

Communication About Cancer Near the End of Life

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Cancer communication near the end of life has a growing evidence base, and requires clinicians to draw on a distinct set of communication skills. Patients with advanced and incurable cancers are dealing with the emotional impact of a life-limiting illness, treatment decisions that are complex and frequently involve consideration of clinical trials, and the challenges of sustaining hope while also having realistic goals. In this review, the authors sought to provide a guide to important evidence about communication for patients with advanced cancer regarding communication at diagnosis, discussing prognosis, decision making about palliative anticancer therapy and phase 1 trials, advance care planning, transitions in focus from anticancer to palliative care, and preparing patients and families for dying and death. *Cancer* 2008;113(7 suppl):1897-910. © 2008 American Cancer Society.

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Cancer communication near the end of life has a growing evidence base, and requires clinicians to draw on a distinct set of communication skills. The recent National Cancer Institute monograph on Patient-Centered Communication in Cancer Care identified 6 functions of patient-clinician communication: exchanging information, making decisions, fostering healing relationships, enabling patient self-management, managing uncertainty, and responding to emotions.¹ Whereas these communication functions shape communication for all patients with cancer, special skills are required for the subset of patients with advanced and incurable cancer who must face death more squarely.²

These patients, with advanced and incurable cancers, are dealing with the emotional impact of a life-limiting illness, treatment decisions that are complex and frequently involve consideration of clinical trials, and the challenges of sustaining hope while also having realistic goals. The clinicians must establish a therapeutic relationship based on trust and mutual respect with patients who often access a great deal of medical information, come from culturally diverse backgrounds, have various levels of social support, and confront the existential and spiritual aspects of dying, all while trying to access complicated healthcare systems.^{3,4} Because new therapeutic technologies enable these patients to live longer with cancer than ever before, the communication challenges faced by oncology clinicians have become ever more complex, involving uncertainty, hope,

TABLE 1
Core Communication Skills

Recommended Skill	Example
I. Identifying Concerns and Recognizing Cues	
Elicit concerns	
Open-ended questions	"Is there anything you wanted to talk to me about today?"
Active listening	Allowing patient to speak without interruption; allowing pauses to encourage patient to speak
Recognize cues	
Informational concerns	Patient: "I'm not sure about the treatment options"
Emotional concerns	Patient: "I'm worried about that"
II. Responding to Informational Concerns	
"Ask-Tell-Ask"	Topic: communicating information about cancer stage
Ask	"Have any of the other doctors talked about what stage this cancer is?"
Tell	"That's right, this is a Stage IV cancer, which is also called metastatic cancer. . ."
Ask	"Do you have questions about the staging?"
III. Responding to Emotional Concerns	
Nonverbal empathy: S-O-L-E-R	
S	Face the patient SQUARELY
O	Adopt an OPEN body posture
L	Lean towards the patient
E	Use EYE contact
R	Maintain a RELAXED body posture
Verbal empathy: N-U-R-S-E	
N	NAME the emotion: "You seem worried"
U	UNDERSTAND the emotion: "I see why you are concerned about this"
R	RESPECT the emotion: "You have shown a lot of strength"
S	SUPPORT the patient: "I want you to know that I will still be your doctor whether you have chemotherapy or not"
E	EXPLORE the emotion: "Tell me more about what is worrying you"

and widely available anecdotes of patients who "beat the odds" available on the Internet and in books.

In this review, we sought to provide a guide to important evidence and best practices about communication for patients with advanced cancer who face life-limiting illness. Because the state of the science has produced few controlled trials, this narrative review also includes relevant observational, survey, and qualitative studies. We have framed the data from the point of view of oncology clinicians who often have relationships with patients that span the trajectory of the illness. Thus we have divided the review into sections relevant to practicing clinicians: core communication skills; communication at diagnosis, discussing prognosis, decision making about palliative anticancer therapy and phase 1 trials, advance care planning, transitions to palliative care, and preparing patients and families for dying and death.

Core Communication Skills

Patient concerns have both informational and emotional components, so patients need both information and emotional support to resolve their concerns.

