

Approaching Difficult Communication Tasks in Oncology¹

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ABSTRACT Effective communication skills enable physicians to improve patients' understanding of their illnesses, improve patient adherence to treatment regimens, use time efficiently, avoid burnout, and increase professional fulfillment. Common communication pitfalls include blocking, lecturing, depending on a routine, collusion, and premature reassurance. Fundamental communication skills include "ask-tell-ask," "tell me more," and responding empathetically. Key communication tasks that are linked to the illness trajectory include: the first visit, giving bad news, making anticancer treatment decisions, offering clinical trials, completing anticancer therapy, and discontinuing palliative chemotherapy. While enhancing or acquiring new skills ultimately requires practice and feedback over time, this article provides a cognitive map for important communication skills that physicians need over the course of caring for a person with cancer. (*CA Cancer J Clin* 2005;55:164–177.) © American Cancer Society, Inc., 2005.

INTRODUCTION

Communication between physicians and patients is a fundamental aspect of cancer care, yet most physicians have had little training in communication. The aspects of communication most valued by patients are those that help patients and their families feel guided, build trust, and support hope. While these may be abstract qualities, they follow from a concrete set of communication skills that can be effectively taught and learned. These communication skills are not the "medical interviewing" skills most physicians learned in medical school, which focused on taking a complete medical, social, and family history. The communication skills needed in cancer care are second-order skills that address difficult situations.

A wide variety of empirical studies document that physician-patient communication is suboptimal. Physicians and nurses typically miss the full range of concerns held by people with cancer.¹ These deficiencies in communication increase psychological and existential suffering of patients and their loved ones.^{2,3} Compounding these problems are the finding that oncologists lack accuracy in detecting patient distress.^{4–6} Finally, poor communication also hampers a physician's ability to provide pain and symptom management.^{7–10}

These studies have led to a widespread call for improving communication between clinicians and patients. The National Cancer Institute named cancer communication as an "extraordinary opportunity" in 1999; the American Society of Clinical Oncology named communication as a key clinician skill;¹¹ and the Institute of Medicine identified communication as one of six fundamental clinician skills sets in improving supportive and palliative care for people with cancer.¹²

Many physicians have not had effective teaching in communication skills and lack confidence that an educational intervention could improve their skills. Furthermore, continuing medical education consisting of lecture-style presentations consistently fail to change physician behavior.¹³ Yet new educational models exist that have been documented to result in physician communication skill improvement, and these models are being used in settings

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ranging from practicing physicians to oncology fellows in training.¹⁴⁻¹⁹ Communication skills training is associated with less burnout and work-related stress.^{20,21}

In this article, we will draw on empirical studies and expert practice to describe important considerations for physicians and other clinicians about communicating with patients and their families. After discussing some general considerations in communication skills, the rest of the article uses a trajectory model of illness to identify key communication tasks. These tasks outline a cognitive map of communication that physicians can follow during a patient's experience with cancer. While this cognitive map cannot replace skills practice and feedback, it can provide a useful starting point for improving communication skills for physicians and other clinicians.

FUNDAMENTAL COMMUNICATION SKILLS

Behaviors to Avoid

Empirical research demonstrates that a variety of common communication behaviors actually decrease the value of the time physicians spend trying to communicate.

Blocking

Blocking occurs when a patient raises a concern, but the physician either fails to respond or redirects the conversation.¹ Sometimes physicians are only partly conscious of this behavior. For example, a woman with metastatic colon cancer might ask, "How long do you think I have?" and the doctor responds, "Don't worry about that," or "How is your breathing?" Blocking is important because physicians typically fail to elicit the range of patient concerns, and consequently are unable to address the most important concerns.

Lecturing

Lecturing occurs when a physician delivers a large chunk of information without giving the patient a chance to respond or ask

questions.²² While lecturing may seem efficient, patients are often unable to follow the pace of the physician's information delivery, and it can be an inefficient use of time. They may have specific questions they are listening for, and thus do not absorb other information the physician provides. Alternatively, the patient may be preoccupied with emotions such as sadness, worry, or feeling overwhelmed.

Collusion

Collusion occurs when patients hesitate to bring up difficult topics and their physicians do not ask them specifically—a "don't ask, don't tell" situation.²³ Patients often assume if something is important then the physician will mention it, whereas physicians assume if patients want to know, they will ask. Consequently, important albeit difficult conversations about prognosis, cure, and end of life do not occur.

Premature Reassurance

Premature reassurance occurs when a physician responds to a patient concern with reassurance before exploring and understanding the concern.^{18,24} This practice is often used by physicians who feel that they "don't have time" to explore a patient concern, yet it can lead to repeated questioning by patients who don't feel their concern was completely understood and addressed.

Behaviors to Cultivate

Ask-Tell-Ask

This principle is based on the notion that education requires knowing what the learner already knows, then building on that knowledge. It also works as a way to build a relationship, as it shows you are willing to listen to and negotiate the patient's agenda. A great deal of communication in clinical oncology involves providing information, but this does not mean

that communication should be largely one-way. For any important communication:

Ask the patient to describe his/her current understanding of the issue. This will help you craft your message to take into account the patient's level of knowledge, emotional state, and degree of education. Some sample questions to open your conversation include:

- What brings you here today?
- What is the most important issue for us to talk about today?
- To make sure we are on the same page, can you tell me what your understanding of your disease is?
- What have your other doctors been telling you about your illness since the last time we spoke?

