Chapter 9
Breaking Bad: Bad News, Unexpected News, and Hope

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"I'm afraid there's really very little I can do."

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> *In some of us, the ceaseless panorama of suffering tends to dull that fine edge of sympathy with which we started…Against this benumbing influence, we physicians and nurses, the immediate agents of the Trust, have but one enduring corrective—the practice towards patients of the Golden Rule of Humanity as announced by Confucius: What you do not like when done to yourself, do not do to others.*
>
> William Osler Aequanimitas

Hope is one of the most important comforts a physician can bring to a bedside. Your patient care begins with providing hope for recovery, and if recovery or cure is not possible, hope for relief of pain and to make your patient more comfortable. Additionally, you must reassure your patients and their family you will support and be available to them throughout the illness.

Harris and DeAngelis, in their article "The Power of Hope," stress that the physician must participate in a "sincere emotional engagement [with patients and] address the patient's fears" [1]. Patients face their physicians with foreboding and apprehension. If all hope is withdrawn, despair follows.

Most, if not all, medical students enter their training with lofty ideals, intense feelings of empathy, a mission to provide care and alleviate suffering, and a formidable drive to achieve exceptional patient care. In order to fulfill their desire to accomplish these goals, it is imperative for trainees in their early years to know the techniques for delivering unpleasant and unexpected news.

One of the core competencies of the ACGME is communication skill, an essential skill for conferences with patients and families. Delivering bad news, that is news that has the potential to change your patient's life in an instant, is a particularly difficult skill, especially if you have only known your patient for a short period of time and have no or only a limited relationship with the patient or their family. Not knowing what to do or say will frequently result in misunderstandings, false expectations, and resentment. The fears trainees have about delivering tragic news can lead them to seem unsympathetic or even callous [2]. We know from personal experience

that patients and families never forgive a doctor who conveys bad news rudely or abruptly. This chapter is meant to help the trainee the first few times they are called upon to execute this most difficult of tasks.

If the news is grievous and life changing, you may have to deliver it in short bouts, allowing the patient and the family to process the information with each visit before going on to elaborate. Often patients who receive an unexpected and unsettling diagnosis will say that after they heard the word tumor, or cancer, or ICU they were not able to hear anything else. This is true even for patients who receive good news. We have had patients tune us out after hearing "benign." It is as if the following 15 minutes or so of conversation, that often includes the treatment plan or expected length of stay, never happened. Be sure your patient is listening and can say back the information you have given them. When you deliver the news be sensitive, be caring, and be careful not to be callous or rude. Maintain some level of hope, even if it is only the hope that you will be able to keep your patient comfortable or to provide compassionate care.

Breaking bad news requires a number of skills. In addition to actually giving the information in a way your patients and families understand, (for convenience we will use "patients,") you must be able to "read" your patients' emotional state, expectations, knowledge level, and the possible impact of the news. A bit later in this chapter we will make some suggestions on how to respond to their emotional state appropriately, enlist your patient into the decision-making process, give some form of hope when the situation is bleak, make a realistic treatment plan that everyone agrees to, avoid any misunderstanding, particularly about prognosis and above all, do not eliminate all hope.

Implicit biases [3] are unconscious attitudes that shape our behavior and affect decision-making. Because these biases are unconscious and formed by life experiences, they are not readily reversed by introspection. Implicit biases can compromise your relationship with your patient. Do not presume you know how your patients feel. Do not relate a personal

experience to what they are experiencing. Avoid religious metaphors unless you discern they will be helpful. If so, a good idea is to ask if the hospital chaplain can visit with your patient, or even better, have the chaplain accompany you in this conversation [4].

SPIKES is a six-step protocol that works well in delivering bad news to patients and their families [5]. It also serves as a convenient mnemonic for rehearsing what you will say. The following is adapted from the SPIKES paper by Baile et al. and used with permission:

*S*et up the interview. Rehearse what you are about to say out loud. Listen to yourself. Have a colleague or the patient's nurse accompany you to be certain you cover all the needed information, but be sure you are the only spokesperson. You, your colleague, and all the consultants must be in agreement. Arrange for privacy. Turn off your phone. Make sure a family member or friend of the patient's choosing is present. Have a notepad for the patient and tissues at the ready. Sit down. This conveys to your patient you have all the time in the world. It also helps to make eye contact, which is critical. If your patient is comfortable with it, lightly touch their arm or hold their hand, or have a same-sex nurse or colleague do this.

Ask your *P*atient: Start by asking your patients what they know about their illness and what they expect. Use open-ended questions. Observe their body language. Body language can communicate much information, especially when words fail [6].