They look to their oncologist for both.⁵⁻⁷ When these concerns are not resolved, they lead to psychological distress and affective disorders.⁸ Introductions help set the stage for a therapeutic alliance.⁹ Core communication skills enable clinicians to elicit concerns and consequently provide more effective and compassionate care (Table 1).

Identifying concerns: eliciting concerns and recognizing cues

For an oncologist to address a patient's information and emotional concerns, the concerns must first be disclosed to and recognized by the oncologist. This occurs in 2 ways: the provider eliciting the concerns from the patient, or the patient spontaneously giving cues about their concerns. Although patients want to talk about their concerns with their oncologist, whether they disclose their concerns depends on how their oncologists communicate with them.^{10,11} Certain provider behaviors have been shown to elicit these concerns: open-ended questions, allowing more time for patients to speak, and empathy (Table 1).¹²⁻¹⁵ Open questions such as "How are you doing with all of this?" or "Is there something else

you'd like to talk about today?"¹⁶ let patients know that their physician will be willing to listen. Patients also give "cues" to providers about their concerns, for example, "I'm not sure what the treatment options are" (cue for information) or "That's 1 thing I have as a big fear" (cue for emotional exploration and support).^{17,18} Physicians tend to focus communication on biomedical topics, and often do not elicit or recognize cues about emotional and psychosocial concerns.¹⁹⁻²¹ Although other factors influence whether patients disclose,¹⁰ oncologist inquiry is an important first step.

Responding to informational concerns: Ask-Tell-Ask

Patients need information about their illness and how it will affect them.²² They use this information to plan for the future and to make medical and life decisions.^{23,24} They want their physician to be honest and realistic in giving information while being sensitive to what information they are ready to hear and how it is affecting them.^{25,26} They want to negotiate when and how information is given, but don't want a greater amount of detail than they are ready to hear.²⁶ They want their oncologist to be open to discussing sensitive topics such as dying, but don't want to be forced to talk about it before they are ready.

The Ask-Tell-Ask technique ensures that the physician: 1) gives information slowly enough to ensure that the patient understands, and 2) remains sensitive to the effect the information is having on the patient and does not give too much information.²⁷ This is accomplished by the oncologist bracketing each piece of information she gives with questions to check understanding and the impact on the patient (Table 1).

Responding to Emotional Concerns: Empathy

The stress of cancer and its treatment are often associated with intense negative emotions: sadness, fear, and anger. Although oncologists often cannot "fix" the causes of these emotions, empirical studies indicate that providing emotional support ameliorates distress. Patients are emotionally supported when their physician shows care for them as a person, by spending enough time with them, allowing them to ask questions, and listening to their concerns.²⁵ Providers can show emotional support by listening and using specific language that expresses empathy, which is simply acknowledging the presence of a patient's emotion without trying to fix or alter it.¹⁸ For example, cancer patients whose physician addressed emotions and presented a "caring attitude" at diagnosis were less anxious a year later.²⁸ Breast cancer patients were more likely to believe the

physician cared about them and were less anxious when the physician expressed empathy.²⁹ Empathy can be expressed without significantly prolonging the time spent talking with patients; as little as 40 seconds of empathic language results in significant changes in patient's anxiety level.^{30,31}

Physicians can respond empathically to patients' expressions of emotion nonverbally and verbally. The acronym S-O-L-E-R described nonverbal expressions such as using one's body posture and facial expression to convey care about the patient and relaxation (Table 1).³² Two techniques are useful guides for expressing verbal empathy: the N-U-R-S-E acronym³³ and "I wish" statements³⁴ (Table 1).