Tell the patient in straightforward language what you need to communicate—the bad news, treatment options, or other information. Stop short of giving a long lecture or huge amounts of detail. Information should be provided in short, digestible chunks. A useful rule of thumb is not to give more than three pieces of information at a time. Avoid medical jargon.

Ask the patient if he/she understood what you just said. This gives you the opportunity to check his/her understanding. Did he/she get the facts straight? Is his/her understanding appropriate? Did he/she hear what was said? Consider asking the patient to restate what was said in his/her own words. This will give him a chance to ask questions, which will tell you where to go next—what details to elaborate, what implications to discuss, what things to repeat. For example, you could say, “Who are you going to tell about this visit when you get home?” or “To make sure I did a good job of explaining this to you, can you tell me what you are going to say?”

Tell Me More

If you find that the conversation is going off track, it is helpful to note that in your own mind. You may even want to mention it to the patient by saying, for example, “I think we're not on the same track.” To get back on track, it is usually helpful to invite the patient to explain where he/she is in the conversation,

and to remember that every conversation really has at least three levels.²⁵ The first level of conversation could be called the “What is happening?” conversation, in which the patient is trying to comprehend information. The second level of conversation has to do with emotions—at this deeper level, a patient is asking himself, “How do I feel about this?” In addition to trying to figure out his/her emotions, he/she is also assessing whether they are valid and whether he/she can express them to the oncologist. The third level of conversation is an identity conversation, involving what the new information means in terms of the patient's sense of self, addressing the question, “What does this mean to me?”

Knowing that these three different conversations are taking place can enlarge a physician's sense of where the “tell me more” request can lead. Some examples of useful invitations to “tell me more” include:

- Could you tell me more about what information you need at this point?
- Could you say something about how you are feeling about what we have discussed?
- Could you tell me what this means for you?

Respond to Emotion

Understanding the patient's perspective will result in physicians discovering more about the thoughts and feelings patients are experiencing. Having discovered all this, how should physicians and other clinicians respond?

The concept of an “accepting response” is helpful here.²⁶ Rather than providing immediate reassurance, rebuttal, or agreement, the accepting response accepts what the patient says without judgment, acknowledges that patients ought to hold their own views and feelings, and validates the importance of the patient's contributions in a therapeutic relationship. It is important to note that acceptance is not the same as agreement. A physician could accept that a patient wishes to be cured of cancer, yet not agree that it is possible. This distinction is important in building and maintaining a relationship.

NURSE

A helpful mnemonic summarizes what to do in responding and accepting patient emotions: NURSE (Table 1).²⁷

NAMING

You can begin by naming a patient emotion for yourself, as a way of noting what is happening in the encounter. You may even want to name the emotion to the patient, as a way of showing that you are attuned to what she is experiencing (“It sounds like you are worried that the cancer may be recurring.”). Naming, restating, and summarizing are all ways to begin accepting and responding to patient emotions. This may require that physicians read nonverbal clues that patients display. It is important that when using naming, the physician is suggestive, not declarative. “I wonder if you’re feeling angry” or “Some people in this situation would be angry,” rather than “I can see you’re angry about this.” People don’t like being told what they are feeling.

UNDERSTANDING

A sensitive appreciation of the patient’s predicament or feelings is an important prerequisite for responding in a way that builds the relationship. Particularly important is to avoid giving premature reassurance at this point, even though the temptation to do this is strong. It is better to make sure that you have a clear understanding, which may require some exploration, active listening, and use of silence. “My understanding of what you’re saying is that you are concerned about the effect of the chemotherapy on your kids” can be an effective way to validate patient emotions. Paradoxically, saying “I cannot imagine what it is like” is a good way to show you understand.

RESPECTING

This can be a nonverbal response, involving facial expression, touch, or change in posture,

TABLE 1 Fundamental Communication Skills: Behaviors to Cultivate

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|---|
| <ol style="list-style-type: none"> 1. Ask-tell-ask 2. Tell me more 3. Respond to emotions with NURSE <p>N = Naming
U = Understanding
R = Respecting
S = Supporting
E = Exploring</p> |
|---|

but a verbal response is helpful because it can be more explicit in giving patients the message that their emotions are not only allowable but important. Acknowledging and respecting a patient’s emotions is an important step in showing empathy. In terms of how much to do on this step, consider matching the intensity of your acknowledgment to the patient’s expression of emotion—a strong emotion deserves a strong acknowledgment. Praising the person’s coping skills can be an effective way to show respect: “I am very impressed with how well you’ve continued to care for your children during this long illness.”

SUPPORTING

Several types of supporting statements are possible. Physicians can express concern, articulate their understanding of a patient’s situation, express willingness to help, make statements about partnership, and most importantly, acknowledge the patient’s efforts to cope. Given that many dying patients fear abandonment, making statements—if truthful—that you will be there for the patient are very useful: “I’ll be with you during this illness, no matter what happens.”

EXPLORING

This is a different use of the “tell me more” principle. Asking focused questions or expressing interest in something the patient has mentioned can be a way for a clinician to deepen an empathetic connection. Patients often offer clues about their emotions initially, and if invited to elaborate, will state their emotions and concerns explicitly.²⁸

KEY COMMUNICATION TASKS LINKED TO THE ILLNESS TRAJECTORY

The First Visit

The first visit can have many different purposes—a patient may talk about a presenting symptom, a diagnostic test may have shown an abnormality requiring further workup, or a diagnosis of cancer may need to be discussed, including further staging and workup or treatment options. Even if the first visit is not a difficult conversation, it is worth remembering that this encounter sets the tone for the entire relationship that ensues. While little empirical study has occurred about the first visit specifically, communication research does indicate the value of a couple of practices that enable physicians to get the relationship off to a good start and use the time allocated to the appointment efficiently.

