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Primary Care; Clinics in Office Practice Volume 28 • Number 2 • June 2001 Copyright © 2001 W. B. Saunders Company

# **Palliative Care**

Breaking bad news and discussing death

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0095-4543/01 \$15.00 + .00

#### Case Study

Shirley Smith, a 43-year-old elementary school teacher, sees her physician, Dr. Williams, because she has been feeling tired. In addition to a careful history and physical examination, the physician suggests some blood tests. The next day, Dr. Williams receives laboratory results that show probable leukemia. He knows that he needs to contact Shirley, but he feels uncomfortable and sad about what he has to tell her. He calls Shirley at work. The school office transfers Dr. Williams' call to the telephone in Shirley's classroom. She does not know who is calling when she answers the phone while standing at the front of her third-grade class. The telephone conversation proceeds in the following manner:

```
"Hello,
this is Dr. Williams. Is this Shirley Smith?"

"Yes,
this is Shirley."

"I have the results of your blood
test. They suggest that you have leukemia, a cancer of the blood. I'd like you
to see Dr. Jones, a cancer specialist at the hospital."

"Oh,"
responds Shirley.
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Dr. Williams says, "I'm confident that Dr. Jones will provide excellent care for you. I'll call him and fill him in on your case. You will want to call his office today. Good-bye."

After he hangs up the phone, Dr. Williams feels discouraged and dissatisfied. Shirley feels overwhelmed. As she begins to sit down in her desk chair, her legs buckle.

The ability to discuss bad news with patients and families in a kind, compassionate, and direct manner is a clinical skill that is essential for primary care physicians. The primary care physician often is called on to deliver bad news to patients who are facing a life-threatening condition. Sometimes these discussions involve a newly diagnosed, serious, acute condition, such as leukemia. At other times, these discussions involve the progression of a chronic condition, such as diabetes or chronic obstructive pulmonary disease, that has not posed an immediate threat of death in the past but is leading to increasing disability and risk of death.



End-of-life care is substandard in the United States. Pain and suffering often go unrelieved. Palliative and hospice care often is not offered to patients or is initiated just before death. [28] [49] Physicians have identified many barriers to providing more effective end-of-life care. [28] Most physicians report that they have received limited training in the care of patients at the end of life, and many report difficulty acknowledging suffering and impending death and talking with patients about suffering and death. The skill of delivering and discussing bad news is an important element of improving the quality of care at the end of life. This article reviews research on giving bad news and presents clinical guidelines based on this review.

### Literature Review

"Death the Healer, scorn thou not, I pray,

To come to me: of cureless ills thou art

The one physician.

Pain lays not its touch

Upon a corpse."

AEschylus. 525-456 B.C.

Each of us has a common sense understanding of what bad news is. However, AExsschylus reminds us that "bad news" is contextual; even death stirs multiple emotions-sadness, tragedy, and, at times, comfort and relief. Folkman and Lazarus<sup>[14]</sup> define bad news as that which engenders a feeling of no hope or threatens a person's physical or mental well-being, their established lifestyle, or their choices in life. In a similar vein, Ptacek and Eberhardt<sup>[34]</sup> state that "news is bad to the extent that it results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received." Both of these definitions focus on the patient's individual cognitive, emotional, behavioral, and physical reaction to information.

Bad news is not merely an individual's experience. [26] The communication of bad news in health care occurs as an interaction between a patient, the physician, the patient's family and friends, and other health care professionals. In its simplest form, this interaction has multiple dimensions: the nature of the bad news (e.g., new diagnosis of a chronic illness versus diagnosis of a terminal illness), the patient's

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understanding of the information, the physician's understanding of the information, the patient and the physician's individual cognitive and emotional reactions to this information, the patient-physician interaction, and the environment within which the communication occurs.[24]

The patient's family often is an important player in the act of giving bad news. Similar to the patient, the family may respond to the bad news in a myriad of ways. Family members may help the patient process and accept information. Many family members are supportive and helpful, whereas some continue long-standing battles into the last days of a patient's life and beyond. Many support open communication with the patient, whereas some may hope to protect the patient by withholding bad news. Some families become angered or withdraw from the situation completely. A physician's skills in the art of breaking bad news begins with the physician-patient relationship and extends to working effectively with the patient's family members who are experiencing their own pain and suffering.