Communication at Diagnosis: Giving Bad News

Most of the cancer communication literature on bad news focuses on diagnosis. Over the past 50 years, physician practices for disclosing the life-limiting nature of cancer has changed dramatically. In 1961, Oken showed that 88% of physicians followed a policy of not telling patients about their cancer.³⁵ The same questionnaire was repeated in 1979 by Novack and colleagues, and in a complete reversal it was found that 98% of physicians reported telling patients their diagnosis.³⁶ This cultural change outpaced training for oncologists in how to give bad news. In a survey of 500 oncologists at the 1998 American Society of Clinical Oncology meeting, only 4.8% of participants reported formal training in breaking bad news.³⁷ Training programs uncommonly use evidence-based methods to build communication skills.³⁸ Given this, it is not surprising that physicians find disclosing bad news difficult. In 1 study, 1 third of physicians reported experiencing significant stress when preparing for and delivering the bad news, and for 86% of these physicians, the stress persisted after the interaction with the patient—for 20%, more than a day.³⁹

What patients prefer when hearing bad news

Retrospective studies have identified what patients want when hearing bad news. They prefer to have bad news discussed in person, and in a private, quiet place; a physician who is able to communicate their diagnosis, prognosis, and treatment options clearly; full attention of the physician; time to ask questions; and to be given information about how the diagnosis will affect their life.^{29,40,41} Patients vary in their wish to have a family member or friend present, with some preferring to have the discussion alone. One study identified 2 factors that decreased patient satisfaction: "The physician rushed through the news," and "The physician seemed to struggle to

TABLE 2
Communication About Diagnosis: Giving Bad News

Recommendations

Find a comfortable and private place to talk
 Ask whether the patient would like to have others present
 Minimize interruptions
 Assess the patient's understanding of the situation
 Let the patient know explicitly that bad news is forthcoming
 Provide information honestly and in simple language
 Give time for questions
 Encourage patient to express emotions and respond empathically
 Check understanding
 Arrange a clear follow-up plan

find the right words."⁴² This same study correlated the following factors with greater patient satisfaction: a comfortable place, no interruptions, "physician sat close to me," "let me know that bad news was forthcoming," "took my personality and emotionality into account," and "tried to empathize with what I was feeling." Although treatment failure clearly represents another type of bad news, no studies have been performed to identify how this kind of bad news should be handled differently. However, patient preferences about disclosure vary considerably by cultural background, as well as level of assimilation.^{43,44} For example, in a survey conducted in Los Angeles, 87% of European Americans felt that a patient with metastatic cancer should be told their diagnosis; only 35% of Korean Americans agreed.⁴⁵ Worldwide, variation in disclosure of bad news is substantial.^{46,47}

Current practice in giving bad news

Physician education in bad news protocols has been widespread.⁴⁸ Although physicians generally self-assess their communication about disclosure favorably, studies of patients show gaps in what physicians think they convey and what patients actually perceive. In a Canadian study, 98% of physicians thought they had accurately described the extent of disease to their patients, but almost 1 third of patients with metastases thought their disease was localized. Similarly, although 90% of physicians reported telling the patient the intent of therapy, almost 1 third of patients being treated palliatively thought that their therapy was curative.⁴⁹

Recommendations for giving bad news

Evidence-based and best practice recommendations are summarized in Table 2. Although protocols for giving bad news have been designed and successfully taught in educational interventions,^{37,50} there are no studies that evaluate the importance of individual

steps of a protocol, compare the use of different bad news protocols, or link them to patient outcomes such as distress or anxiety after the bad news visit. In addition, despite attention to different cultural preferences in information sharing, there have been no studies to date that have examined disclosure approaches designed for patient populations with variable cultural preferences. Finally, many bad news conversations involve patients and family members, and there are no studies that have identified communication strategies for multiple participants in a bad news conversation.⁵¹

Discussing Prognostic Information

Discussing prognosis is challenging because oncologists face conflicting directives. The medical literature contains both studies that suggest that patients want and need a great deal of information disclosure, and other studies indicating that patients want to limit their discussions about poor prognoses. This mismatch has clinical consequences: a large study of patients indicated that patients with unrealistically optimistic views of their prognosis were more likely to die after intubation or cardiopulmonary resuscitation (CPR).⁵²