1. Negotiate an Agenda for the Visit

The first practice is to begin the visit by negotiating an agenda for that visit. This negotiation has the following steps. Clarify the patient's understanding of the reason for the appointment and his/her expectations. When the patient appears to be done, asking "Is there anything else?" can be an effective probe that helps elicit concerns that patients may otherwise hold until the end of the visit.²⁹ The physician should then explain whether there are any medical issues that she feels it is important to cover that day. Then the physician can propose a way to use the visit—the topics that will be covered, any examination that is necessary, any tasks like jointly viewing an x-ray, and a summary of what was covered and the next steps—and ask the patient for feedback. The value of this brief negotiation and joint agreement, even though it takes a minute, is to set expectations for both the patient and physician about what can be done in the time available for that visit. It can also help the physician avoid encountering new, important, and complex questions at the very end of the visit.

2. Learn About the Patient's Views of the Illness

While this is not a standard history question, it can be extremely useful to ask a question about how the patient views his/her illness.³⁰ For example, "I know you've heard about it from other doctors, but tell me what you think is going on with your cancer?" This can provide data about the patient's understanding, his/her ways of coping, and the meaning of the illness. This can help the physician use time efficiently by customizing the discussion to the needs of the patient.

3. Ask About the Patient As a Person

A variety of empirical studies indicate that patients place considerable importance on the feeling of being treated like a whole person. While it is impossible for physicians to learn everything about a patient in the first visit, it is often easy in the course of a visit to explore something about a patient's life outside the clinic or hospital: "Tell me about yourself so I can begin to get to know you."³¹ This can function as an invitation to a richer relationship.

4. Express Your Interest in Improving the Patient's Well-being

While it is easy to assume that patients know you are working on their behalf, it is nonetheless important to state explicitly your intention to provide the best care possible. Being explicit helps align you with the patient and family and sends a clear message about your commitment.^{32,33}

5. Discuss Ways That Patients Can Participate in Their Own Care

Although many patients are interested in what they can do to participate in their care,³⁴ physicians can be hesitant to make requests of patients undergoing a course of anticancer therapy. One way of viewing the physician-patient relationship is a partnership in which both parties need to participate in different ways.

Giving Bad News

This is perhaps the communication task that has been studied the most extensively.³⁵ Bad news can be defined as any information that adversely alters one's expectations for the future. Oncologists give bad news thousands of times during the course of a career and it can be highly stressful. In a large survey of oncologists, 20% reported anxiety and strong emotions when they had to tell a patient that their condition would lead to death.¹² In a more detailed study of 73 physicians, 42% indicated that, despite the fact that the stress often peaks during the encounter, the stress from a bad news encounter can last for hours—even up to three or more days afterward.³⁶ Giving bad news is more difficult when the clinician has a long-standing relationship with the patient, when the patient is young, or when strong optimism had been expressed for a successful outcome. On the other hand, when bad news is communicated in an empathic manner, it can have an important impact on outcomes such as patient satisfaction and decreased patient anxiety and depression; and the physician's caring attitude can be more important than the information or reassurance given.³⁷ As with any medical procedure, giving bad news requires a coherent strategy in order for it to be accomplished successfully. In this case the strategy encompasses a series of six distinct communication steps, that can be summarized using the mnemonic SPIKES.³⁸ This protocol includes recommendations endorsed by practitioners and patients (Table 2).³⁹

1. Setup

Prepare yourself with the necessary medical facts, take a moment to have a plan in your mind, and find a quiet place if possible. Ask yourself how difficult it will be to have the discussion; it maybe worthwhile to have a nurse or social worker accompany you. Turn your pager off or give it to someone else so you are not interrupted. Sit down, make eye contact, and get reasonably close to the patient. Anticipate that the patient will be upset and have tissues available.

TABLE 2 Giving Bad News with SPIKES

S = Setup
P = Perception
I = Invitation
K = Knowledge
E = Empathize
S = Summarize and strategize

2. Perception

Find out the patient's perception of the medical situation. What has he/she been told about the disease? What does he/she know about the purpose of the unfavorable test results you are about to discuss? If this is a first contact, what has he/she been told about why he/she should see you in referral? What are his/her expectations of treatment? What are his/her goals? Correct any misconceptions or misunderstandings the patient may have. Note any strong denial or its mimics (eg, avoidance of topics or excessive optimism).

3. Invitation

Find out how much information the patient wants. These days most patients want a lot of information but this is not universally true, especially as the disease progresses and patients may want to focus on "What do we do next?"

4. Knowledge

Use language that matches the patient's level of education. Be direct. Avoid using jargon as it will confuse the patient. Give a warning that bad news is coming: "I have some serious news to tell you." This will allow the patient to prepare psychologically. If the patient's perception (step 2) was inaccurate, review pertinent information: "Now you remember we sent you for the MRI to assess how the chemo was working? Well, what we found is that the chemo has not worked. The tumor has grown larger." After giving this news, stay quiet for at least 10 to 15 seconds—resist the urge to tell the patient how to feel. Give the patient time to absorb the information and respond.