Although many authors have provided advice on giving bad news, there is only a small body of research that investigates the giving of bad news. One group of studies explored patients and families' actual experiences and stated preferences regarding receiving bad news. A second group explored physicians' actual experiences and professional opinions regarding giving bad news. A third group of studies used randomized controlled trials to test the value of specific interventions, such as providing patients with an audiotape of a consultation so that they can review it later. A fourth group of studies used a systematic method to develop professional consensus regarding how to discuss bad news and validated this consensus by surveying patients, physicians, and other health care professionals.

### Patients, Families, and Bad News

## What Patients and Families Experience

When patients and families are asked about their experiences discussing bad news, many report a moderate to high degree of satisfaction with their physician. [24] [26] Patients and families also report some consistent difficulties, however. One common problem reported by patients is the physician's use of technical language that the patient does not understand. Concepts that are familiar to physicians, such as *median survival* and *risk reduction* are not understood by most patients. [29] Other common problems cited by patients include discussing bad news in a hallway, waiting room, or other location that lacks privacy; neglecting to offer social support from clergy or others; being perceived as lacking sympathy, lacking information, and being unable to answer questions; and neglecting to prepare family members for the possibility of an autopsy in circumstances in which one may be required by state law. [24] [26]

### What Patients and Families Want

Many studies have surveyed patients and their families to describe how they believe physicians should give bad news. [24] [27] [38] These studies have covered a wide range of patient and family experiences, including diagnosis of cancer, a child born with a birth defect, and family members surviving a patient's death from traumatic injury. Four common themes emerge from these studies: Patients want (1) a clear, direct statement of the news; (2) time to talk together in private; (3) openness to emotion; and (4) ongoing involvement in decision making.

First, most patients as well as family members with responsibility for health care decision making want the physician to provide clear and accurate information regardless of whether the news is good or bad; this includes accurate information about the probable course of the illness, prognosis, and expected life span. When providing this information, patients want the physician to use direct, nontechnical language.

Second, patients advise physicians to communicate in a private setting that allows ample time for the patient to talk and ask questions. They value physicians who are informed and can help them answer their questions. Patients also appreciate physicians who offer resources such as clergy and support groups and arrange for follow-up discussion.

Third, patients want physicians to address the emotional dimensions of communicating bad news. They want the physician to communicate a caring attitude and be kind, compassionate, hopeful, and confident. Patients want the physician to be open to the emotional experience of the patient. Being open to the patient's emotional experience means allowing patients to talk, listening carefully, acknowledging the patient's strong feelings of sadness or anger, and accepting the patient's feelings.

Fourth, patients and family members often want to maintain a sense of personal control by being actively involved in treatment decision making. Treatment decision making sometimes can become quite detailed. Many patients have disease-specific or situation-specific concerns that they want the physician to address, including treatment options, side effects, pain and symptom management, and maintenance of independence. Patients with a terminal illness often want to know specific information about the dying process.

When physicians are discussing bad news with parents regarding a newborn, parents prefer that the physician talk to both parents together and as soon as possible. [26] [28] Parents prefer that the physician, when possible, discuss the news with the infant present and being held by either a parent or the physician.

# Diversity Among Patients and Families

In addition to the common themes described previously, there is substantial diversity among patients and families. Some of this diversity is attributed to individual differences. Patients and family members vary in coping style and vary in the degree to which they want detailed information, social support, spiritual counsel, and reassurance. Culture, ethnicity, sex, age, disease, religion, family context, and other factors shape patient preferences and lead to diversity. [2] One example of diversity among patients is provided by the issue of physicians using physical touch to reassure and comfort a patient. In a study of 54 surviving family members of patients who died from trauma, 9 desired a hug, handholding, or a pat on the shoulder when receiving bad news, and 16 did not want any type of physical touching. [24] In a study of 16 patients diagnosed with head and neck cancer, 12 did not want the physician to touch them when giving bad news. [25]

Another example of diversity, one that illustrates cultural diversity in truth telling, is when family members ask a physician to refrain from telling their relative the truth about the terminal diagnosis ("Don't tell Dad that he is dying from cancer"). [2] [18] [21] As Hallenbeck<sup>[18]</sup> points out, the prevailing belief in Western health care that a patient has the right to know is not a universally held belief in all cultures. Patients and families from some cultures believe strongly that the dying patient should not be told and that other family members should assume the role of medical decision making.

