language that is easy to understand. Use words like "worse" rather than

“progressing.” Check understanding regularly. When language is a barrier, use a skilled medical translator (see Module 2: Communicating Bad News).

6. Manage symptoms effectively. Sudden illness, particularly trauma, is accompanied by multiple symptoms and suffering. Always ensure that all symptoms are managed effectively, throughout the course of the illness.

7. Consider the impact of stress on caregivers. The chaos and occupational stress of situations involving sudden illness can have considerable impact on caregivers. They experience a range of emotions during any given case of sudden illness. As cases accumulate, so may the stressors. These may be manifested in a caregiver’s personal and professional life and may affect clinical decision making.

Each guiding principle will be discussed in the sections that follow.

Guiding principles

1. Provide structured interaction

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. The family is trying to cope with the shock of the situation, things may be happening very quickly, and 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. Coordinating information about the patient's condition and potential decisions can become a challenge.

A structured communication process can help reduce confusion and facilitate effective *decision making*. Encourage 1 person on each side (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, or another physician.

The spokesperson for the family does not necessarily have to be the decision-maker. If there needs to be a health care proxy or family decision maker, identify who that person is early (see Module 1: Advance Care Planning, and Plenary 2: Legal Issues).

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.

It is helpful if 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.

Use good communication skills (see Module 2: Communicating Bad News). 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.

2. Communicate the range of possible outcomes

In situations of prognostic uncertainty, communicate the full range of possible outcomes.

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.

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 general, it is best to be specific about all possible outcomes. Use concrete examples to help the family understand. 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. Where possible, use evidence-based information to support discussions. When the situation is particularly difficult, consult with colleagues who have a broad experience (eg, intensivists) and/or knowledge of the relevant, evidence-based literature.

Acknowledge the limits of individual case experiences, both yours and the family's. Don't say 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 is more likely or less likely.

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 (see Module 7: Goals of Care).

Use other health care team members such as nurses, social workers, and chaplains to help support the patient and family as well as to 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 the emotions that are generated. This is discussed in more detail in Module 2: Communicating Bad News.

3. Identify decision points in advance

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 care 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

It is particularly helpful to identify decision points in advance. Clarify which decisions need to be made immediately and those that will need to be made in the near future. For instance, 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.

Even when things are uncertain, the physician should be very clear that there will be decisions to be made. All options for care are open for discussion, from aggressive attempts to reverse the disease to purely comfort measures.

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, eg, "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."

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

4. Use the goals of care to guide decision making

As prognosis changes and decisions come up, use the general goals of care to guide decision making about treatment priorities and 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 (see Module 7: Goals of Care). 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 reprioritize the goals of care in light of the recent developments, the patient's values, advance directives, and the range of possible outcomes.

Informed consent

The goal of informed consent is to enable patients, or parents if the patient is a young 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?" or "What would she say?" (See Module 7: Goals of Care).

Steps in decision making

Patients, parents, and proxies need to know the nature of the illness, recommended treatment, reasonable alternatives, the chance of each choice achieving its intended goal, and the burdens and benefits of each option. Clarifying the nature of the illness serves to verify that the patient, parent, or proxy has an accurate understanding of the situation. Discussing the recommended treatment includes a description of what is recommended and how it will be done. This information could also include the rationale for the treatment based on the patient's current medical condition. When clarifying the chance of each alternative achieving its intended goal, give information on what the most likely outcomes of each alternative are, and the evidence on which the statements are based. 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 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” or “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.”

Benefits and burdens of time-limited trials

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. 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.

A time-limited trial can provide structure to situations of uncertainty. However, 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. Otherwise, a time-limited trial may result in an undesired outcome and a decision to stop treatment may seem more difficult.

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.

5. Sociocultural differences

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 have a unique set of values, beliefs, and experiences related to the health care system and unique choices about the type of health care that is appropriate for him or her. In addition, each individual will 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 be sensitive to these differences, and acknowledge and address them openly. In the end, the final decision about treatment remains with the patient and family.

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, ensure that information is communicated through a medically trained translator who is sensitive to the cultural nuances of the patient and family members. Subtleties in language can lead to significant differences in understanding. Try to avoid using a family member to translate who may be wrapped up in the drama of the situation and unable to convey information accurately, particularly when emotions are heightened (see Module 2: Communicating Bad News).

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 Therapy.

6. Manage symptoms

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. (See Module 4: Pain Management; Module 6: Depression, Anxiety, Delirium; Module 10: Common Physical Symptoms; and Module 12: Last Hours of Living.)

7. The impact of stress on professionals

The impact of stress on professionals can be significant and debilitating.

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 professionals.

Physicians and other health care professionals have their own responses to sudden illness in the patients they are caring for. Unrecognized, these responses may lead to occupational stress and burnout. All members of the health care team may feel stress, loss, and grief in relation to their needs, values, and hopes for patients. 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) and may 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 and will enhance the possibility of meaningful human interactions that can sustain rather than stress the clinician.

Nonetheless, many clinicians find additional support necessary in order to continue functioning effectively. Support may come in the form of professional counseling or it may come informally from family members, from religious advisors, or from supportive colleagues, some of whom may meet regularly in small groups to discuss their feelings.

Summary

Confusion, chaos, and stress often accompany sudden illness. Structure communications with care. Meet with the patient and family frequently, communicate clearly, and discuss all of the available information that might shed light on the patient's prognosis. Identify expected decision points and develop a timely plan for care. Reassess the goals and plan for care regularly, especially as the prognosis becomes clearer. Conduct informed consent discussions with particular attention to the merits and burdens of time-limited trials. In all situations consider the influence of patient and family values, beliefs, and experiences and adjust discussions accordingly. 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.

Key take-home points

7 guiding principles

1. Provide structured interaction.
2. Communicate the range of possible outcomes.
3. Identify decision points in advance.
4. Use the general goals of care to guide decision making.
5. Take sociocultural differences into account.
6. Manage symptoms effectively.
7. Consider the impact of stress on caregivers.

Pearls

1. Discuss more than the most extreme possible outcomes (full recovery or death).
2. Acknowledge uncertainty openly and explicitly.

Potential pitfalls

1. Postponing communication. Don't wait for more information.
2. Losing clear judgment. Don't let chaos/excitement overwhelm you.
3. Avoiding emotional components of experience. Stay close enough to be empathic but do not get distracted.

Resources

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