Discussing Disease Progression and End-of-Life Decisions

Review Article [1] | July 01, 1999 | Ovarian Cancer [2], End-of-Life Care [3], Palliative and Supportive Care [4]

By Walter F. Baile, MD [5], Gary A. Glober, MD [6], Renato Lenzi, MD, FACP [7], Estela A. Beale, MD [8], and Andrzej P. Kudelka, MD [9]

Because most patients now want to know the truth about their diagnosis and prognosis, the ability to discuss the cancer diagnosis, disease recurrence, or treatment failure, and to solicit patients’ views about resuscitation

Introduction

In the course of a career, an oncologist may meet numerous times with patients and usually their families to disclose or discuss unfavorable medical information, such as the diagnosis of cancer, a poor prognosis, or the failure of curative treatment. These encounters are often stressful for both the patient and doctor.[1,2] Physician discomfort with breaking bad news may be increased further when the physician or patient experiences sadness or other negative emotions related to the discussion.[3]

Observational studies have indicated that many physicians struggle to find a comfortable way to conduct these “bad news” discussions with patients and families.[4,5] At the 1998 annual meeting of the American Society of Clinical Oncology (ASCO), a symposium on breaking bad news was attended by nearly 700 participants, including medical and surgical oncologists. They were surveyed, using an automated, real-time response system, regarding their experiences with giving bad news to patients.

Almost half of the audience indicated that they gave bad news to patients at least 10 times per month. However, fewer than 5% had received any formal training in this area. It is not surprising, then, that nearly 50% of participants rated their own ability to break bad news as only poor to fair. Furthermore, nearly 70% of attendees indicated discomfort when faced with the need to respond to patients’ emotional reactions, such as crying, anger, or denial.[6]

In addition to being concerned about the emotional responses of the patient and family members, clinicians who break bad news may be concerned that this news will destroy patients’ hope.[3,6,7]

However, the relationship between the provision of disease-related cancer information and patient level of hope appears to be complex. A small number of patients may prefer to have minimal information and to let the physician direct treatment with little involvement from them.[8] There is convincing evidence, however, that most cancer patients want the physician to provide them, in a sensitive way, with thorough information about their diagnosis, prognosis, and treatment options.[9-12] In addition, there is evidence that when patients who desire complete disclosure are provided with incomplete information, when only the positive aspects of treatment are discussed, or when the clinician attempts to disguise a poor prognosis, patient hopefulness may actually be eroded.[13] Many physicians, however, underestimate the amount of information that patients wish to have.[14,15]

Whether due to the physician’s concern about upsetting the patient or lack of awareness of the patient’s need for information, the provision of inaccurate or incomplete information will likely create a “cascade effect”; i.e., patients who are uninformed are unable to participate fully in decision-making—an important goal for many cancer patients today.[16] In camouflaging the bad news, physicians may also harm their relationship with patients, since attempts to shield the patient from bad news through partial disclosure may be perceived as “dishonest.”[17]

For patients who wish to be completely informed, there is always the risk that unfavorable information may cause them to become emotionally upset for a short time. However, over the longer term, when physicians provide the information that the patient desires in an empathic manner, they can increase patient satisfaction, promote patient compliance, and even facilitate patient coping.[18-21]

In the mental health area, communication with the patient is an important component of treatment.
Discussing Disease Progression and End-of-Life Decisions
Published on Cancer Network (http://www.cancernetwork.com)

In this setting, verbal interventions aimed at initiating and maintaining rapport with the patient, eliciting the patient[s] concerns and opinions, and engaging the patient[s] collaboration in treatment are recognized as being therapeutic in and of themselves. These techniques include active listening, clarifying and exploring the patient[s] statements and feelings, and using empathic responses to acknowledge and validate the patient[s] concerns. In the area of medical education, acquisition of these skills comprises an important goal of curricula focusing on doctor-patient communication.[22-24]

Studies in which these communication principles have been applied to the disclosure of unfavorable medical information (breaking bad news) have shown that medical students can learn a strategy for breaking bad news when they are given appropriate education and an opportunity to role-play.[25] Likewise, oncologists who attend workshops to enhance communication skills can increase their confidence in managing difficult communications with cancer patients.[26]

In this article, we present dialogues between a physician and a hypothetical patient with advanced ovarian cancer. These conversations illustrate how specific communication skills may be used therapeutically at various critical stages of the illness. We have included dialogues that occur after the disclosure of the diagnosis since discussing subsequent unfavorable news may be more difficult for oncologists than is divulging the diagnosis.[6]