5. Empathize

Use empathic statements to respond to patient emotions. This will assist in patient recovery and dampen the psychological isolation that the patient experiences when they hear the bad news. If a patient begins to cry, remember NURSE and use an empathic response such as, “I know that this must be disappointing for you.” Resist the temptation to make things better; for example, rushing to propose a treatment that is unlikely to work. This kind of response can be a reaction to your own sense of helplessness and perhaps of failure. Ask if the patient has questions or concerns and keep asking until he/she says no.

6. Summarize and Strategize

Summarize the clinical information and make a plan for the next step, which may be further testing or discussion of treatment options. Be as concrete as possible and check on the patient’s understanding of what has been discussed: “Does this make sense to you?” “Are you clear about the next steps?”

Making Anticancer Treatment Decisions

A number of empirical studies demonstrate that patients are interested in having some role in decision making; the question is, what kind of role does the patient wish to have? Table 3 describes a spectrum of different types of patient involvement in decision making according to five different theoretical models, from paternalism to consumerism.⁴⁰ As the data from this study involving 999 women with early breast cancer indicate, most patients desire some decision-making role for both patient and physician, and a majority prefer shared decision making. One of the reasons for patient interest in the Internet for medical information is to enable them to verify treatment options they are offered and to check about options that were not offered.⁴¹ Shared decision making does not have to take more time and is associated with greater patient satisfaction. How can it be put into practice?

TABLE 3 Preferences for Medical Decision Making of 999 Women with Breast Cancer

Theoretical Model	Decision Making Process	Percentage
Paternalistic	Physician makes decisions	18
Physician as agent	Physician makes decisions after considering patient input	17
Shared decision making	Physician and patient make decision together	44
Informed decision making	Patient makes decisions after considering physician input	14
Consumerism	Patient makes decisions	9

1. Elicit Patient Preferences for Information and Decision Making

This can be done with a couple of questions: “Are you the kind of person who wants to hear all the information, both good and bad, about this illness? People vary in how they want to make medical decisions. Some people want to make the decisions themselves, some people want to share decision making with the doctor, and some people want the doctor to make the decisions. Where do you stand?”

2. Identify the Choice To Be Made

A common pitfall for physicians is to launch into an explanation of a treatment before identifying the choices that the patient is dealing with. Providing the patient with a roadmap of the conversation in a sentence or two can give a sense of what lies ahead. “There are basically two different treatment options for us to consider for metastatic pancreatic cancer. I’ll tell you what they are before I describe them in more detail. Then you can ask any questions you might have. The first option is...”

3. Describe Treatment Options and Confirm Understanding

Most patients say that they want all available information, and many clinicians say that they observe patients becoming overwhelmed during the course of a visit about treatment op-

tions. It is useful to give information in small chunks (a useful rule of thumb is to give no more than three pieces of information at a time) and check patient understanding: "Are you following me?" or "Did that make sense to you?" This allows the physician to titrate the amount of information that can be covered in a particular visit. Confirming understanding can also enable the physician to correct misperceptions or inaccuracies. Since emotions can shape perceptions and decision making, it is useful to respond empathetically to the patient's emotions: "It sounds like this information is different from what you expected, and I think it would be upsetting for anyone."

Reinforce accurate understanding: "I agree that Option 1 would be the roughest in terms of side effects." If necessary, add further information as relevant to ensure that patient's thinking is medically accurate and expectations are reasonable: "Well, let me say more about Option 2. The oral chemo is easier to take but it does not shrink the cancer as often as the IV chemo."

Offer to give numerical information: "Are you the kind of person who likes to hear all the numbers?" If the patient says yes, then continue: "The IV chemo will shrink the cancer for about two out of three cases, and in one of three cases the cancer will not shrink and may even grow despite chemo." Notice that this statement is double-framed—the doctor has mentioned both how often the cancer responds and how often it does not respond.

Offer to talk about prognosis: "Some patients want to know how much longer they have to live. Is that something you want to talk about?" If yes, respond with something like, "Well, we know that for patients who have this kind of cancer, if they have the chemo, they live from months to a year, and on rare occasions, somewhat longer. If they choose not to have the chemo, they live for a few weeks."

4. Discuss How the Patient's Values and Concerns Relate to the Treatment Options

For patients who want the physician to take a role in decision making, it is useful to step

back and relate the biomedical information to the patient's larger values and concerns. "Now could we step back for a minute—I'd like to know whether you have a sense of how these treatment options relate to the concern you mentioned earlier about 'not wanting to end up like your aunt.'" Or the physician can simply ask for the patient's reaction: "What's your reaction to all this?" Increasing physician participation in the conversation is an effective way to increase patient satisfaction.²²

5. Offer to Make a Personal Recommendation

Because trust in the physician is a significant issue in treatment choice,⁴² it is worth offering a personalized recommendation based on medical expertise and knowledge of the patients' values and concerns. Even if the patient wishes to make the decision himself, this recommendation can be framed as another piece of data, the judgment of an experienced clinician: "Would you like to hear my recommendation at this point?" If the patient answers yes: "Based on what I've heard from you so far, the most important consideration for you is quality of life, and you're concerned about the side effects of the chemo, especially if it does not work. But you are also concerned about wanting to be present for your daughter's graduation in 4 months. So I think for you it would be worth giving the IV chemo a try, knowing that you could stop if the side effects are too much. What do you think about that?"