*I*nformation: You must decide how much information your patients can process. It is often not possible to complete the entire task in one sitting. Some patients want to know the reason for and the result of every test, while others just the bottom line. We had one long-term patient's family tell us they only wanted to hear "good news." Unfortunately, good news was sparse, but we knew we had to find something just so we could communicate on a regular basis. Each day we would tell the family which tests we ordered, but we would offer the results only when they asked for them or if they needed to make a decision.

*K*nowledge-Foreshadow and impart: After the preliminary questions, foreshadow what you are about to say; "I have some unexpected news…" or "The test results indicate we will have to adjust our treatment…" Use nontechnical words. Do not go into unwelcome detail. Do not over prognosticate. No one knows the exact future of anyone. Avoid bluntness. Never, ever use the phrase "At least you…" Many patients will tune out after they hear words like untreatable, cancer, severe, sadly, bad news. Wait for them to regain composure and focus. If necessary, you can ask for permission to tell their accompanier limited details.

*E*mpathize: Sit close to your patient. Lean forward. Touch your patient's arm if they are amenable to this and signify with a nod that you understand their response. If they freeze, ask them what they are feeling. Respond by validating their emotions. It can be helpful to your patient to "echo back" to them what they have just said to you. This validates whatever they are feeling. Offer a tissue if needed. Empathize. "I am feeling that too," or "We were all hoping for a better result." Or "I wish I had better news." Remember to reinforce you are still on their team. They have not disappointed you. You will always be there for them. Ask your patient if they have any specific questions, fears, or concerns. Be sure to acknowledge them as appropriate, whatever they are, and address each one by responding directly or offering a plan. Do not blow off any fear or question, as the patient may interpret this as the worst-case scenario. Never say "I know how you feel." Even if you have been in exactly the same situation, you cannot know how someone else feels.

*S*trategize treatment or comforting measures. Make certain your patient understands what you have told them. Ask them to "say back" to you what they heard. Be certain you tell them you will revisit in an appropriate time.

Although it is of little consolation, the two events uniting all of us on this planet are birth and death. This is something trainees might not keep in mind. Before you speak to your patient, consider how you might want to hear the same news when it is your time to share this universal experience. As usual, the Bard expressed it very well: "We are such stuff

as dreams are made of: and our little life is rounded with a sleep" [7]. Your patient will feel isolated and abandoned and fearful. Allay those fears.

How you deliver unexpected news will influence your patient's expectancies concerning the illness, and this, in turn, will affect your patient's decision to cooperate with your treatment plan. A sad demeanor or foreshadowing incorrectly by using words to indicate pessimism may leave your patient feeling helpless and under the impression that treatment is futile.

Different patients will respond to the same news in different ways: anger, denial, depression, anxiety. Their own implicit biases will affect their responses, and their interpretation or understanding of any facts you may give them will be shaded to a mild or greater degree by their beliefs and the manner in which you deliver the message. At times, their "say back" to you will have little relationship to what you have told them. Therefore, it is very important to have them repeat any diagnosis or treatment plan you have given them to be certain they are in full understanding. Do not withhold the truth or offer false hope. Never, ever lie in any way. Eventually your patients will discover what it is you did not want to tell them, and from that point on, they will not trust anything you say.

It has been our experience that a realistic, hopeful assessment of your patient's illness and your commitment to never abandon your patient throughout their illness will result in a better social and emotional adjustment. Even offering only optimism about your ability to reduce or eliminate pain and suffering, or mitigate the side effects of therapy will help your patients manage the debilitating aspects of their disease. The following case studies will provide some suggestions to offer you support and knowledge for those occasions where you have to deliver discouraging or unexpected news.

Susan C. was a 56-year-old nurse diagnosed with advanced pancreatic cancer, a disease that carries a 95% 5-year mor-

tality. Her doctors advised her that surgery would provide the best chance for her survival. She elected to travel to an international cancer center for the procedure, where the specialist cancer surgeon, after reevaluating her prognosis, recommended she not proceed with surgery. He explained he would not be able to remove the cancer. He offered no further recommendations or any treatment plan. He advised her to return home and see what developed. Susan did not believe death from the cancer was inevitable. "I wasn't about to let a group of malignant cells decide what was going to happen," she said.

Upon her return home, she met with her oncologist. He advised her to treat the cancer like a chronic disease, not a fatal one, and he promised to try every reasonable treatment available, short of surgery. After chemotherapy and radiation, Susan experienced a long-term survival. The referral surgeon's lack of all compassion and what was essentially his withdrawal of care devastated Susan and her family. One might describe Susan's reaction to his consultation as denial, anger, or depression—even irrational or quixotic to feel hope when struggling against a disease with a 95% mortality. Susan had what is called a generalized hope, a sense that maybe something helpful and beneficial could be done. Her oncologist helped direct that hope to a specific one, a treatment that might not be curative but would result in a prolongation of her life and a chance to live that life in a meaningful way. Most importantly, he validated her feelings and let her know that whatever happened, he would support her.