More research is needed to explore diversity in end-of-life beliefs and practices. Research never can prepare the primary care physician completely for the myriad of situations encountered in practice, however. No standard approach can replace a physician's careful, individualized, patient-centered approach<sup>[39]</sup> to each patient and family.

#### Physicians and Bad News

Geppert<sup>[1,5]</sup> stated, "When death is seen not as a technological state or a legal act, but as a mysterious transition, then it transforms a physician's ethical responsibility ... to meet their dying patients in what Kierkegaard would have called the 'truth of subjectivity,' where doctor and dying patient encounter each other as self-aware and vulnerable human beings without the barriers and protections of medicalization."

Most physicians struggle with giving bad news and offer many reasons for avoiding it, as follows:[2] [12] [28] [25] [25]

- 1. Lack of training in giving bad news
- 2. Fear of the patient's emotional reaction
- 3. Fear of one's own emotional reaction
- 4. Fear of being blamed for bad news
- 5. Fear of uncertainty and not knowing all the answers
- 6. Fear of patient's suffering and death
- 7. Fear of one's own mortality

Physicians find the task difficult and may avoid or delay discussing bad news even when patients are interested and ready to talk. [2] This level of discomfort and struggle is not surprising because most physicians report that they were trained inadequately in medical school and residency. [25] This situation has a substantial impact on the health care environment. Greater than 90% of physicians report that they have felt frustrated or angry with the way bad news has been delivered to a patient and thought that they had to take steps to improve the situation. [25]

Physicians face many barriers in addition to lack of training. [123] [243] As mentioned in the previous list, many physicians are concerned about the patient's emotional response to the news--what can the physician do to help a patient who feels deep grief, sadness, or anger? Physicians often fear how the patient may respond to them--will the physician be blamed for the bad news? A patient's strong anger and blame can provoke substantial anxiety in the physician. Although strong emotional reactions are normal when bad news is presented, physicians generally are not trained to deal with strong emotional reactions from their patients.

Another factor, as noted in the previous list, is the physician's fear of his or her own emotional response. Physicians are trained so thoroughly in being objective and clinical that they may feel uncomfortable expressing any personal emotion in front of patients. Discussing bad news often evokes strong feelings, however. Emotions can be particularly strong when confronting bad news with a patient that is well known or well liked or a young patient or when it involves an unexpected loss. Consequently, fear of losing control in front of the patient may cause a physician to avoid delivering bad news.

Presenting bad news is challenging because the physician may not know all the answers and may fear looking ignorant. Some of this fear may be owing to an individual lack of knowledge. Although information about prognosis is growing, it is still not disseminated widely. Also, because medical knowledge is expanding rapidly, the primary care physician may fear that he or she will present out-of-date or inaccurate information. Some of this fear is owing to the inevitable lack of certainty that surrounds each patient's illness. These factors often cause primary care physicians to delay giving much needed information (and much needed emotional support) until the patient can see an *expert*.

The final barriers that the physician must face are the mortality of the patient and the mortality of the physician. Physicians often report feeling afraid of the patient's suffering and death--"How will they die?" "Will I be able to ease their pain?" "What can I offer?" "How can I comfort them?" In addition to facing a patient's death, the end of a life makes one acutely aware of one's own mortality. This barrier

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can be particularly daunting if the physician has concerns for his or her own health or the health of a loved one. Given society's aversion to death, it is not surprising that many physicians feel uncomfortable when discussing these issues.

## Randomized Controlled Studies of Giving Bad News

A group of randomized controlled studies examined the impact of specific interventions on the process of giving bad news. [3] [3] [3] [3] [3] [3] [3] [4] Some of these studies provided patients with written summaries or audiotape recordings of a consultation in which bad news is given. Other studies used standardized protocols for guiding the discussion, including a question prompt sheet for the patient. Walsh et al [42] provided a helpful overview of many of these studies. These studies have examined three outcomes for patients and families: (1) accurate recall of the bad news discussion, (2) satisfaction with the discussion, and (3) psychologic coping after the discussion. In general, these studies have shown that using a patient-centered communication strategy, such as question prompts, an individualized written summary, or an individualized audiotape of the consultation, increases patient and family satisfaction. Impact on patient and family memory of the consultation and coping is less clear, however, because some studies show a benefit, whereas others do not. General information that is not customized to the individual patient seems to be less helpful than information that is created specifically for the patient. [19]

### Consensus Guidelines for Discussing Bad News

Much of the medical literature offering advice on how to discuss bad news has been based on the advice of one or several skilled and experienced clinicians. Several studies by Girgis and Sonson-Fisher, [16] [12] sponsored by the New South Wales Cancer Council and the Postgraduate Medical Council of New South Wales, Australia, have taken a more rigorous approach. This research team has (1) reviewed systematically the relevant literature on giving bad news; (2) developed a draft set of guidelines for giving bad news; (3) presented these guidelines to a diverse panel of 28 experts (medical oncologists, general practitioners, surgeons, nurse consultants, social workers, clergy, and human rights representatives); (4) presented these guidelines to 100 patients diagnosed with a terminal illness; (5) revised the draft guidelines based on feedback from professionals and patients; and (6) validated the resulting guidelines by further patient and professional review.