Patient preferences in prognostic disclosure

In surveys, the majority of patients tell researchers that, in general, they want a great deal of prognostic information. A national survey revealed that 85% of Americans want a "realistic estimate" of how long they have to live if their cancer "leads to death in less than a year."⁵³ In a British survey of 2331 cancer patients, 87% wanted "all possible information."⁵⁴

However, studies also show that a significant minority of patients want their oncologist to limit discussion of prognosis, especially when survival is limited. In an Australian study, 40% of patients wanted to negotiate when to discuss prognostic information.²² In the British survey, 5% of patients did not want to hear bad news.⁵⁴ In focus groups, patients and family members said that they did not want the oncologist to be "too blunt."²⁵

What patients want in prognostic discussions is influenced by their views on hope, cultural background, and beliefs about discussing or acknowledging how a poor prognosis impacts physiological processes. Sustaining and maintaining hope is a well-described function of the therapeutic relationship in oncology.⁵⁵ Patients articulate their interest in maintaining hope and seem to be more flexible in their formulation of hope than oncologists, who interpret hope in terms of a biological cure. However, patients and families also derive hope from interac-

tions with their oncologist even when prognostic information is unfavorable.⁵⁶ Certain cultural beliefs lead patients to believe that an explicit discussion of a poor prognosis becomes a prediction that comes true.⁵⁷ However, even when an explicit discussion is not approved, patients and families may acknowledge an impending death indirectly.⁵⁸ A randomized study showed that providing patients with a prompt list of questions led to more discussion with oncologists about prognostic information.⁵⁹

Physician practice in prognostic disclosure

Physicians describe facing a quandary in talking about prognosis with patients. Physicians are aware of their responsibility to talk about prognosis and the important role it plays in advance care planning and realistic goal setting.⁶⁰ Yet physicians also believe they are “giving a death sentence,”⁶¹ are aware that a subset of patients do not want to discuss prognosis explicitly, and are aware that their prognostic predictions often prove to be inaccurate. A descriptive study asking oncologists to describe their emotions when describing these conversations includes: “unhappy,” “unpleasant,” “frustrating,” “bothersome,” “difficult,” “hard,” “exhausting,” and “draining.”⁶²

Given these conflicting physician motivations, it is no surprise that physician behavior in disclosing prognosis is quite variable. In a study of cancer patients referred to hospice, 37% of physicians said that they would disclose a prognosis they thought was accurate, 40% would disclose a prognosis they thought was partially accurate (usually optimistic), and 23% would refrain from disclosing prognosis even if asked directly by the patient.⁶³

Physicians and patients influence each other in how much explicit discussion of prognosis occurs. Some behaviors in limiting talk about prognosis involve tacit agreements by the physician and patient, which has been well documented. For example, in a qualitative study of patients with nonsmall cell lung cancer in the Netherlands, the phenomenon of collusion was identified in which physicians did not offer prognostic information and patients did not explicitly seek it—a tacit agreement to avoid an uncomfortable topic.⁶⁴

Only limited studies examine the impact of specific communication practices on patient comprehension in the setting of advanced cancer. Interestingly, it seems to be the absence of pessimistic statements, not the presence of optimistic statements, that most significantly influences patients' perception of prognosis. In 1 study, advanced cancer patients were more likely to agree with their oncologists' estimate of prognosis if the oncologists gave a

TABLE 3
Discussing Prognostic Information

Recommendations
Ask how much prognostic information the patient wants
For patients who want explicit information, ask what kind of information (eg survival, response to treatment, ability to attend a future event)
Frame statistical information positively and also negatively (eg, by 2 years, 50% will have died, 50% will still be alive)
Offer to describe survival in a range (eg, “months to a year”) in addition to a specific period (“median survival of 1 year”)
Consider a separate conversation with a family member who wants more information (as long as the patient gives permission)
Respond to patient emotions, but do not assume that intense emotion means you should not have disclosed the prognosis
For patients who do not want explicit information, try to understand their perspective

pessimistic statement during a consultation, whereas optimistic statements did not affect agreement.⁶⁵