Abede H. was an Ethiopian male with angina, diabetes, coronary artery disease, heart failure, and end-stage renal disease for which he required chronic dialysis. His doctors had ruled out coronary artery surgery as being of little benefit due to the severity of his disease, and he required frequent admissions for heart failure. Abede was a very outgoing, courteous, and good-natured man with a wonderfully supportive and

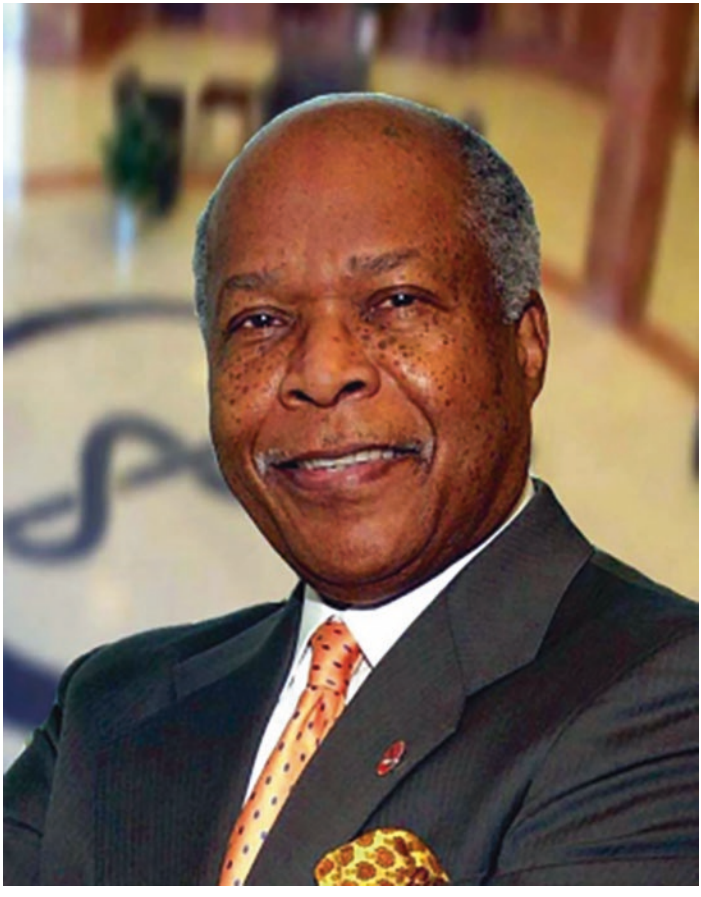
loving wife and a great desire to continue living. He and his wife did not like his emergency admissions to the university hospital where the physicians caring for him reinforced the grim nature of his disease and his very poor prognosis. In contrast, the more experienced senior cardiologist at his community hospital supported and reassured him, promising that he would improve with each hospitalization. After several years of this cycle, Abede required admission due to refractory heart failure. He did not respond to supportive measures. When the intensive care physicians explained his hopeless condition, he and his wife became angry and refused to allow care to be withdrawn. The senior cardiologist had always reassured them this was a treatable disease, they explained, and that he would improve. This unrealistic and untruthful assessment of his illness gave false hope to both Abede and his wife.

In this situation, the hope from his physician misled Abede and his family. His cardiologist could have explained the following—that Abede's heart failure could be managed but would recur, that good medical management could control his diabetes and improve his blood pressure, and working as a team they could prolong his life but he would not be cured of his disease. At some point, he would not respond to their treatments, and he would not survive a hospital admission. While it is not likely a patient with such a complicated condition is likely to understand the unrelenting nature of his disease, most patients will understand the broad implications. But at the same time as preparing his patient for the inevitable, the doctor can offer the hope of having some effect on the course of his patient's condition. Providing your patient with an honest, realistic, and truthful assessment of their illness and prognosis is often very difficult without causing harm. But an inappropriately positive attitude and unrealistic offering of hope is as hurtful and unhealthy as a blunt uncompromising outlook.

Always make sure you and your colleagues are on the same page. The following is an all-too-common example of one physician delivering bad news devastating to the patient only to have another disagree. We had one pediatric patient with severe lung disease. One attending, covering for another who was away at a conference, told the family the child would die. When the admitting physician returned to care for the infant, he corrected the family's misimpression, and after a rather long hospital stay, the baby did quite well. She was discharged off all medication and off supplemental oxygen. When the father, several years later, ran for public office, he made the point that he was from a "family of fighters." As evidence, he displayed his 8-year-old daughter to the news cameras and said, "The doctors told us she would die, but here she is. She's a fighter, too."