SPIKES Six-Step Protocol

The dialogues presented in this paper illustrate an individualized, patient-centered approach for breaking bad news. This approach is called the SPIKES six-step protocol for breaking bad news.[27] We use this protocol because, in addition to increasing the clinician[s] confidence in breaking bad news,[6,25] it is rated highly by oncology practitioners[6] and incorporates the recommendations of communication experts, patients, nurses, and oncologists for disclosing unfavorable information to cancer patients.[1,28-31] Briefly, the protocol covers six steps or areas:

- **Get the Setting Right**—Ensure privacy and comfort (of both physician and patient). Deliver bad news in person, allowing sufficient time. Check to see whether the patient wants a family member or significant other present.

- **Understand the Patient’s Perception of the Illness**—Ask what the patient knows about his or her illness and/or the purpose of tests. Where there is an information gap, educate.

- **Obtain an Invitation to Impart Information**—Find out how much information the patient wants to have about the results, including the prognosis.

- **Provide Knowledge and Education**—Warn the patient about the arrival of unfavorable news. Provide information using simple language, frequently checking the patient[s] understanding. Avoid excessive bluntness, partial disclosure of information, or false hope. Give broad prognostic time frames. Avoid the phrase, “There’s nothing more we can do.”

- **Respond to the Patient’s Emotions With Empathy**—Address the patient[s] (and the physician[s]) emotions with empathic responses and gestures (eg, touching). Provide support by clarifying, exploring, and validating the patient[s] feelings and concerns.

- **Provide a Summary Strategy**—Review the information provided. Respond to questions and discuss treatment options. Provide information about support services. Offer to answer questions at a future date.

The SPIKES protocol can be applied to a number of situations in which negative information is disclosed, such as discussing the lack of curative treatment options, unfavorable diagnostic results, or news about the progression of disease.

Brief Case History

A 53-year-old woman recently completed six cycles of chemotherapy with cisplatin (Platinol) and paclitaxel (Taxol) for stage IIIC suboptimally tumor-reduced, poorly differentiated, epithelial ovarian cancer. She returns for a follow-up visit after chemotherapy. Her computed tomographic (CT) scan shows multiple peritoneal nodules 0.5 to 1.0 cm in diameter. There are no parenchymal visceral metastases.

After the physician greets the patient in the examination room, he takes a brief interval history and performs a physical examination, including a pelvic inspection. He suggests that the patient dress and move to the consultation room for review of the current situation. The following dialogue ensues.

Communication Task: Disclosure of Treatment Failure
Step One: Assessing the Patient’s Information Needs and Preferences

Doctor: Is there anyone with you today whom you would like to join us?
Patient: No. My husband is out of town and I came alone today.
Doctor: Would you like to wait until he can be with you?
Patient: No, I think I will be all right.
Doctor: OK. I’d like to discuss the details of your test results with you. Would that be all right?
Patient: Yes.
Doctor: Before I do that, I’d like to verify that we both have the same understanding of why we did these tests. Could you tell me, in your own words, why you think the tests were done?
Patient: Well, you’ve ordered the tests to see if the chemotherapy worked.
Doctor: That’s right. We did the tests to see how well the cancer has responded to the treatment now.

Prior to disclosing specific disease information, the physician checked to see whether the patient wished to include a family member or significant other. Most patients do prefer to have someone present for such discussions, and a significant other can support the patient and help him or her remember information. This is important because a number of studies have documented significant information gaps in patient understanding about their cancer diagnosis and evaluation procedures.[32-34] Also, by not saying immediately that everything is fine, the physician begins to prepare the patient for bad news.

By using an open-ended question (“Could you tell me in your own words...”), the physician also allowed the patient to express her understanding of why he had asked for the tests. Knowing what a patient understands about the purpose of procedures and evaluations will prevent the clinician from breaking bad news to a patient who is unprepared for unfavorable information.

