2012 SAEM Ethics Curriculum
Module 4: Patient Communication Skills

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ACGME EM Milestones:
- ICS1 (Patient centered communication)
- PROF1: (Professional values – putting patient first)

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4.1: Delivering Bad News (Jacobus)
4.2: Establishing Goals of Care (Lamba)
4.3: Difficult Patient Situations (Abbott)

4.1: Delivering Bad News (Jacobus)

Objectives:

1. Be able to clearly and compassionately deliver bad news to a patient or family members.
2. List the steps in the SPIKE and GRIEV_ING mnemonics.
3. Discuss practitioner pitfalls in the delivery of bad news.

Case 4.1.1 – request by family not to talk to patient:

You are taking care of a 76-year-old Japanese man who has been battling prostate cancer for years. You have just diagnosed metastases to the brain. The patient does not have many mental status changes but as you go in to deliver the news you are stopped by the patient’s sons who ask you to tell them the news first. They are concerned that bad news may upset the patient.

Case 4.1.1: Questions:

1. What is your legal and ethical obligation to the patient in this case?
2. How do you respond to the sons?
**Case 4.1.2 – Delivering bad news re. a child:**

A 6-year-old girl, in remission from acute lymphocytic leukemia (ALL), is brought to the ED by her mother for evaluation. She has developed painless lumps in her right axilla over the last week. You draw a CBC and it confirms what you were suspecting: a recurrence of her ALL.

**Case 4.1.2: Questions**

1. How do you deliver the news to the mother?
2. Should you tell the patient, and if so, when?
3. The mother is concerned that the bad news will upset the patient and asks you not to tell her. How do you respond?
4. Would it make a difference if the patient were 10? Or 4?

**Case 4.1.3 – Phone notification of death:**

A 27-year-old construction worker is brought to your ED after falling off the fifth story of a building. He was pulseless in the field and you quickly pronounce him. The social worker contacts the patient’s wife and tells her to come to the ED, but the wife says that she’s stuck at home alone with their newborn daughter and won’t be able to come in for at least a few hours. She asks to speak to you to find out what’s going on.

**Case 4.1.3: Questions**

1. What do you tell her?
2. Would it make a difference if she had a friend or a family member over at the house?

**Case 4.1.4 – Death notification to spouse:**

A 74-year-old man who was involved in a high-speed MVC is brought to your ED. He is badly injured with multiple rib and extremity fractures and a partial foot amputation, but is awake and talking to you and in a great deal of pain from his injuries. He is hypotensive and winds up dying in the ED before his wife can come to the hospital. When you deliver the news to his wife she asks if it was sudden and if he was suffering in his final moments.

**Case 4.1.4: Questions:**

1. What do you tell her?
2. Is it ethically acceptable to lie to spare her the image of her husband suffering as he died?

**Background Information**

Delivering bad news to a patient or to surviving family members is one of the most difficult and emotionally taxing tasks in the skill set of the emergency physician. The people who receive this news are going to remember the conversation, as well as much more subtle observations such as your tone and posture, for the rest of their lives. Clear, compassionate delivery is essential. An unhurried discussion in a quiet, calming environment is ideal but often not feasible in a busy emergency department. However, we must do whatever we can to block off time and find a quiet area to have these life-altering conversations.

Several step-wise protocols and mnemonics exist for bad news delivery. They all focus on addressing the setting and participants, finding out what they know, delivering the information you have, allowing them time to process the information, and wrapping up. We will briefly discuss the two that are covered in the curriculum of the Essential Skills in Palliative and End-of-Life Care for Emergency Medicine (EPEC-EM) course: SPIKE and GRIEV_ING.