6. Negotiate a Timeframe for the Decision

Ask how much time the patient needs to finish making a decision. Ask what other family members or friends the patient may want to talk with during the decision-making process. Ask if any other information would assist them in decision making. When the patient decides on a time frame (eg, "I'll come back in two days and tell you"), verify that the time frame is reasonable. If the patient's proposed time frame is not clinically practical (eg, two days for a patient in the ICU when you need a decision in the next two hours), ask for the reason underlying the patient's time frame decision,

show you understand the reason, but state the reason why the time frame is not practical and suggest an alternative that incorporates their preferences to some degree.

Offering Clinical Trials

The empirical studies that have been done on clinician communication with patients about clinical trials describe a wide variation in how physicians talk about research, and there are no studies yet that correlate physician presentation with patient willingness to participate or even patient understanding. Ethicists emphasize that informed consent is a process, yet little research has addressed how physicians can guide the process. Although patients indicate they are interested in a high level of information,⁴³ it is also clear that many patients and families leave conversations with a poor understanding of clinical trial characteristics such as randomization.⁴⁴ The possibility of clinical trial participation usually occurs when physicians and patients are discussing treatment options. Thus these recommendations build on the preceding recommendations about discussing treatment options.

1. When Introducing the Treatment Options, Describe the Clinical Trial as One of the Treatment Options

In creating a roadmap for the conversation as described in the section earlier, the clinical trial should be mentioned alongside standard treatment: “There are three different treatment options for us to consider for metastatic pancreatic cancer. I’ll tell you what they are before I describe them in more detail. Then you can ask any questions you might have. The first option is chemotherapy intended to slow the growth of the cancer. The second option is a clinical trial of a new medicine intended to slow the growth of the cancer (a Phase II trial). The third option is supportive and palliative care without anticancer therapy. While supportive care will be part of any treatment plan, at times we focus completely on quality of life.” The clinical trial can be described as an alternative to the “best therapy we currently know”—ie, standard therapy.

2. When Talking About the Clinical Trial Option, Ask About the Patient’s Perception of Research and Clinical Trials

In the same way that eliciting a patient’s perception of his/her illness helps a physician individualize communication, eliciting the patient’s perception of research can help a physician improve patient understanding of a clinical trial: “I was wondering if you have ever thought about being in a research study like a clinical trial? Could you tell me your thoughts and concerns, if you have any?” These concerns, which in studies range from patient concerns about harm, patient interest in the latest treatments, patient difficulties with practical logistical issues such as transportation, and patient concerns about trust in research, are important to get on the table for discussion.

3. Make It Clear That Opting for a Clinical Trial Is Something That the Patient Needs to Actively Choose

Prepare the patient for participating in research: “Being in a clinical trial is a little bit different from receiving one of the treatments that are part of standard care. You will need to actively choose to be in a trial, and part of this is reading and signing consent forms that are more involved than if you were being treated with the best-known treatments not on a clinical trial. The consent forms will go through the possible benefits and possible risks in considerable detail. If the trial involves randomization, make it clear that in this type of trial neither the patient nor the patient’s personal physician selects the exact treatment.

4. Describe How a Patient Can Withdraw from the Clinical Trial

One of the fundamental things that a patient who is a potential research subject needs to understand is the right to withdraw from the trial at any time for any reason. “It’s important to know that you can withdraw from the clinical trial at any time, and for any reason. You just need to tell us that you would like to

withdraw.” However, for many oncologic clinical trials, there may be treatment side effects that linger, and in some types of research (ie, stem cell transplants) it may not be possible to simply withdraw. In these cases, the consequences of withdrawing early need to be explained.

5. Discuss How the Patient's Medical Care Will Be Transitioned at the End of the Trial, or If He/She Withdraws

When a patient is seeing a physician specifically because of an available clinical trial, that physician should discuss how medical care will be transferred back to the patient's primary oncologist or physician after the participation in the clinical trial has ended or if the patient withdraws.

Completing Anticancer Therapy Given with Curative Intent

The end of a planned course of anticancer therapy is a source of ambivalent feelings for many patients. While it is a relief to be finished with anticancer therapy and its side effects, many patients also worry about not being watched as carefully, losing the support of their medical providers, and cancer regrowth if chemotherapy is no longer ongoing. In addition, as patients begin to resume activities that have been on hold, they often discover new concerns that they are unprepared to deal with, including sexual concerns and economic consequences of being out of work.

1. Acknowledge the Patient's Contribution to the Treatment

It is hard work at many levels to complete a course of anticancer therapy, and it is important for physicians to recognize the effort, sacrifice, and hard work that patients put into their anticancer therapy. “Congratulations! You have really worked hard and dealt with a lot to get to this point, and I appreciate your cooperation. I think you have done a great job.”

2. Invite Any Concerns That Might Be Related to Finishing Anticancer Therapy

This could start with a normalizing statement: “Many patients tell me that while they are excited to be done, they also have concerns about finishing. Do you have any concerns that you want to talk about?” Or: “Some patients wonder if their cancer could return and I was wondering if that is something you'd like to talk about.” Respond empathetically to emotional concerns using NURSE.

3. Discuss a Concrete Follow-up Plan

For patients to cooperate with a follow-up plan, they need to understand what the plan consists of and the rationale. This may require discussion of tests that are not being done routinely as much as discussion of tests that will be done: “I recommend that you return to clinic every three months for the first year, with the following tests..., and every six months after that.”

4. Mention the Possibility of Survivorship Issues and Useful Resources

The physician could say: “Many patients find that they are dealing with issues related to being a cancer survivor at some point after they finish their treatment. One useful resource that I think is good is the National Coalition for Cancer Survivorship (www.canceradvocacy.org). They have some programs specifically designed for survivors. Also know that you can call us back anytime if you have concerns.”