In this case, if a gap in the patient’s knowledge were revealed, explanation of the test results would be contraindicated until the physician had summarized the previous treatment and the purpose of the imaging studies. In other words, the physician should eliminate the knowledge gap prior to disclosing new information. Occasionally, discordance between the patient’s and the doctor’s understanding of key information about the illness may represent a manifestation of the patient’s psychological denial that needs to be explored.[35]

Determining the patient’s information needs is also important because the patient’s preparedness to understand and assimilate information may vary over the course of the illness. For example, early in the illness, patients may be more naive about the technical aspects of their care. At that time, complete information can help patients deal with the uncertainties surrounding evaluation and treatment. Patients whose condition has worsened, on the other hand, may want less specific information about disease progression, for example, and may prefer that the physician focus on further treatment options.[36]

Specific communication techniques demonstrated in the above dialogue include validating the patient’s perception through use of the statement “that’s right” and providing a lead-in to a subsequent statement (“We did the test...”). Validating statements (also called “normalizing”) is one way of providing support to the patient.


Desired Outcomes: Establishing patient comfort and rapport. Lending structure to the interview. Ascertaining whether an information gap or patient denial exists. Providing support through validation of the patient’s concerns.

Step Two: Forecasting and Imparting the Bad News

Doctor [responding to the patient’s explanation of why the tests were done]: That’s right. We did the tests to see how well the cancer has responded to the treatment. Unfortunately, the test results were not as good as we had hoped for [doctor pauses]. I’m sorry to tell you that the treatment has not shrunken the tumors [pause]. Sadly, they have actually grown somewhat.

Before disclosing the ineffectiveness of the latest treatment, the physician alerted the patient to the fact that bad news was coming. In other words, he “fired a warning shot.” This was accomplished through the direct statement, “The test results were not as good as we had hoped for, and by the
Discussing Disease Progression and End-of-Life Decisions
Published on Cancer Network (http://www.cancernetwork.com)

use of the words "unfortunately," "sorry to tell you," and "sadly." Forecasting the arrival of bad news and then pausing briefly allows patients to brace themselves to hear the unfavorable information.[37] On the other hand, breaking the bad news too abruptly can contribute to psychological disorganization (shock) or can mobilize pathologic denial.[29]

**Key Communication Skills Illustrated:** Forecasting the bad news (also called "firing a warning shot"). Using pauses to allow patients time to assimilate information. Giving the information in discrete chunks.

**Desired Outcome:** Facilitating understanding and assimilation of the information.

**Step Three: Responding to the Patient’s Emotional Reaction**

**Doctor** [to the now-tearful patient who has just been told of the unsuccessful outcome of chemotherapy]: I know this result is very upsetting [physician pulls his chair closer to the patient, offers her a tissue, and pauses].

**Patient:** I was just so sure the cancer was gone. I had talked myself into believing it.

**Doctor:** I also wish that we had gotten a better result [pause]. You must be very disappointed to have had your hopes dashed like that [pause].

**Patient:** It’s just that I feel so bad for my husband.

**Doctor:** Your husband?

**Patient:** You know he is getting ready to retire, and last year we bought some land out west. We were planning to build a house. I feel like such a burden.

**Doctor:** A burden [pause]?

**Patient:** Well, if I weren’t sick we would be able to go ahead with our house.

**Doctor:** I understand your concern. Although you will need more treatment, we will see if it’s possible to adjust it to your plans.

Also, let me mention that many patients feel guilty because their illness inconveniences others in the family [pause]. If that feeling continues to bother you, we can arrange for some counseling [pause]. In the meantime, I know that you and your husband are attending a support group, and that might be one place where you can discuss these feelings.

When patients receive life-threatening information, they may react in an emotional manner, often with shock, disbelief, and/or crying.[28,38] As this patient was expecting that her treatment would have a favorable outcome, the bad news was particularly upsetting.

When patients do become emotional, it may be awkward or uncomfortable for the physician; even short periods of crying may seem as though they last forever. However, while it is common for patients to become upset, it is rare for patients to have extreme reactions to bad news (eg, to become psychotic or threaten suicide). Many patients are embarrassed about crying, and will often say, "I thought I was stronger than that," and will compose themselves rather quickly. It is important to remember that crying serves a useful function: it releases tension and allows the patient to move on to cognitive tasks, such as discussing further treatment plans.

When patients cry, there are several things that physicians can do. In this example, the physician addressed the patient’s distress and his own discomfort by using empathic responses directed at both himself and the patient (eg, "you must be very disappointed" and "I also wish we had gotten a better result"). Empathic responses are indicated whenever a strong emotion is expressed. They serve to acknowledge and validate the patient’s feelings, thus reducing the sense of isolation that can occur when bad news is received.[28]

Rather than encouraging additional emotional expression by the patient, empathic responses actually can facilitate the patient’s emotional recovery. Pulling one’s chair closer, offering the patient a tissue, and, when appropriate, touching the patient’s arm or holding his or her hand are also empathic responses. Empathy does not mean that the physician needs to actually feel what the patient is experiencing, but rather, that the physician expresses an awareness of the distress that the patient is suffering.