The SPIKE mnemonic was initially developed for oncologists breaking bad news in the office setting, but works well for emergency providers as well. It stands for:

- **Setting up**: have all the facts prepared and at your disposal before starting the conversation.
- **Patient’s perceptions**: assess what knowledge the patient already has about the situation.
- **Invitation** from patients to hear information: not every patient wants full disclosure about the details of their diagnosis or prognosis. Find out what the patient wants to know.
- **Knowledge sharing**: deliver the news clearly and directly. Attempts to soften the blow by using euphemisms or medical terms such as “glioblastoma” may only muddy the waters and cause confusion. It may help to give a warning before delivering the information such as, “I’m afraid I have some bad news.” Being seated during the conversation helps convey your interest and the gravity of the situation; touching the patient, as long as there are no cultural prohibitions, helps reinforce an emotional bond. Dealing with requests to withhold information, for example a young child or an elderly parent, can be especially difficult for the emergency physician. This often requires discussion with the family about their reasons for wanting to withhold the information, such as cultural norms, and involvement of the patient’s primary care physician.
- **Emotion exploring and empathy**: acknowledge the patient’s emotional reaction, ask further questions about their feelings, and show empathy.
**Summarizing and strategizing:** verify that the patient understands what you have told them and lay out the next steps in your treatment plan.

The GRIEV_ING mnemonic was developed to teach death notification skills to emergency medicine residents based on current research and consensus. The steps in GRIEV_ING are:

- **Gather** the family: preferably in a quiet, comfortable area. If many family members are present it may not be practical or possible to talk to them all at once. In this case, find out who was closest to the patient and bring them into the room for the notification. They can then relay the news to the rest of the family.
- **Resources:** assemble the people necessary to help you as well as the family. This can include nurses, chaplains, and social workers.
- **Identify**: identify yourself to the family, identify the patient by name, and identify what knowledge they have up to this point.
- **Educate**: inform the family of the events leading up to the patient’s death and what was done by pre-hospital and in-hospital personnel in attempts to save them.
- **Verify**: tell the family that their loved one has died. It is imperative to be clear here, you must use the words “dead” or “died” to avoid confusion. Euphemisms like “he passed,” “he’s gone,” or “he’s in a better place” can be construed as meaning that the patient had a good result on a medical test or was transferred out of your facility. This confusion only makes it harder for the family when you need to clear the confusion.
- **Space**: allow adequate time for the family to understand and process the news you have just delivered. Realize that silence while they are taking in this information is normal and desirable. Emergency physicians are action oriented people by nature, it can be difficult for us to tolerate silence. The family, though, will need this space to fully comprehend the news that you have just delivered.
- **Inquire**: find out if the family has any questions that you can answer. They will often want to know if their loved one died suddenly and if they suffered. Even if their death was not sudden and even if they were in pain at the end of their life, give some careful thought to whether you want to share this information. This knowledge can lead to haunting, traumatic memories for the survivors.
- **Nuts and bolts**: you may need to discuss medical examiner notification, autopsy, organ donation, personal belongings, or funeral home arrangements.
- **Give**: condolences and contact information. Family members are often so stunned by the death of their loved one that they don’t remember questions until days later. It is important for them to have a way to reach you in the coming days. Some emergency physicians give their personal phone numbers with an invitation to call anytime in the following days if questions arise. Even giving the ED phone number with a commitment to return their call will help prevent them from feeling disconnected and abandoned.

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**Case Discussions & Notes**
The SPIKES and GRIEVING protocols can be very helpful but remember that they are just mnemonics. They are not a substitute for the judgment of an experienced provider. They also do not cover every circumstance and some circumstances not covered by them warrant discussion.

**Cases 4-1a and 4-1b** deal with situations in which you are asked by family to withhold bad news from the patient. In both cases, a family member is trying to shield the patient from the distress of the bad news. In the first, the patient’s family is trying to accept the burden of the bad news and the subsequent decision-making on themselves so as to spare the elderly patient. This is a common practice in some cultures. Despite family preference of cultural norms in the US the physician’s primary legal and ethical obligation is to the patient. As discussed in the *Invitation* section of the SPIKES mnemonic above, the physician must find out from the patient what he or she wants to know. If they give their permission to discuss the bad news and leave decision-making to their family then it is acceptable to withhold information. If they decide that they want to know, then it is unethical to keep that information from them.