The resulting guidelines include 16 principles to guide the physician in **breaking bad news** as well as 13 steps to follow in **breaking bad news**, summarized in the accompanying box. This research represents the most rigorous, systematic, and valid attempt to develop practical clinical standards for giving bad news. One limitation of the research is the fact that it focuses on a single population and culture. Future research no doubt will apply this method to other populations so that clinicians might extend their understanding to other populations and cultures.

## Australian Cancer Counsel Guidelines for Giving Bad News

### Principles of communicating bad news

- 1. One person should be responsible for breaking bad news
- 2. The person who breaks the news should be the primary care physician or senior consultant
- 3. The patient has a legal and moral right to accurate and reliable information--the physician has a duty to disclose information to the patient
- 4. The physician's primary responsibility is to the individual patient
- 5. Give accurate and reliable information so that the patient understands any implications
- 6. Always ask the patient how much information he or she wants about prognosis

- 7. Give information in a staged process over several visits
- 8. Prepare the patient as soon as possible for the possibility of bad news
- 9. Do not give test results individually unless the patient knows you are waiting for further tests
- 10. Tell the patient the diagnosis as soon as it is certain
- 11. Tell patients in person
- 12. Make sure there is sufficient time available for questions
- 13. Ensure privacy and help the patient feel comfortable
- 14. Give the patient choice of having others with him or her to provide support
- 15. When possible, arrange for other health care workers (e.g., nurses, hospice workers) who will be participating in care to be present for initial and ongoing discussions
- 16. Communicate with the rest of the health care team what was discussed with the patient
- 17. Use nonverbal cues to convey a caring, compassionate attitude
- 18. Use a trained interpreter whenever there is a language difference
- 19. Be aware of cultural and social factors that may affect how the patient will deal with bad news

# Steps in communicating bad news

- 1. Share the information in a quiet, private place
- 2. Allow enough uninterrupted time
- 3. Assess the patient's understanding of the situation
- 4. Give the information simply and honestly but not bluntly
- 5. Allow patients to express emotions freely
- 6. Respond with empathy
- 7. Avoid giving a definitive prognosis (say "weeks to months" instead of "you have 3 months to live")
- 8. Avoid the phrase "nothing can be done"; emphasize what can be done for comfort measures
- 9. Arrange follow-up in the immediate future
- 10. Discuss treatment options and side effects whenever the patient is ready
- 11. Discuss whom the patient would like to tell about the diagnosis
- 12. Give information about support services
- 13. Document for yourself and for the patient what has been discussed

Adapted from Girgis A, Sanson-Fisher RW: **Breaking bad news**: 1. Current best advice for clinicians. Behav Med 24:53-60, 1998, Heldref Publications; with permission.

# A Clinical Approach to Giving Bad News

"A physician's own humanity may at times be the most powerful healing instrument."[15] Consider the following case example.

### Case Study

Lois, a 56-year-old woman, sees her physician for a routine physical examination. She has a past medical history of atrial fibrillation and aortic insufficiency. She presently has no complaints. Current medications are warfarin, metoprolol, and digoxin. Her family history is unremarkable except for an aunt with cancer of unknown type. Her physical examination, including breast and pelvic, is

unremarkable except for an irregularly irregular heartbeat. A total and high-density lipoprotein cholesterol, Papanicolaou smear, and mammogram are ordered. Two weeks later, the physician, Dr. Wood, receives the mammogram report, which shows abnormal calcifications in the right breast. A stereotactic biopsy of this area shows ductal carcinoma in situ. Dr. Wood's nurse calls Lois, tells her that the test results are back, and asks her to schedule an appointment along with her husband for the next day.