Notice that in this case, the doctor explored the patient’s response to the bad news by repeating the phrase "a burden" as a question. By doing so, he invited the patient to expand on what she meant and was able to ascertain that the source of her distress was not only the negative health information but also a psychosocial concern—her guilt at disrupting her husband’s retirement plans. Exploratory responses, such as repeating the patient’s own words or inviting the patient to expand on a statement (eg, "tell me more") can help identify sources of patient concern.

Patients may be reluctant to discuss additional concerns unless invited to do so for fear that it is inappropriate to raise these concerns or that they are taking up too much of the doctor’s time. In
this example, once the physician understood the source of the patient's distress, he was able to provide her with some realistic hope that she still might be able to carry out some of her retirement plans.

The physician also acknowledged that he was concerned about the patient's feelings. Patients appreciate the physician's interest in the personal aspects of their illness and report that this is very important in helping them cope.[39,40]

In addition, the physician normalized the patient's feelings by telling her that many patients feel guilty. This is one way of diminishing the patient's feelings of responsibility and providing support. Finally, by giving the patient information in small parcels, a technique known as chunking, the physician facilitated the assimilation of the points that he was attempting to convey. During the deliberate pauses, he observed the patient's verbal and nonverbal cues.

**Key Communication Skills Illustrated:** Physically responding to the patient's emotional reaction (e.g., using tissues, pulling the chair closer). Making empathic responses. Exploring and validating the patient's feelings. Offering strategies to deal with patient concerns.

**Desired Outcomes:** Expressing the physician's concern and support. Ensuring that the patient feels (1) less guilty about being a burden to her husband, (2) more hopeful about the disruption of her and her husband's plans, and (3) reassured that assistance will be available. Ensuring that the physician feels (1) supportive to the patient, (2) more informed about issues of importance to the patient, and (3) effective in addressing the patient's emotional and family concerns.

**Step Four: Tailoring the Educational Message**

After addressing the patient's emotional distress, the physician answers several questions that the patient has about the test results.

**Doctor:** Now, I had planned to discuss further treatment today if that's okay with you [pause]. If you would like to wait until your husband is able to join you, we can have that discussion another time.

**Patient:** No, I'd like to do it now.

**Doctor:** All right. Now, before we go on, let me check with you to make sure that I know what you understood about the test results.

**Patient:** You told me that the chemotherapy didn't shrink the cancer very much. In fact, you said it had grown.

**Doctor:** That's right. Now regarding future treatment plans, it would be helpful for me to know how much detail you would like to have.

In the above dialogue, the doctor left open the possibility that the patient was not prepared to have a discussion of further treatment plans. He also made sure that the patient understood what he had said about her response to treatment. Finally, he asked the patient how much she wanted to know about the subsequent treatment and left room for the patient to ask about her prognosis.

Patient education does not mean that the doctor must provide every detail of treatment, but rather, that the doctor should tailor the information to the individual patient's needs. This tailoring of information is important because the amount of medical information a patient desires is determined by a variety of factors that differ from one patient to the next. These include such factors as personality[8] and stage of disease.[36]

The physician can determine how much information a patient wants simply by saying, Some people want to have lots of detailed information about their disease and its treatment while others are more comfortable with just a general idea regarding their condition and prefer not to hear every detail. What do you prefer?[7]

**Key Communication Skills Illustrated:** Checking with the patient as to readiness for additional information. Ascertaining the patient's knowledge.