Recommendations for discussing prognosis

Existing evidence suggests that patients should be offered a discussion of prognosis and may be upset or disappointed on hearing the information, and that physicians should frame the information both positively and negatively. Although evidence indicates that these discussions can be difficult for physicians, there is little empirical data to indicate how physicians can prepare themselves or how they can manage the personal impact of these conversations. Similarly, little evidence exists to guide physicians in discussing prognosis with patients who do not wish to have explicit discussions, including those with cultural beliefs that discussion could be harmful. A “how much do you want to know” communication strategy has been proposed, although it has not been empirically tested (Table 3).^{66,67}

Communicating Evidence for Decision Making About Palliative Anticancer Therapy and Phase 1 Clinical Trials

Slightly different from the challenges of talking about prognosis are those challenges that oncologists face when talking about anticancer treatments with patients whose cancer has progressed despite evidence-based therapy.

Patient perceptions of palliative chemotherapy and phase 1 studies

Cancer patients have different perspectives on the benefits and burdens of chemotherapy than those without cancer. They are more willing to undergo treatments with small benefits and major toxicity, and little patient-level information is available.⁶⁸ In

addition, several studies suggest that a significant subset of patients receiving palliative chemotherapy hold misconceptions about the intent of the therapy. Specifically, these patients indicate in surveys that they believe that the therapy is intended to cure them. For example, in a study of 149 patients with incurable cancer, 45 (31%) believed their cancer was incurable, 61 (42%) were uncertain, and 39 (27%) believed their cancer was curable.⁶⁹ The limitation of such surveys is that because the actual conversation was not analyzed, it is unclear what the physician said or whether the physician allowed a misconception to persist. Thus, although these studies suggest that communication could be improved, the reasons it failed are unclear.

Studies of patients participating in phase 1 studies also suggest that oncologist-patient communication could be improved. Although the overlying long-term objective of phase 1 experimentation is to improve care, the immediate goal of the specific study is to determine the toxicity profile and, often, the maximum tolerated dose. Historically, the benefits of phase 1 participation are low, and only 5% of these participants experience clinical benefit with a median survival of 6.5 months.⁷⁰ Existing studies suggest that patients have an incomplete understanding of this reality. In a study of 328 patients surveyed after informed consent for a phase 1 trial, the median benefit expected was rated at 60%.⁷¹ In another study of 27 patients, only 33% could state the purpose of the study.⁷²

Current practice in communication about palliative chemotherapy and phase 1

Existing evidence, albeit scant, indicates that oncologists spend more time talking about the option of active anticancer therapy than the option of focusing on supportive care. In a European study of audiotaped visits, medical oncologists talked to patients with metastatic cancers in all cases, but mentioned focusing on supportive care (called “watchful waiting” in this study) in only 50% of visits (and in nearly half of these visits, oncologists said only 1 sentence about this).⁷³ In an Australian study of audiotaped consultations, most patients were told that the aim of anticancer treatment was palliative (84.7%), and that their cancer was incurable (74.6%). In this Australian study, alternatives to anticancer treatments was presented to 44.1% of patients, 36.4% were informed about how anticancer treatment would affect quality of life, and 29.7% were offered a management choice. Oncologists checked patient understanding in only 10.2% of consultations.²³ No comparable audiotape studies exist that analyze

TABLE 4
Communicating Evidence for Decision Making About Anticancer Therapy

Recommendations
Offer to discuss treatment options, impact on survival and quality of life with patients considering palliative chemotherapy
When discussing treatment options, explicitly mention the option of supportive care without anticancer therapy
For patients considering clinical trials, explicitly discuss the purpose of the trial, risks and benefits, and the patient's ability to withdraw at any time
After your discussion, check patient understanding

what physicians say when they talk about phase 1 studies with patients. Thus, although existing studies indicate that patients consenting to participate in phase 1 trials have a limited understanding of trial purpose, an unrealistic expectation of the benefits and risks associated with trial participation, and a questionable appreciation of their right to abstain or withdraw,⁷⁴ it is unclear what physicians have actually told them and how physician communication practices impact patient understanding in this specific area.