Dr. Wood has begun the process of giving bad news in a systematic and compassionate manner. The clinical model presented here for giving bad news is adapted from Ambuel and Weissman<sup>[1]</sup> and draws on the work of Girgis and Sanson-Fisher<sup>[1,7]</sup> as well as other research reviewed earlier. This protocol also has been influenced by the work of many skilled clinicians that have written about discussing bad news with patients.<sup>[4]</sup> [1,3] [2,3] [2,3] There is substantial agreement among these various sources regarding how physicians best can deliver bad news to patients. The model presented here has six tasks. These tasks are described in approximately sequential order. Clinical circumstances and patient needs and preferences vary greatly, however. A guiding principle that carries throughout the process is for the physician to remain patient-centered and practical in focus: What are the patient's needs? What limitations exist because of circumstances that cannot be controlled? How can the physician best adapt this model to meet the patient's needs in these circumstances? The six tasks for giving bad news are summarized in the accompanying box.

## **Clinical Protocol for Giving Bad News**

# Create an appropriate environment

Comfortable, quiet room with seating for all

Determine who should attend (i.e., patient, family, health care team)

Turn off pager, check personal appearance

Review medical record and talk with consultants

Consider goals of meeting

### Open the meeting

Greeting and introductions

Attend to patient's comfort

Determine what patient and family know

Provide summary of patient's illness

#### Discuss bad news

Speak slowly, deliberately, and clearly

Provide information in small chunks; check patient's understanding

Give fair warning

Present bad news directly and simply; use nontechnical language

Allow patient and family to talk early and often; provide information at their pace

Acknowledge, validate, and reflect emotion

Communicate compassion, kindness, and caring

Provide patient with a summary of discussion (written, audiotape, or videotape)

## Develop a follow-up plan

Negotiate plan for follow-up meeting

Refer patient and family to social support (i.e., chaplain, support group)

Summarize plan and expectations for follow-up team

#### Document the conference

Who attended, what was discussed, and what is the plan

## Engage in self-reflection

Recognize and acknowledge your own feelings

Accept your emotions

Share thoughts and feelings with a colleague or in a journal

Adapted from Ambuel B, Weissman DE: Delivering bad news. In Weissman DE, Ambuel B, Hallenbeck J (eds): Improving End-of-life Care: A Resource Guide for Physician Education. Milwaukee, WI, Medical College of Wisconsin, 2000, p 165; with permission.

## Creating an Appropriate Environment

The first step in presenting bad news effectively is to establish an environment that will support the discussion. Alert staff to the meeting and ask them to avoid unnecessary interruptions and turn off your beeper or give it to someone who can monitor calls during the meeting. Choose a quiet and comfortable room where you, the patient, and others can meet. If possible, arrange the seating in a circular pattern.

Consider who should be present for the discussion. Some people prefer to speak with a physician alone, whereas others prefer a spouse or family members to be present. Ask the patient who, if anyone, he or she would like to include in the discussion. If the patient's decision-making capacity is tenuous, ensure that the designated health care power of attorney attends. Decide if it would be beneficial to include a specialist consultant, chaplain, or social worker, then obtain the patient's consent. If the patient or other

family members do not speak English, a skilled medical interpreter should be obtained, and if the patient is deaf, an American Sign Language medical interpreter should be obtained. Consider the patient's ethnic, cultural, and religious background.

Prepare yourself for the encounter. Check your personal appearance. Have a pen and notepad and think through the goals for the meeting. Remind yourself that the patient or family may have different goals; be open to discovering the goals of the patient and family. Time permitting, make sure that you know basic information about the patient's disease, prognosis, and treatment options. Talk to specialists that have provided consultation for the patient so that you know what the specialists are advising. Write down the patient's name and names of other family members or friends who will be attending. Thorough preparation may not always be possible. In urgent or emergent situations, you may need to proceed with a discussion when information is incomplete. Therefore, have a plan in mind ahead of time about how to handle incomplete information and questions that cannot be answered with information that currently is available. Finally, remind yourself that patients and families want a caring physician who provides direct, nontechnical information and allows the patient and family to talk and ask questions.