**Desired Outcomes:** Determining (1) how much information the patient has assimilated, (2) how much additional information the patient desires, and (3) when to provide the additional information. Even when patients desire detailed information regarding their condition and treatment, they may have difficulty assimilating this information during the brief time allowed by the usual medical interview. They may, therefore, find it helpful to have a written description of their condition and of the treatment plan. One patient with newly diagnosed breast cancer asked to take home the paper covering the examining table after her doctor outlined, on this paper, the steps that would be followed in her treatment (chemotherapy, radiation, laboratory tests, decisions about further treatment). The patient tacked up the paper in her kitchen. Some patients also may find audiotapes of the interview or a letter summarizing the diagnosis and treatment plan to be helpful.[41]
Communication Task: Making the Transition to Palliative Care

Step One: Preparing the Patient for the Discussion

Since the patient in our scenario will receive a second-line treatment for a solid tumor, it is likely that, sometime in the future, the nature of her treatment will shift from curative to palliative. Eventually, therefore, it will be necessary to present this transition to the patient. This discussion can be one of the most difficult interactions a physician has with any patient. Preparing the patient ahead of time for the possible need for palliative care sometime in the future may reduce the emotional burden when that discussion actually takes place. Rather than putting off the discussion, preparation can be an effective way to exploit the fact that the human psyche is quite adept at dealing with the issues at hand while at the same time planning for the future, even if the future is threatening. It follows, then, that the physician can discuss further anticancer therapy and also raise the issue of its probable reduced effectiveness. This still allows patients to have hope while psychologically preparing them for a negative outcome. The continuation of the above dialogue illustrates this point.

Patient: I'd like to know how long the next treatment will last, and what are the chances that it will be successful? Will the side effects be any worse than those from the chemo I just took? What if this treatment doesn't help?

Doctor: Let me respond to the first question, and then I will address your other concerns. As I mentioned, at this point, we can proceed with another chemotherapy of a different type. This next treatment is one of several we usually recommend when the first one, the one that you just received, has not been as effective as we had hoped [pause]. The duration of the treatment depends on how helpful it is to you. Typically, patients have at least two and no more than eight treatments over 1-1/2 to 6 months [pause].

The probability of getting a good response is anywhere from 10% to 20%, and like your other chemotherapy, this type of chemotherapy does have unpleasant side effects [pause]. There is also the option of not pursuing any further anticancer chemotherapy and focusing on maximizing the control of symptoms as they arise.

Patient: What you're telling me sounds pretty bad [pause, tears in eyes]. I think I'll have to discuss this with my family and have them come with me to speak with you.

Doctor: I know this is a difficult decision, and I'd be happy to meet with you and your family.

Patients who are told that first-line treatment has not been successful may be expected to be very anxious about the next treatment plan. In this exchange, the doctor gave this patient several messages that can help reduce uncertainty. The first is the hopeful message that there is further treatment that is commonly used in her situation. The second message is that there is a plan extending into the future. A plan can reassure the patient that the doctor will continue to care for her.

At the same time, the physician's explanation helps the patient to prepare mentally for the possibility that the treatment may not be successful in controlling her disease. Offering the patient the opportunity to forgo further therapy can bolster this point. While it is likely that most patients will pursue curative treatment, bringing up the possibility of no further anticancer therapy allows the doctor to prepare the patient for a subsequent discussion about palliative care should the second-line treatment prove unsuccessful.

During the conversation, the physician mentioned that further treatment would have only about a 10% to 20% chance of producing a significant effect. Giving the patient an estimated range of efficacy is important, since it introduces the option of not undergoing further chemotherapy. Offering patients treatment options allows them to have some control over aspects of care when there is significant uncertainty and anxiety about the future. In addition, providing patients with treatment options may reduce the sense of responsibility that the physician feels when treatment is unsuccessful.

Key Communication Skills Illustrated: Forecasting the bad news about long-term prognosis. Educating the patient. Providing options for further care.

Desired Outcomes: Establishing a treatment plan. Involving the patient in treatment decisions. Introducing the possibility that further treatment has a low probability of being curative. Allowing...
Step Two: Discussing the Futility of Further Curative Treatments

The patient in our scenario has now received docetaxel (Taxotere) and then gemcitabine (Gemzar). This therapy resulted in two 6-month periods of partial remission. The patient now has extensive peritoneal metastases and ascites. The oncologist goes to see her in the hospital, where she was admitted with bowel obstruction secondary to peritoneal carcinomatosis. In the following dialogue, after eliciting her understanding of the illness, the doctor communicates the information about the failure of the most recent chemotherapy and raises the question of further treatment.

**Doctor:** I guess you must be wondering where we go next with regard to treatment possibilities.

**Patient:** Yes, I have been thinking about that a lot.

**Doctor:** If you remember, when we started the most recent course of chemotherapy, I mentioned that, at most, there was a 10% to 20% chance that it would work, and that another option would be to forgo chemotherapy and to focus on controlling the symptoms caused by your cancer. Now, I’m afraid that we find ourselves at the point at which any more chemotherapy would do you more harm than good.