The science of medicine is ever changing, but the art of medicine remains constant because human nature does not change. Patients bring fear, anxiety, and self-pity into the exam room and the consultation room. As their physician, it is our responsibility to calm their fears as best we can while at the same time be forthright and honest about what they have to face. Hope and optimism about some aspect of your patient's care may not alter the medical outcome, but can assist your patient in achieving some degree of comfort and acceptance [8–10]. This is true for psychiatric disorders as well as physical illness.

Delivering bad news incorrectly may seem like a trivial thing compared to a missed diagnosis or a poor surgical outcome. However, once words are exchanged they can never be taken back. You can correct a missed diagnosis with additional studies and observation, and with skill and good timing you can correct a poor surgical outcome, but once hurtful or misunderstood words are spoken, they live forever.



Louis Wade Sullivan, M.D.

Clinician, Scientist, Educator, National and World Leader in Public Health

Your first impression of Dr. Sullivan is his warm smile, attractive personality, and the sincere straightforward interest he has in what you have to say. Louis Wade Sullivan was born on November 3, 1933, in Atlanta, Georgia, but grew up

in rural Blakely, Georgia, where his family settled shortly after he was born. A gifted student, Dr. Sullivan graduated from Atlanta's Booker T. Washington high school as Class Salutatorian, at Morehouse College magna cum laude, and earned his medical degree, cum laude, from Boston University School of Medicine in 1958. His postgraduate training was at the Cornell Medical Center followed by a clinical fellowship in pathology at Massachusetts General Hospital, and a research fellowship in hematology at the Thorndike Memorial Laboratory of Harvard Medical School, Boston City Hospital. In 1966, he became co-director of hematology at Boston University Medical Center and, a year later, founded the Boston University Hematology Service at Boston City Hospital. Dr. Sullivan remained at Boston University until 1975 advancing to professor of medicine.

In 1975, Dr. Sullivan returned to Atlanta as the founding dean of what became the Morehouse College School of Medicine. Dr. Sullivan was president of Morehouse School of Medicine for more than two decades leaving in 1989 to accept an appointment by President George H.W. Bush to serve as secretary of HHS. He is an active health policy leader, minority health advocate, author, physician, and educator. His achievements in his HHS post were exceptional and include the following:

1. Leading the effort to increase the National Institutes of Health (NIH) budget from $8.0 billion in 1989 to $13.1 billion in 1993.
2. Establishing at NIH, the Office of Research on Minority Health, which has become the National Institute on Minority Health and Health Disparities.
3. Inaugurating the Women's Health Research Program at NIH.
4. The introduction of a new, improved Food and Drug Administration food label.
5. The release of Healthy People 2000, a guide for improved health promotion/disease prevention activities.
6. Educating the public regarding the health dangers from tobacco use.

7. Leading the successful effort to prevent the introduction of "Uptown," a non-filtered, mentholated cigarette.
8. Inaugurating a $100 million minority male health and injury prevention initiative.
9. Implementing greater gender and ethnic diversity in senior positions of HHS.
   (a) The appointment of the first female director of NIH.
   (b) The first female (and first Hispanic) Surgeon General of the U.S. Public Health Service.
   (c) The first African-American Commissioner of the Social Security Administration.
   (d) The first African-American Administrator of the Health Care Financing Administration (now the Center for Medicare and Medicaid Services).

In 2003, Dr. Sullivan helped create the Sullivan Commission on Diversity in the Healthcare Workforce with a grant from the W.K. Kellogg Foundation to Duke University School of Medicine. The commission was composed of 16 health, business, higher education, and legal experts and other leaders. Their mission was to make policy recommendations to bring about systemic change to address the scarcity of minorities in the health professions. This was a time when enrollment of racial and ethnic minorities in nursing, medicine, and dentistry has stagnated despite America's growing diversity. The Commission's report provided the nation with a blueprint for achieving diversity in the health professions [11–14].

Dr. Sullivan is the recipient of more than 70 honorary degrees. He is the author of *The Morehouse Mystique: Becoming a Doctor at the Nation's Newest African American Medical School* (with Marybeth Gasman, 2012, Johns Hopkins University Press) and his autobiography *Breaking Ground: My Life in Medicine (with David Chanoff, 2014, University of Georgia Press)*.

Issues Discussed in This Chapter

- How to deliver unexpected or sad news
- How to "read" your patient

- What you can offer when there is nothing left to offer
- The SPIKES protocol and how to use it
- Unconscious (intrinsic) biases and patient care

Study Guide

1. If the information you have for the patient is grievous or life changing, how should you communicate that to the patient?
2. What are some examples of implicit biases?
3. What can you offer a patient whose condition is hopeless?

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