## Opening the Meeting

Open the discussion by greeting the patient. Introduce yourself if this is a first meeting. If other people are present, each person should introduce himself or herself. You may want to write down the names of people as they introduce themselves. Any immediate needs that may distract from the discussion should be attended to (e.g., patient will have difficulty participating if he or she is in pain, is otherwise uncomfortable, or needs to use the bathroom).

You will want to determine what the patient and family already know. Do not make any assumptions about this because the patient and family members may have obtained information from many sources, including medical consultants, family friends, and the internet. One can elucidate the patient's and family's understanding by asking, "What is your understanding of your present condition?" or "What have the doctors told you about your condition?" Eliciting the patient's or family's understanding is not appropriate in all situations. Consider a patient, accompanied by a spouse, who presents to the emergency department complaining of chest pain. While in the emergency department, the patient suffers a myocardial infarction and is transferred to the intensive care unit. You meet with the spouse to discuss the patient's medical status. In this circumstance, the spouse knows very little about the patient's condition and wants to hear immediately from the physician.

Sometimes, before presenting bad news, it may be helpful to provide a summary of the patient's illness, diagnostic procedures, and medical status. Be careful to use simple, nontechnical language in this summary. A summary can be particularly helpful as a method of bringing family members or consultants up-to-date with one common source of information. As with questions about the patient's or family's understanding of the illness, the physician needs to use judgment about the proper timing for providing a treatment summary. In some situations, it may be appropriate to provide this summary before presenting bad news, whereas in other circumstances, it may be most appropriate to offer a treatment summary after presenting bad news (e.g., in response to the patient or family wanting additional information).

### **Discussing Bad News**

When giving bad news, speak slowly, deliberately, and clearly. Provide information in small chunks, and check the patient's reception frequently. Give fair warning that you have bad news, then pause for a moment ("Unfortunately I have some bad news for you..."). The bad news should be presented in a

direct and simple manner using nontechnical language. Be prepared to repeat the information or present additional details in response to the patient and family.

After presenting the bad news, allow the patient and family time to absorb the information and respond. You may wait for the patient to respond, or offer personal support (e.g., with a statement such as "I'm so sorry"). Avoid the temptation to fill silence with a physician-directed discussion laced with medical details. Instead, give early and frequent opportunities for the patient and family to talk or ask questions.

Anticipate and expect emotional reactions to bad news; the most common is sadness, and the second most common is anger. Patients and families often also experience fear, anxiety, denial, numbness, shame, or loneliness. People may even experience relief because the information the physician presents, although unwanted, answers questions and resolves uncertainty. Although one emotion may be predominant at any one time, patients and families often experience a mixture of emotions over time.

Allow the patient and family time to talk. Listen carefully to the emotional meaning of what they say and to their questions and concerns. The patient and family's reactions should be acknowledged and validated (e.g., by saying, "This is very difficult news" or "I know this is very hard"). Recognize the patient and family's emotions and reflect these feelings back in a caring manner. When a patient begins to cry, the physician may be quiet at first, then say, "I see that you are crying" or "Tell me about your tears." If a patient shouts in anger, "This is unfair," the physician might say, "You are feeling very angry" or "This feels very unjust." Reflecting emotion in this manner tells the patient that you are listening; makes the patient more aware of his or her own emotional responses, which may help with coping; and allows the patient to correct or clarify your understanding of his or her emotions if you are mistaken in interpretation. After you have recognized and acknowledged the patient's emotions, you can ask, "Is there something I can do to help?"

When the patient and family want additional information, provide information at their pace. The discussion is analogous to an archeologic dig, with successive layers of discussion providing additional information to the patient and family. This discussion may be aided by a prompt sheet that provides a list of questions that patients commonly ask. Provide simple, direct, and nontechnical information that does not overwhelm with details. Assess the patient's and family's understanding by asking them to explain back what you and other physicians have told them. Ask the patient and family if they have questions or would like additional information. Provide an additional layer of information when the patient and family want additional information. Remember that patients and families often need to hear information multiple times as part of the normal process of integrating and understanding. Be willing to review information previously discussed, move from a simple to a complex level of information, or provide an overview in response to the patient's and family's needs.

### Creating a Follow-Up Plan

Before concluding the discussion, a follow-up plan should be agreed on. Ask specifically, "How can I help?" Negotiate with the patient or family a specific follow-up strategy, as follows: "I will return later today, write down any questions you have and we can discuss them at that time" or "I suggest that we meet in the next week to talk about how things are going and answer any questions that you have." Provide the patient with a written summary, audiotape, or videotape of the discussion. Assess thoughts of depression and self-harm during the current discussion and in later meetings. Suggest additional sources of support that are available locally, (e.g., a hospital chaplain, a religious leader chosen by the family, a medical social worker, and local support groups). It is most effective to offer referrals to multiple resources.