**Patient:** What do you mean?

**Doctor:** Well, the treatment may be so tough on your body that you’d be sick a lot or end up in the hospital from complications of the treatment itself.

When all cancer treatment options have been exhausted, the doctor-patient relationship takes a turn. The physician and patient are faced with accepting the facts that their attempts to cure or control the cancer have failed and that death, in the near future, is inevitable. At this point, palliation of symptoms and maintenance of the best possible quality of life become the primary treatment goals.

Informing the patient that there are no further viable anticancer treatment options is among the most emotionally trying and difficult tasks for the oncologist, especially when he or she has a long-standing relationship with the patient. The physician is exposed to feelings of sadness and failure. For the patient, anxiety over the prospect of death becomes more palpable.

In the above dialogue, the patient did not herself bring up the issue of further treatment. This is not unusual since, as was mentioned previously, as cancer progresses, patients may be less inclined to ask disease-related questions.[36] However, the physician decided that no matter how painful, it was in the patient’s best interest to initiate a discussion about the futility of further anticancer therapy. As a prelude to this discussion, the clinician made an “educated guess” regarding what the patient may have been thinking. He led into his explanation by reminding the patient that he had previously discussed the possibility that the treatment might not work (bridging). Notice that he avoided telling her that “there is nothing more that we can do for you.” This is important because the patient may perceive such a statement as abandonment. Instead, the physician framed the issue of further treatment in the context of how more chemotherapy could worsen the patient’s quality of life.

Since most patients want to know their diagnosis and prognosis, no matter how painful this news is,[10,9,42] it is usually in best interests of both the patient and physician to deal openly with the fact that no curative treatment exists. As mentioned previously, this discussion may be easier for both patient and physician if the patient has been prepared for it at an early stage of treatment. This is especially true for patients who present with advanced disease, in whom there is little likelihood for cure.

In the above dialogue, the physician delivered the bad news about no further curative treatment by emphasizing two things: his concern for the patient’s quality of life and his commitment to maximizing that quality.

**Key Communication Skills Illustrated:** Bringing up a difficult topic by making an “educated guess.” Using a summary of the previous treatment to introduce a difficult topic. Informing the patient that reasonable curative treatment options have been exhausted. Providing a rationale for further care. Using summary statements to “bridge” the past with the present and future.

**Desired Outcomes:** Ensuring that the difficult topic is discussed. Bridging the current discussion with past events to facilitate comprehension. Bringing the patient to a point of understanding regarding further treatment options at this point in time.

Step Three: Providing Hope in the Face of a Poor Prognosis

In the following dialogue, the patient responds to the physician’s explanation of the impact of further aggressive treatment.
Discussing Disease Progression and End-of-Life Decisions
Published on Cancer Network (http://www.cancernetwork.com)

Doctor: Well, the treatment may be so tough on your body that you’d be sick a lot or end up in the hospital from complications of the treatment itself.

Patient: Oh, I don’t think I’d want that. I couldn’t put my family through it. But what will happen? Will you continue to take care of me? Is there anything we can do?

Doctor: Yes, I will continue to take care of you. However, much of your care can also take place at home [pause] with the assistance of a hospice [pause]. In this way, we can focus on managing your symptoms so that you can stay out of the hospital and spend time with your family [pause]. This would include controlling your pain, doing our best to reduce the chance of your getting that intestinal blockage again, and making you as comfortable as possible if a blockage does occur again.

An important barrier to discussing the futility of further curative treatment is fear on the part of the clinician that the patient will lapse into despair if no further anticancer therapy is available. In actuality, while some patients continue to seek a cure or a treatment to induce a remission until they die, most patients can accept the fact that when an aggressive treatment will cause suffering with little prospect of a response, it is time to stop that treatment. Although cure may be the ultimate goal for almost all patients, patients also highly value effective control of pain and nausea, comfort, and the reassurance that, when possible, they will receive continuity of care even toward the end of life.[13]

In the dialogue above, the physician paused after mentioning the word hospice. This gives the patient an opportunity to ask questions about hospice care. The physician also provided reassurance that he would not abandon the patient. Such reassurance serves to reduce the patient’s risk of becoming depressed or despairing.