Discontinuing Palliative Chemotherapy in the Setting of End-of-Life Care

In the context of an ongoing clinician-patient relationship, palliative care issues can become part of an ongoing dialogue and early discussion can facilitate symptom control, decision making, and opportunities for life closure.^{45,46} Yet one of the most challenging tasks faced by oncologists is talking to a patient with a life-threatening cancer about discontinuing palliative chemotherapy that has proven itself

to be ineffective. Although this is well known to oncologists as a challenge, there has been little empirical study of this task, perhaps because of the difficulty of capturing these conversations.

This section is not meant to imply that Phase I or Phase II clinical trials are not worth offering. We support the importance of Phase I and Phase II clinical trials and feel they have an important place in the cancer therapeutic regimen. We also are aware of data that indicate that patients generally enter Phase I trials because they hope to benefit, even if the physician, discussions, and consent form all say that the trial is designed to benefit other, future patients.

Studies suggest that oncologists lacking communication skills training are more likely to prescribe third- and fourth-line chemotherapy,¹² and there is a substantial volume of chemotherapy given in the US outside standard indications, even in the last three months of life.⁴⁷ When oncologists discuss the possibility of discontinuing chemotherapy, they often have feelings of guilt and failure that they were unable to rescue the patient from impending death.⁴⁸ Patients and their families may inadvertently worsen oncologists' feelings of guilt by saying, "Isn't there something you can do?"

1. When Starting Palliative Chemotherapy, Explicitly Discuss How Progress Will Be Evaluated and the Criteria for Continuing or Discontinuing Chemotherapy

Framing palliative chemotherapy up front as a therapeutic trial can be a helpful tool. Rather than focusing strictly on benefits and risks, this discussion would also talk about how progress will be evaluated, when this evaluation will occur, and what will happen as a result. "We will repeat your CT scan after two months of chemotherapy. If the CT shows that the cancer is shrinking, we will continue the chemotherapy at that point for at least two more months. If the CT shows that the cancer is growing larger, we will stop the chemotherapy."

In preparing patients for the time when palliative chemotherapy will be discontinued, it is

worth mentioning that if a patient is not receiving anticancer benefit, they are nonetheless receiving all the toxic side effects. It may also be worth mentioning that palliative chemotherapy regimens have not been documented to be of benefit for patients whose performance status is 3 or 4, and that for those patients cytotoxic chemotherapy may hasten death rather than prolong life.

2. Discuss Clinical Evidence That Indicates Treatment Failure

This may require a bad news conversation (see earlier section), although the perception step may focus more on the patient's expectations regarding reevaluation—they may not recall the conversation described above. It is important to work with their perception in that moment rather than remind them and quiz them about a conversation that happened two or more months previously.

3. Step Back to Address "The Big Picture" by Using Questions That Elicit Patient Values

Here we recommend that the physician specifically direct the patient into a conversation about values and goals before going to the issue of what next (Table 4): "In short, it looks like the chemotherapy has not been working. So now I would like to step back for a minute and talk about the big picture. Given this situation, which I know you're disappointed about, what is most important to you now?" Other useful questions to elicit patient values include: "What is your life like outside the clinic (or hospital)?" "What are your biggest concerns right now?" "What do you enjoy doing? How can we help you do more of that?" or "When you think about the future, what concerns you the most?"

TABLE 4 Key Questions to Elicit Patient Values When Initiating Discussions About Palliative Care

<p>What do you enjoy doing now? What is life like outside the hospital/clinic? What is most important to you right now? What is the hardest part of this for you and your family? When you think about the future, what concerns you most?</p>
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For patients who respond that the most important thing is to “live as long as possible,” one potential response is to talk about how further chemotherapy at this point would do more harm than good. For patients who respond that the most important thing is to “have more chemotherapy,” a potential response is to ask, “If that is not possible, what would be the next most important thing?”

Some patients have not previously thought about these issues and aren't ready to articulate them. Those patients may simply need some space and silence within your conversation so they can think, and allowing silence is important. In some instances, after silence has passed, patients may still be at a loss and you may want to volunteer important patient values. A qualitative interview study identified important qualities of end-of-life care that can be useful to suggest to patients who are stuck: “We know from studies of patients that there are some things that most people are concerned about. These things are: (1) good pain and symptom control; (2) strengthening relationships with loved ones; (3) relieving burden on family; (4) achieving a sense of control; (5) avoiding inappropriate prolongation of dying.”⁴⁹

4. Respond to Patient Emotion and Acknowledge Loss

In the setting of advanced cancer, it is particularly important to acknowledge patient losses, which may include dreams, hopes, and functional abilities. Having a clinician acknowledge loss can reassure patients that their loss was important and worth grieving. Disregarding loss or failing to acknowledge it can send an inadvertent message that the patient's concerns are unimportant. There is a tendency among oncologists to respond to patient distress with more chemotherapy. Yet using the tools we have discussed above for responding empathetically, it is possible to distinguish and deal with sadness, grief, anger, and worry without fixing these emotions. Clinicians can make it clear that they will support and accept patients and their emotions during difficult times.

Both patients and clinicians are concerned about supporting patient hope, and in our opinion it is possible for clinicians to discuss hopes throughout the course of treatment⁵⁰ and also to acknowledge hopes without necessarily endorsing them. Using “I wish” statements can be a useful tool to acknowledge what patients are hoping for and align with their hopes and also acknowledge that their hopes cannot be fulfilled (Table 5).⁵¹ For example, an oncologist might say “I wish I had a kind of chemotherapy that could cure this metastatic cancer.”