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After the meeting, provide a summary of the meeting to other members of the health care team, which might include other specialists who are participating in care and the triage nurse at your clinic. Be explicit and clear if you expect other team members to do anything as part of the follow-up plan.

## Documenting the Conference

After the conference, document relevant information in the medical record so that adequate notes will be available during follow-up appointments. This documentation does not need to be a lengthy verbatim note but should include basic information, as follows: Who was present for the meeting? What information was discussed? How did the patient and family respond? What concerns and questions do they have? What actions need to be taken now? What follow-up is planned?

## Self-Reflection

As discussed earlier, bad news has meaning and emotional impact on the physician as well as the patient and family. Self-reflection by the physician is an essential element of any protocol for giving bad news. This self-reflection occurs after the patient and family have left the consultation room, perhaps during a few moments in the middle of the day or during the drive to work in the early morning. Ask yourself. "How has this experience affected me?" "What am I thinking and how am I feeling about my patient's experience?" "How might this affect my work with the patient and family?"

Physicians often have strong emotional feelings in response to giving bad news, such as the following:

Sadness: "How can this happen to such a good person?"

Anger: "I wouldn't be in this situation if my patient had seen me for a regular checkup."

Fear: "They are going to blame me for this." or "The patient is my age. The same thing could happen to me."

Guilt: "This is my fault. I missed an early symptom." or "The patient is so upset. I'm not supposed to cause emotional pain."

The physician can support himself or herself through the process of self-reflection in the same manner that the physician provides emotional support to patients. First, recognize and acknowledge your emotional responses to the bad news. Second, accept the emotional responses as a normal part of caring for patients. Third, express your feelings in conversation with a colleague or by keeping a journal. Finally, if you become aware of persistent feelings of hopelessness, depression, anger, or disengagement, you should seek help from a therapist to explore ways of renewing your vitality.

### Giving Bad News by Telephone

Giving bad news by telephone should be avoided whenever possible. Patients do not like to receive bad news by telephone. The physician using the telephone to give bad news is handicapped because he or she cannot read the patient's body language; the patient cannot read the physician's body language either. Options include a home visit, office visit, or meeting at the hospital. If an important test result is expected, an office visit can be scheduled in advance to review results. There may be times, however, when the telephone is the only practical method for delivering bad news. When telephone notification is necessary, following the suggested scenario in the box can help avoid potential serious errors while facilitating discussion.<sup>[23]</sup>

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## Responding to Requests for Nondisclosure

As Hallenbeck discusses, requests that the physician refrain from telling the truth about a terminal illness often are rooted in deeply held cultural beliefs and practices. When the physician inquires further about a request for nondisclosure, the family may explain that talking with the patient directly about his or her death is a foreign concept. Telling the patient, in the family's view, may hasten the patient's death. The family is expected to assume the burden of the bad news and subsequent decision making.

### Giving bad news by telephone:

Be sure to make the phone call when you have sufficient time to talk. When you make the phone call, begin by verifying whom you are speaking with and their relationship to the patient:

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"Hello, is this Julie Smith?"

"Yes."

"The
Julie Smith who is the daughter of Noland Smith?"

"Yes."
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Next, introduce yourself and describe your role in the patient's care. Find out if the person you are calling is able to talk now. Give fair warning, for example, "Unfortunately I have some bad news regarding your father." Proceed with the discussion as you would with a face-to-face meeting. Because you cannot use body language to communicate care and concern, you will want to be sure to convey your feelings in words ("You and your family have my deepest sympathy." "I enjoyed knowing your father--he was a fine man."). In some cases, you might offer to meet with the individual at the hospital or office. Because people notified of bad news by the telephone often feel a greater sense of isolation, offer to contact someone else for them, such as a family member, clergy, or neighbor. Offer follow-up and support just as you would if you were meeting them in your office.

Hallenbeck<sup>[18]</sup> describes a seven-step process for negotiating a family's request not to tell a relative about a terminal diagnosis or other bad news:

- 1. Begin with a statement of respect: "I understand that people have different beliefs about how to handle this situation. Thank you for talking with me about your concern."