The doctor may be very uncomfortable if the patient pleads to continue treatment despite the fact that it would be futile. When physicians are faced with such comments as there must be something else you can do, the best way to respond is to make empathic remarks. That is, the doctor responds to the emotional content of the patient’s message (desperation) rather than the factual request. Attempting to address the factual request by repeating that one has done everything possible usually will not satisfy the patient, whose emotions need to be understood and acknowledged.

**Key Communication Skills Illustrated:** Responding to the patient’s concerns. Outlining a treatment plan. Addressing the issue of continuity of care.

**Desired Outcomes:** Ensuring that the patient understands the futility of further curative treatment. Ensuring that the patient feels hopeful about control of symptoms and continuity of care.

### Communication Task: Discussing Resuscitation

An important part of end-of-life discussions is bringing up the issue of cardiopulmonary resuscitation. This discussion is often uncomfortable, even for the physician who has previously had an open relationship with the patient regarding treatment and prognosis. The discussion can feel very much like a breaking-bad-news interview.

Because cancer is often a chronic disease, it may be appropriate to discuss cardiopulmonary resuscitation at an early stage of the patient’s illness, such as at the time of hospitalization for a serious recurrence. This discussion must take place prior to referral to a hospice. This avoids the situation in which a patient becomes so ill that he or she cannot make the choice about whether to be resuscitated, and the uncomfortable decision is then left up to family members, who may not know the patient’s wishes or desires.

**Doctor:** There’s an important issue I’d like to discuss with you.

**Patient:** What’s that?

**Doctor:** In patients who are very ill, as they become sicker, their heart may stop beating or they may stop breathing. Usually, this occurs in the last phase of life, but it may occur at any time [pause]. The more ill that patients are, the less likely it is that attempts to restart their heart will be successful [pause]. My experience is that patients with advanced disease, such as yourself, do not benefit from measures to revive them, but instead, just undergo unnecessary trauma from chest compression and often need to be put on life support. In order to prevent the doctors from attempting resuscitation, I would need to indicate it on your chart. Before I would do that, I’d like to get your feelings about it.

**Patient:** How much of a chance would I have, doctor?

**Doctor:** Studies show that patients with advanced cancer have very little chance of being...
Discussing Disease Progression and End-of-Life Decisions
Published on Cancer Network (http://www.cancernetwork.com)

In this discussion, the physician used a technique called “sign posting” to initiate the discussion. He then gently explained the futility of resuscitation to the patient, in the context of caring for her quality of life. He did not clearly ask for permission to write a do-not-resuscitate order but remained alert for signs of the patient’s emotions and was ready to explore them and support the patient. He responded to the difficult question, “How much of a chance would I have?” by referring to experiences with patients in similar situations. That type of response gives patients a “reference point” for understanding their own situation.

Key Communication Skills Illustrated: “Sign posting” (getting the patient’s attention). Educating the patient. Responding to a difficult question.

Desired Outcomes: Ensuring that the patient feels that his or her input is important. Ensuring that the patient understands that the physician’s rationale for the recommendation is based on his perception of the patient’s best interest.

Discussion

In this paper, we illustrated the application of strategies for communicating with a patient with advanced cancer. Two important features of our approach are that it is individualized to the patient’s needs and is “patient-centered.” The patient-centered approach emphasizes that the primary goal of the clinical encounter is to meet the informational, decision-making, and psychological needs of the patient.[43] By determining the informational and decision-making needs of each patient, the disclosure of unfavorable information can be tailored to these needs and to the patient’s coping style.

During times of patient crisis, stress, or uncertainty, oncologists can have an impact on the well-being of patients through their communication and interactions.[24,39,44] In fact, it appears that emotional support from the physician is an expectation of many cancer patients.[2,45]

Incorporating communication techniques that allow the physician to “tune in” to the patient enhances the patient’s trust and the feeling that he or she is being supported.[46]

Key Communication Techniques

Several key communication techniques used in applying the SPIKES protocol to the patient discussed in this paper merit further discussion.

Using Directive, Open-Ended Questions: This type of question about a specific issue (directive) frees patients to answer in any way that they feel is appropriate (open). They will then give the physician maximum information about their physical or emotional condition. “Tell me more about your pain” is one example of such a question.

Aligning with the Patient: Making “we” statements when referring to expectations, plans, and shared feelings emphasizes the fact that the therapeutic endeavor is a cooperative effort between the patient and the physician to achieve the therapeutic goals.

Making Hopeful or Encouraging Statements: Even when the situation or prognosis is unfavorable, there is always something hopeful that the physician can address.[13] For example, expressing hope that a course of treatment will go well (eg, “I have seen some patients respond to this treatment”) can provide encouragement.