Cases like 4-1b, in which the mother asks you to withhold information from her young daughter, are more difficult because the patient may be too young to fully understand the information and, additionally, the mother has decision-making power for the child. In most cases even a young child will realize that something is wrong by the emotional reactions of the people around them and the initiation of new treatment. Allowing the parent to tell the child herself, after some preparation, is fine, but withholding the information entirely is ethically unsound. Finding out more about the mother’s reluctance and working with her to form a plan to inform the child may be helpful.

**Case 4-1c** deals with the issue of how and when to inform a family member of a death when they are not able to come into the emergency department. Sometimes the patient’s next-of-kin may be in another state or even another country. In these cases the notification may have to be done over the phone. Questions the physician must consider in cases like these include:

- Is there a social worker, nurse, or chaplain available to talk to the family member and give support after you have delivered the news?
- Does the family member have anyone else to support them wherever they are?
- Does the family member have any immediate responsibilities that will be affected by the delivery of this bad news? For example, are they at work and will they be able to continue their duties after you deliver the news?

In some cases you may need to delay the notification until they are in a situation where they can hear the news.

**Case 4-1d** raises the issue of whether it is ethically acceptable to lie to a family member about their loved one’s death. The image of their family member suffering in his last moments can be a haunting, scarring memory that persists for years. Another common scenario involves the family member asking if there was anything they could have done to prevent their loved one’s death. The guilt of knowing that they were, in some way, responsible will likely stay with them forever. With the patient deceased, the physician
will have to carefully consider his or her duties to the family and whether the duty to be truthful outweighs the humanitarian duty to prevent the family’s suffering.
4.2 Establishing Goals of Care (Lamba)

Objectives

1. Identify possible goals of care and how they interrelate and change
2. Understand how to negotiate goals of care
3. Be able to communicate prognosis and its uncertainty
4. Be able to set limits on unreasonable goals
5. Understand how to identify goals when patients lack capacity
6. Be able to ask questions to help surrogates describe their loved one’s values.

Case 4.2.1 – Dementia patient with new pneumonia:

A 79 year old nursing home resident presents to the emergency department for fever, lethargy, cough and hypoxemia. He has Alzheimer’s dementia and at baseline is confused and dependent for all his activities of daily living. He has been in the nursing home for a year. He is diagnosed with multi-lobar pneumonia. His wife and son are at bedside and concerned about his clinical status.

Case 4.2.1: Questions

1. How do you assess this patient’s values and preferences?
2. How do you communicate the prognosis and its uncertainty to the patient and family?
3. Does the ultimate disposition of patient change based on eliciting patient goals of care?
4. How do you recommend treatment options based on patient values?

Background Information

There are many possible goals of health care, including curing disease, prolonging life, relieving distressing symptoms, providing a good death, and improving overall quality of life. These goals vary from patient to patient and priorities may change for a person over time as their health status changes. In general, multiple goals of care may apply simultaneously, such as efforts made to cure disease while we manage suffering due to distressing symptoms. For some patients their goals could even be contradictory or one goal may have a much higher priority than another. Every clinical decision ideally flows from an open dialogue with the patient or surrogate about their illness, their prognosis and their goals. The ED clinician must therefore be able to identify what is reasonable for the patient and family to expect in the next hours of care, elicit patient values and preferences for care, and recommend treatments to help patient reach his or
her goals. Communication skills are required to elicit these goals of care in a culturally sensitive manner with appropriate language that respects patient wishes and hopes. Goals of care conversations serve as ‘road maps’ and guide patient-value based care. If you can find out where the patient wants to go and what they want to avoid, then you can recommend the best treatment plan to achieve their objectives. Key to understanding patient goals is the “whys” behind a decision as opposed to the ‘yes’ and ‘no’ answers.

**Negotiating goals**

It is important to first understand patient/family overall goals of care before addressing specific treatment priorities. For example, ask in general about what the patient values and what are his/her concerns or fears. Then it is easier to share recommendations and decisions regarding a specific therapy like CPR. The following are important steps to delineate overall patient goals:

**Communicating prognosis**

Patient or family usually are looking for an answer to two fundamental questions
- What is wrong with me or her/him?
- What will happen to me or her/him?