- 2. Explore why the request has been made: "Tell me more about why you suggest that we handle things in this manner. Do you have a specific concern about what might happen if I talked directly with your relative?"
- 3. Explore where the family thinks the patient would stand on the issue: "Do you think that your relative would agree with this approach? Have you talked with him or her about how to manage decision making during this hospitalization? How has your relative managed similar situations in the past?"
- 4. Describe your own values: "In the United States, physicians usually talk directly with the patient about a decision like this; this is the approach I usually take. It is important for me to tell the truth when talking with patients and families about an illness."
- 5. Propose a negotiated approach: "I respect your family's beliefs about how to approach medical decisions for your relative. What I would like to do is confirm with your relative that he or she is

- okay with leaving the decisions to you."
- 6. Set ground rule for discussion: "If your relative agrees to leave the details of his or her illness and medical decisions to the family, I will be glad to support that approach. If your relative says that he or she wants to know the details of his or her illness and to participate in medical decisions, then I need to respect the patient's wishes. Do you understand and agree with this approach?"
- 7. Talk with the patient: "I have been talking with your family about how you and your family usually make decisions about medical care. Your family has recommended that I talk with them about the details of your illness and treatment decisions, rather than discussing these details with you. Do you agree with this approach? Would you like your family to manage details of your illness and treatment decisions?"

If the patient agrees to defer autonomy to other family members, the physician can proceed with the family's suggested approach. If the patient indicates that he or she wants to know the details of the disease and wants to participate in decision making, the physician will want to talk with the patient and family together about their different views.

# Role of Continuity in Helping Patients Cope With Bad News

Primary care physicians often maintain long-term relationships with patients. This continuity plays a role in the delivery of bad news that has not been well described or studied. Consider two different yet common disease trajectories in primary care. First, consider the case of a patient who has a chronic illness, such as heart failure, diabetes, or chronic obstructive pulmonary disease. The primary care physician often is involved in the initial diagnosis and subsequent management. The early stages of these chronic illnesses often have limited impact on a patient's life; however, as the illness progresses, the patient's health and function are compromised increasingly. Medical management often focuses on minimizing symptoms and maximizing function. As the disease progresses, the patient's prognosis gradually deteriorates, and as a result, the primary care physician often finds himself or herself delivering bad news chronologically as the disease progresses. The primary care physician often is in the best position to discuss issues of prognosis, palliative care, and death.

Consider a different trajectory of illness that can come with the diagnosis of a serious acute condition, such as a solid tumor. The primary care physician may be the first person who discusses a concerning sign or symptom with a patient. This discussion is often an early, although inconclusive, indication that the patient may be facing bad news. The patient may be referred to a specialist for additional assessment. Often the specialist makes a definitive diagnosis and discusses findings with the patient, a discussion that occurs without the primary care physician. The patient may or may not schedule a follow-up appointment with the primary care physician, and the specialist may or may not provide a simple, clear explanation and support to the patient.

Primary care physicians can benefit their patients by taking a proactive role in this longitudinal process. When referring a patient, ask the patient to schedule a follow-up visit with you after the appointment with the specialist. In the referral letter to the specialist, indicate that you expect feedback from the specialist that summarizes findings and the discussion with the patient. When this consultation is received, ask the receptionist to contact the patient for a follow-up appointment. These steps can keep the primary care physician involved with the patient in the process of diagnosis and treatment decision making.

## Summary

The ability to discuss bad news with a patient and family is a clinical skill that is essential to providing

effective end-of-life care. Patients and families value direct, nontechnical explanations that are given by a physician with compassion and kindness. Patients and families value time to talk, express their feelings, and ask questions. Patients need the physician's humanity as much as the physician's technical expertise. As Loxterkamp<sup>[30]</sup> stated, "...patients often demand just our presence. They need us not only for what we can do, but for the suggestion of what they might become: changed, well, whole, happy. Or barring that, at peace before they die."

Preparation of this article was supported in part by a grant from the Robert Wood Johnson Foundation, Improving Residency Education in End-of-Life Care, David Weissman, Principal Investigator. The authors would like to acknowledge David Weissman, Jim Hallenbeck, and Tracy Lewis for their contributions to our understanding of this issue; Linda Oddan, for assistance with our literature search; and Helen Ambuel and Beth Mazzone for their support and encouragement.

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