5. Propose a New Care Plan Based on the Patient's Values and Goals

By using the patient's own values and goals, it is possible to align with them even without providing more chemotherapy. “So based on your goal of wanting to stay at home as much as possible so you have time to spend with your family and friends, I propose that we do the following...” Make a recommendation about things that will be done first, and mention things that will not be done, including palliative chemotherapy, afterward. The things to be done might include hospice; the things that will not be done might also include CPR and mechanical ventilation.

If patients and/or family members request treatment that you feel is futile, physicians may feel that their competence or judgment is not trusted. More often these requests are generated by patients' feelings of desperation, com-

TABLE 5 Difficult Questions and Responses That Acknowledge Underlying Emotions

Question	Response
“How long do I have to live?”	“I wonder if it is frightening not knowing what will happen next, or when.”
“Does this mean you're giving up on him?”	“Absolutely not. But tell me, what do you mean by giving up?”
“Are you telling me that I am going to die?”	“I wish that were not the case, but it is likely in the near future. I am also asking, how would you want to spend the remaining time if it were limited?”

plex family relationships, or family dynamics. It is worth thinking through a “differential diagnosis” of what is going on with a given patient and family.⁵² Finally, we note that while most requests for futile therapy can be addressed by understanding patient and family concerns—especially emotional concerns—we also recognize that a small number of these requests are persistent and go beyond a communication issue. In those cases, we suggest talking to an ethics committee, palliative care service, or other resources for negotiation in your health system.

6. Propose a Time to Follow Up and Reassess This New Plan

This will make it clear that the oncologist deals with the patient, not simply the chemotherapy, and will reassure patients and family that there will be more time in the future to deal with difficult issues. “So let’s try this for a month. I’d like to see you back in the clinic after a month, and see how things are going.” This follow-up is useful to offer even if the patient will be seen by hospice in the interim because it makes it clear that the physician is not abandoning the patient when chemotherapy is no longer the treatment of choice.

OTHER IMPORTANT ISSUES

Other important communication skills include supporting hope,⁵⁰ dealing with cultural diversity,^{53–55} responding to requests for hastening death,^{56,57} dealing with family members,⁵⁸ and talking about spiritual issues.⁵⁹ From the patient’s perspective, palliative and supportive care issues throughout the course of the cancer trajectory have now been addressed in a book for patients and family members.⁶⁰

CONCLUSION

In this article, we have provided a guide for improving communication, a kind of cognitive road map for clinicians. We have used the empirical literature where it is available and recognize that substantial research needs to be done to expand the evidence base for these recommendations. We also recognize that improving communication skills is much easier in the context of educational programs that provide protected time for focusing on these skills and constructive feedback. Our hope is that many more of these educational opportunities will be available for clinicians in oncology in the future.

REFERENCES

- Maguire P, Faulkner A, Booth K, et al. Helping cancer patients disclose their concerns. *Eur J Cancer* 1996;32:78–81.
- Derogatis LR, Morrow GR, Fetting J, et al. The prevalence of psychiatric disorders among cancer patients. *JAMA* 1983;249:751–757.
- Cherny NI, Coyle N, Foley KM. Suffering in the advanced cancer patient: a definition and taxonomy. *J Palliat Care* 1994;10:57–70.
- Ford S, Fallowfield L, Lewis S. Doctor-patient interactions in oncology. *Soc Sci Med* 1996;42:1511–1519.
- Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer* 1994;70:767–770.
- Wenrich MD, Curtis JR, Ambrozy DA, et al. Dying patients’ need for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families, and health care providers. *J Pain Symptom Manage* 2003;25:236–246.
- Cleeland CS. The impact of pain on the patient with cancer. *Cancer* 1984;54(11 Suppl):2635–2641.
- Cleeland CS, Gonin R, Hatfield AK, et al. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 1994;330:592–596.
- Coyle N, Adelhardt J, Foley KM, Portenoy RK. Character of terminal illness in the advanced cancer patient: pain and other symptoms during the last four weeks of life. *J Pain Symptom Manage* 1990;5:83–93.
- McCarthy EP, Phillips RS, Zhong Z, et al. Dying with cancer: patients’ function, symptoms, and care preferences as death approaches. *J Am Geriatr Soc* 2000;48:S110–121.
- Cancer care during the last phase of life. *J Clin Oncol* 1998;16:1986–1996.
- Foley KM, Gelband H. *Improving Palliative Care for Cancer: Summary and Recommendations*. Washington DC: National Academy Press; 2001.
- Davis D, O’Brien MA, Freemantle N, et al. Impact of formal continuing medical education: do conferences, workshops, rounds, and other traditional continuing education activities change physician behavior or health care outcomes? *JAMA* 1999;282:867–874.
- Fallowfield L, Lipkin M, Hall A. Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom. *J Clin Oncol* 1998;16:1961–1968.
- Back AL, Arnold RM, Tulsky JA, et al. Teaching communication skills to medical oncology fellows. *J Clin Oncol* 2003;21:2433–2436.
- Maguire P, Pitceathly C. Key communication skills and how to acquire them. *BMJ* 2002;325:697–700.
- Razavi D, Delvaux N, Hopwood P. Improving communication with cancer patients. A challenge for physicians. *Ann N Y Acad Sci* 1997;809:350–360.
- Razavi D, Merckaert I, Marchal S, et al. How to optimize physicians’ communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. *J Clin Oncol* 2003;21:3141–3149.
- Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or careers. *Cochrane Database Syst Rev* 2004;CD003751.