This prognostic information is crucial for patients to plan for the future or set priorities. Admittedly this is very difficult in the ED setting and under or overestimation errors may occur. Maintaining a positive attitude and framing a discussion as ‘hoping for the best but planning for the worst’ may help patients/families set realistic goals.

**Appropriate language to describe goals of care**

There are unintended consequences and patients/families may feel abandoned with statements with a negative connotation like, ‘do you want us to discontinue care or to stop aggressive therapy?’ Emergency clinicians have to be aware and use more suitable language in the setting of life-limiting chronic illness, for example:
- We will concentrate on treatment that improves the quality of your life.
- We want to help you live meaningfully in the time that you have.
- We want to ensure that your father receives the kind of treatment he wants.
- Your father/mother’s comfort and dignity will be our top priority.
- Let us discuss how we can work towards your wish to stay home

Therefore, it is important how we ask patients about their goals since that may directly influence what they say. Using open-ended questions may help in identifying goals that are in the forefront of their minds and allows those goals to be articulated in a patient’s own words.

**Elicit patient values preferences with questions such as:**
- What are you expecting in the next few days, weeks…?
- What do you most want to accomplish?
• What is most important to you in your life right now?
• What kind of results are you hoping for?
• What do you hope to avoid at all costs?
• What do you think will happen?
• Have you seen or been with someone who had a particularly good death or a particularly bad death? Can you tell me about it?

Review and re-assess goals and treatment priorities when there is uncertainty or a change in health status. The ED, at the time of sudden downturn or crisis, is often a good place to help patients and families reassess goals of care.

Reconciling goals of care

Often in the ED setting sudden bad news may be a shock to patient/family. A time period to adjust to the news may be necessary before the ED clinician is able to elicit further preferences (steps to deliver bad news are found in Module 4-I). Suggesting and implementing a time-limited trial so families/patients have a chance to cope, adjust and weigh the risks and benefits may be a valid and suitable alternative. It is important when you discuss time-limited trials with families that you a) tell them what the proposed treatment plan is, b) what are the goals that you are hoping this treatment will achieve, c) what you will be looking for to determine whether we are able to meet those goals, and d) over what period of time will we see if the treatment “works or does not work.”

On occasion unrealistic, unreasonable or illegal goals may be put forth by patient/family and the physician maybe challenged to set limits without implying abandonment. In this situation, it may be best to make the conflict explicit and then offer to help find an alternative solution. For example, “I understand your goal is not to be a burden to your family and you would like me to assist you to die. Unfortunately, I cannot do that. I can however help with the distressing symptoms. Is there an alternative way that I can help you so that you will not be a burden?”

Eliciting goals of care when patient lacks capacity

Critically ill patients will often require conversations with proxy decision makers. The physician should guide the proxy to understand his/her role in determining what the patient would have wanted based on current medical condition and available information. The process of substituted judgment implies that the proxy is reminded to use the patient’s values and preferences to determine the goals of care. Written advance directives, patient’s prior verbal statements, evidence of their general values and beliefs, and information about how the patient lived his or her life can all be useful. This process demonstrates respect for the patient, and builds trust that both health team and proxy are acting in the best interests of the patient. This approach also reduces guilt or decision regret for the participants. Asking some of the following questions may assist;

• Help me to understand what he/she was like before he got sick. What was most important to her/him?
Has he ever said anything about how he would want to be treated if he could no longer make decisions for himself?
What would he say in this situation?
Based on everything you know about him, what do you think he would have wanted in this situation?
Did he ever talk to you about what he would want should he get a lot sicker or if the treatments stop working?"