Providing hope should be distinguished from false reassurance (“I’m sure you won’t have any problem with side effects”) or unwarranted optimism (“This drug has been a gangbuster in clinical trials”). Although the latter strategies may allow both the physician and patient to feel better temporarily, they can undermine the trust of the patient if the course of treatment does not go well.

Making Empathic Statements: To make empathic statements, three steps are necessary. First, the physician must identify the feeling (the physician’s or the patient’s). Second, the physician must identify the reason for the emotion (eg, bad news, guilt about upsetting retirement plans). Third, the physician must connect the feeling and the reason with an empathic statement (eg, “I can see how surprised you were to hear this”).

When the doctor feels distressed about having to break bad news, it is not a sign of weakness or loss of professionalism. Rather, it is a human response. In this situation, the physician should make an empathic statement about his or her own response, such as “It is also difficult for me to tell you this.”

Identifying Latent Concerns: Patients often withhold or only hint at their emotional or psychosocial concerns because they are embarrassed by them, do not want to take up the...
Discussing Disease Progression and End-of-Life Decisions
Published on Cancer Network (http://www.cancernetwork.com)

physician’s time, or feel that they might not receive a receptive response. Therefore, the physician needs to be alert to situations in which further clarification or explanation is needed to understand the patient’s concern, whether it be the side effects of the medication, or, as in the above scenario, the patient’s husband’s retirement plans. Exploratory responses merely ask the patient to amplify on statements that are vague or provide only partial information (eg, ‘I feel like such a burden’).

Guidelines for Communicating With Patients
We have approached the challenge of illustrating the application of communication skills to the clinical situation by creating hypothetical dialogues between a physician and a patient with ovarian cancer as she progressed through different stages of the illness. Our intent was to demonstrate how the clinician can frame effective responses to the psychological and information issues that parallel the medical events related to the patient’s illness.

We do not propose that these dialogues in any way be imitated or that they are an exclusive approach or gold standard. Instead, physicians should view them as guidelines that can be adapted to their own style and personality and the individual circumstances of patient care. Physicians may be reassured to know, however, that these dialogues incorporate most elements of current ‘best advice’ for clinicians on how to break bad news,[30] as well as important communication strategies that are recommended for inclusion in medical curricula.

Physicians’ Emotional Reactions
Physicians’ emotional reactions to the patient can play an important part in coloring the nature of the communication process and can even influence the treatment that the patient receives. Physicians who feel that they have failed the patient or who take personal responsibility for the patient’s plight may avoid or delay a difficult conversation with the patient or may camouflage information to make it seem less unfavorable. When the message is ambiguous, patients may frame it in an overly optimistic light and develop unrealistic expectations.

Physicians who feel that they have failed the patient may be more likely to continue chemotherapy in futile situations.[47] In order to cope with the anxiety of breaking bad news, some physicians may develop a stereotyped and/or rigid approach to all patients, regardless of inevitable individual differences. On the other hand, good communication skills can actually buffer against the stress that may lead to depression in the doctor.[48]

Physicians who encounter angry patients or patients in denial may become negative and defensive, in part, because they may feel that their help has been rejected. These emotions may impair the doctor’s ability to explore the patient’s reaction and the underlying basis for his or her behavior. The communication strategies illustrated in this paper have the potential to improve the physician-patient interaction. However, self-awareness training, an important but neglected part of physician training and development, can also improve the outcomes of the interview.[44] An in-depth discussion of this topic is beyond the scope of this article.

Summary

The principles discussed in this article are not new to medicine. They have been practiced for years but tend to become lost in the current emphasis on biotechnology. Fortunately, a growing body of scientific research is confirming the importance of these concepts in improving the satisfaction of both doctors and patients with their relationship.

References:


45. Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, et al: Cancer patients: Their desire for


Source URL: http://www.cancernetwork.com/discussing-disease-progression-and-end-life-decisions-2

Links:
[1] http://www.cancernetwork.com/review-article
[5] http://www.cancernetwork.com/authors/walter-f-baile-md
[6] http://www.cancernetwork.com/authors/gary-glober-md
[7] http://www.cancernetwork.com/authors/renato-lenzi-md-facp
[8] http://www.cancernetwork.com/authors/estela-beale-md
[9] http://www.cancernetwork.com/authors/andrzej-p-kudelka-md