20. Graham J, Potts HW, Ramirez AJ. Stress and burnout in doctors. *Lancet* 2002;360:1975-1976.
21. Ramirez AJ, Graham J, Richards MA, et al. Burnout and psychiatric disorder among cancer clinicians. *Br J Cancer* Jun 1995; 71:1263-1269.
22. Siminoff LA, Ravdin P, Colabianchi N, Sturm CM. Doctor-patient communication patterns in breast cancer adjuvant therapy discussions. *Health Expect* 2000;3:26-36.
23. The AM, Hak T, Koeter G, van Der Wal G1. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000;321:1376-1381.
24. Faulkner A, Maguire P. *Talking to Cancer Patients and their Relatives*. Oxford: Oxford University Press; 1994.
25. Stone D, Patton B, Heen S. *Difficult Conversations: How to Discuss What Matters Most*. New York: Viking; 2000.
26. Silverman J, Kurtz S, Draper J. *Skills for Communicating with Patients*. Abingdon Oxon, UK: Radcliffe Medical Press; 1998.
27. Smith RC. *Patient-centered interviewing: an evidence-based method*. Philadelphia: Lippincott Williams & Wilkins; 2002.
28. Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview. *JAMA* 1997;277:678-682.
29. White J, Levinson W, Roter D. "Oh, by the way...": the closing moments of the medical visit. *J Gen Intern Med* 1994;9:24-28.
30. Roter D. Patient-centered communication. *BMJ* 2004;328:E303-E304.
31. Platt FW, Gaspar DL, Coulehan JL, et al. "Tell me about yourself": The patient-centered interview. *Ann Intern Med* 2001;134:1079-1085.
32. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med* 1995;122:368-374.
33. Crawshaw R, Rogers DE, Pellegrino ED, et al. Patient-physician covenant. *JAMA* 1995;273:1553.
34. Sharp L, Laurell G, Tiblom Y, et al. Care diaries: a way of increasing head and neck cancer patient's involvement in their own care and the communication between clinicians. *Cancer Nurs* 2004;27:119-126.
35. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. *JAMA* 1996;276: 496-502.
36. Ptacek JT, Ptacek JJ, Ellison NM. "I'm sorry to tell you..." Physicians' reports of breaking bad news. *J Behav Med* 2001;24:205-217.
37. Roberts CS, Cox CE, Reintgen DS, et al. Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer* 1994;74:336-341.
38. Baile WF, Buckman R, Lenzi R, et al. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302-311.
39. Girgis A, Sanson-Fisher RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Oncol* 1995;13:2449-2456.
40. Lee SJ, Back AL, Block SD, Stewart SK. Enhancing physician-patient communication. *Hematology* 2002;464-483.
41. Ziebland S, Chapple A, Dumelow C, et al. How the internet affects patients' experience of cancer: a qualitative study. *BMJ* 2004;328:564.
42. Daugherty C, Ratain MJ, Grochowski E, et al. Perceptions of cancer patients and their physicians involved in phase I trials. *J Clin Oncol* 1995;13:1062-1072.
43. Sorensen JB, Rossel P, Holm S. Patient-physician communication concerning participation in cancer chemotherapy trials. *Br J Cancer* 2004;90:328-332.
44. Kodish E, Eder M, Noll RB, et al. Communication of randomization in childhood leukemia trials. *JAMA* 2004;291:470-475.
45. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". *JAMA* 2000;284:2502-2507.
46. Lo B, Quill T, Tulsky J. Discussing palliative care with patients. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine. *Ann Intern Med* 1999;130:744-749.
47. Emanuel EJ, Young-Xu Y, Levinsky NG, et al. Chemotherapy use among Medicare beneficiaries at the end of life. *Ann Intern Med* 2003;138:639-643.
48. Baile WF, Globler GA, Lenzi R, et al. Discussing disease progression and end-of-life decisions. *Oncology* 1999;13:1021-1031.
49. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;281:163-168.
50. Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. *Ann Intern Med* 2003;138:439-443.
51. Quill TE, Arnold RM, Platt F. "I wish things were different": expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med* 2001;135:551-555.
52. Goold SD, Williams B, Arnold RM. Conflicts regarding decisions to limit treatment: a differential diagnosis. *JAMA* 2000;283:909-914.
53. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "You got to go where he lives". *JAMA* 2001;286:2993-3001.
54. Kagawa-Singer M, Kassim-Lakha S. A strategy to reduce cross-cultural miscommunication and increase the likelihood of improving health outcomes. *Acad Med* 2003;78:577-587.
55. Crawley LM, Marshall PA, Lo B, Koenig BA. Strategies for culturally effective end-of-life care. *Ann Intern Med* 2002;136:673-679.
56. Back AL, Starks H, Hsu C, et al. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med* 2002;162:1257-1265.
57. Quill TE, Lee BC, Nunn S. Palliative treatments of last resort: choosing the least harmful alternative. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med* 2000;132:488-493.
58. Speice J, Harkness J, Laneri H, et al. Involving family members in cancer care: focus group considerations of patients and oncological providers. *Psychooncology* 2000;9:101-112.
59. Lo B, Ruston D, Kates LW, et al. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. *JAMA* 2002; 287:749-754.
60. Foley K, Back AL, Bruera E, et al. *When the Focus is on Care: Palliative Care and Cancer*. Atlanta, GA: American Cancer Society; 2004.