Recommend a care plan based on the goals

Finally, it is crucial that once the goal(s) is/are established, ED clinician then reviews the patient’s current treatments (e.g. antibiotics, pressor drugs), monitoring (e.g. telemetry and pulse oximetry), planned tests (e.g. bronchoscopy), and interventions (e.g. central line for sepsis treatments), and decides which ones will help meet, or not meet the patient’s goals. Anything that will not help meet the goals should be discussed with patient and family for potential discontinuation (sometimes a time-limited trial may be suggested). Depending on the specific patient condition, some other issues that are naturally discussed at this point include:

- Invasive laboratory and radiology tests e.g. lumbar puncture, Ct scan
- Resuscitation orders/code status.
- Use of blood products, dialysis or pressors
- Disposition options to best meet the goals (e.g. home hospice referral versus ICU admission).
4.3. **Difficult Patient Situations (Abbott)**

**Objectives**

1. Review situations in which the physician and the patient/family have different agendas for an ED encounter.
2. Discuss strategies for saying “no” to patients who have unrealistic requests.
3. Review reasons why patients are perceived as “difficult” and how to view these interactions in an ethical framework.
4. What is “moral distress” and how do you experience it?

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**Case 4.3.1 – Frustrations of obesity:**

A morbidly obese wheelchair-bound 56 year old patient has a permanent tracheostomy and presents for the 20th visit this year to have her trach suctioned. She lives in her home, and her rather feeble father helps care for her; he frequently has difficulty keeping it unclogged.

**Case 4.3.1: Questions**

1. What feelings do you have in picking up this chart, assuming you have seen her a few times before yourself?
2. What slang do you hear thrown around in the ED when a patient like this presents, and what frustrations do those names reveal.
3. Which visits by “frequent flyers” are inappropriate, and is this patient in that category?
4. Narrative ethics is the a construct whereby providers attempt to understand the patient’s experience of illness and the details of this person’s life, in order to be able to empathize with them (see also Module 1.1). How might knowing this patient’s story change your image of her?

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**Case 4.3.2 – frequent “flyer” sickle cell patient:**

A patient with sickle-cell disease presents for exacerbation of her pain. She is on MS Contin 60 mg twice daily, and is taking 8-10 Roxicet for breakthrough pain for the past week. She has two small children and missed her last clinic appointment. Her last ED visits was 2 weeks before, and this is a recurrent pattern, as your nurse points out to you.

**Case 4.3.2: Questions**

1. What do you think of when you hear the term “difficult patient?”
2. What are some physician factors that play into a difficult interaction?
3. What are some strategies you could use to work with this patient?
**Case 4.3.3 – patient requesting inappropriate tests:**

47 year old ex-construction worker presents with chronic back pain from an accident 10 years previously falling off a ladder. He has had two diskectomies, and presents carrying his MRI from 3 months ago, as well as records from another city. He has increasing pain down the back of both legs for the past week, since he moved to your city. He is out of the usual 6-8 Percocet he takes a day, and requests a repeat MRI scan since he knows something new is wrong with his back. The last time it was this bad, he needed surgery.

**Case 4.3.3: Questions**

1. What makes this patient frustrating? How does the patient carrying his records, his imaging studies or his Google printout make you feel?
2. Would you get a repeat MRI on him? What would make you image him?
3. How do you say “no” to this patient?
4. What advice do you give him?
5. What system problems may contribute to your “moral distress” in this encounter?

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**Background Information**

There are several types of patients who are considered “difficult” by ED providers. While the exact definition may vary, common themes emerge: the “non-compliant” patient, the patient whose problems are primarily psychiatric, the patient with no known medical diagnosis, the alcoholic or addict, the morbidly obese patient. In various surveys of general practice, “difficult patients” account for anywhere from 15 – 60% of encounters. The ED is certainly no less likely to provoke frustration, since patients and doctors haven’t self-selected, the ED is busy, and time is short. You will note that there are cases in several other modules in this series that reflect difficult interactions. (Module 1, Case 1.1.1; Module 5, Cases 5.2.1 and 5.2.2; Model 10, Case 10.1.3.)

There is, however, also a physician in the equation of the “difficult” patient. In fact, physician attitudes that align with a strictly biomedical model of medicine, and marginalize psychosocial and economic factors in the individual are the highest predictors of frequent difficult patient encounters (Jackson) Physician predictors of high frustration included working > 55 hours per week, depression and anxiety, and a larger number of patients with psychosocial problems or substance abuse (Krebs).

The term “compliance” is a problematic one. The term is somewhat judgmental, and splits patients into “good” patients and “bad” ones, without curiosity about the barriers to adherence to the complex medical recommendations and regimens that some patients are on. Most providers must confess to being less than compliant in various aspects of their own lives and health. Everyone makes choices, and sometimes those
choices involve saving money by splitting medication doses or forgetting to take the last few days of a course of antibiotics. How would we react to having to present to an infusion center for daily IV antibiotics for a stubborn infection? How often do we eat as well as we should, floss daily or exercise as our own physician advises?

**Moral distress** is a relatively new term first coined by our nursing colleagues. It is descriptive of the feeling a health care provider has when facing an encounter or a situation within the workplace where the provider feels that s/he knows the “right” action to take, but is blocked – either by the patient, the system or situation within which the provider works, or by other external pressures like lack of insurance (Ulrich). Curiosity about the patient can sometimes alleviate the moral distress and frustration that occurs when patients are seen frequently in the ED. Several studies have highlighted the fact that a large number of these “frequent flyers” have severe medical disease, higher admission rates and mortality rates than the average ED patient. Sometimes their circumstances can be difficult – the patient in case 4.3.c above was an old military nurse who was fiercely independent, had taken care of her own trach for many years, and was determined to live independently, even if she died earlier because of her choice. She had become massively obese due to inactivity over the 15 years of her visits to the ED. Often, cleaning her trach allowed her to be discharged from the ED, for which she was grateful. Understanding these details was very helpful to allow the staff to realize how much they were helping her live as she wished to.

What are some strategies that might help when the EM physician feels frustration in the midst of an encounter?

1. Recognize the frustration and the emotional content of the interaction.
2. Step back – take a breather and regroup to avoid escalating the situation or responding in kind to an emotionally difficult patient.
3. Ask a few questions to separate the situation from the patient:
   a. Why would a normal person respond to our encounter in this manner?
   b. What is the patient’s purpose in being here?
   c. What can I do to help the patient today, and what is beyond my control?
   d. Does this patient have comorbidities that press my buttons – like alcoholism, morbid obesity, a disease associated with chronic pain?
   e. Does this patient have psychiatric disease that is interfering with our ability to interact or his/her ability to follow through? (Particularly patients with Axis II disorders like borderline personality make what are perceived as unreasonable demands on the healthcare system, and can need a very structured approach that outlines what we can and can’t be expected to do to help the patient in an ED visit.)
4. Explicitly discuss with the patient what you can and cannot do in the ED, and what diseases are not well treated in this setting (like chronic pain, which requires a multidisciplinary approach over time). Focusing on what is best for the patient helps lower the “heat” of the encounter.
5. Be open to compromise on “best practices” by negotiating a treatment plan with the patient and accepting the fact that you may have to factor in
difficulties the patient faces (e.g. inability to take “qid” medicine, no access to a clinic for follow-up) in the plan.

6. Share the frustration with your colleagues privately. Sometimes the best that can be done with a particularly difficult encounter is to share the distress. One British group has (only partly in jest) suggest that encounters should be scored by degree of difficulty as well as skill in management – as in the Olympics.

There are certainly some patients whom the EM physician cannot help – who have very unrealistic expectations or unusual concepts of disease and who have agendas not possible to respond to within our professional scope of practice. On the other hand, it is important to learn about diseases that we do see frequently. Some diseases are perceived as being caused by the patient – while physicians may know that addiction, obesity, and borderline personality are “diseases,” there is often a frustration based on the idea that “If you would just stop, you would get better.” A better understanding of such chronic diseases as alcoholism, addiction and the pathophysiology of chronic pain help physicians be more understanding of the burdens their patients face. Good reviews of fibromyalgia, borderline personality, schizophrenia and other co-morbidities that our patients have exist on the medical literature. Learning more about these can help relieve the frustration and get providers beyond the generic label of “difficult.”

Bibliography