Recommendations for communication about palliative chemotherapy and phase 1 trials

Existing studies indicate that patients considering palliative chemotherapy and phase 1 trials often have an incomplete understanding in a variety of areas important to informed consent, and limited data from direct observation of physicians talking with patients suggest that physicians may not be discussing difficult issues explicitly enough for patients to completely understand. Thus we recommend that physicians use the core communication skills mentioned earlier to establish a clear idea of patient understanding of their situation, and offer to discuss key aspects including treatment options, anticipated impact on survival, and anticipated impact on quality of life (Table 4). For patients considering enrollment in a clinical trial, physicians need to prepare patients to engage in an explicit discussion of the purpose of the trial, the risks and benefits, and the patient's ability to withdraw from the trial⁷⁴—and because of the requirement of informed consent, it does not seem reasonable to allow patients to opt out of these discussions.

Advance Care Planning

Advance care planning was developed by bioethicists responding to high-profile cases of patients who wanted to discontinue life-sustaining treatments.⁷⁵ Most advance care documents address 2 broad pre-

ferences: first, a surrogate decision maker who can represent the patient's wishes if the patient loses decision-making capacity (a durable power of attorney for healthcare); and second, patient preferences about future use of specific life-sustaining therapies, such as CPR.

Patient preferences about advance care planning

Although most patients want to be involved in decisions about care at the end of their lives, and a majority of patients want physicians to initiate the discussion with them,⁷⁶ a minority of cancer patients have advance directives. Cancer patients may be reluctant to initiate discussion with oncologists because they are worried that the oncologist will "give up." In 1 study only 9% of cancer patients had talked to their oncologist about advance care plans, and only 23% of the remaining patients wished to do so—although 69% had discussed advance care plans with someone.⁷⁷ As illness progresses and functional status declines, some patients are more willing to accept life-sustaining treatments that would result in a diminished state of health.⁷⁸ Patients who use spiritual coping (eg, belief in divine intervention) are somewhat less likely to engage in advance care planning.⁷⁹ Also, patients who do not want to engage in advance care planning may be most likely to need it. In a study of 343 patients undergoing stem cell transplantation, 171 had some form of advance care planning, and failure to engage in advance care planning was associated with a significantly greater risk of death.⁸⁰

Current practice in advance care planning

Studies of living wills suggest that they have a limited effect on outcomes for patients who ultimately die of cancer. Empirical studies done examining advance directive communication highlight several deficiencies; despite data indicating that patients want their physicians to raise the issue of advance directives, physicians rarely discuss the topic with even seriously ill patients.⁸¹ When they do talk about the topic, they tend to focus narrowly on technical decisions, fail to elicit patient values, and do not clearly discuss the likelihood that the life-sustaining intervention will meaningfully prolong life. In an audiotaped study of discussions about CPR in an outpatient setting that compared experts to nonexperts, it is clear that experts communicated differently. Although this study involved primary care physicians (18 experts and 56 nonexperts), it is the only study examining expert practice around CPR discussions. The experts spent longer conducting the discussion, were less verbally dominant, and spent

TABLE 5
Advance Care Planning

Recommendations

Elicit patient values and goals relevant to medical care
 Explain why advance care planning is worth discussing
 Ask about patient perceptions of life-sustaining treatments such as cardiopulmonary resuscitation and correct misinformation
 Make recommendations about life-sustaining treatments based on the patient's goals and values in the context of the clinical situation
 Ask the patient about their reaction to the recommendations
 Note that any advance care plans can be changed in the future at the patient's discretion
 Document the discussion (in chart, POLST, etc)

POLST indicates Physician Orders for Life Sustaining Treatment.

more time on psychosocial issues and positive talk. In short, experts are more likely to discuss patient values and personal goals related to end-of-life care and to embed the CPR discussion in those discussions, rather than leading a discussion about dying with CPR.⁸²

Recommendations for advance care planning discussions

In general, discussion about advance care planning should focus more on goals of care than on specific treatments, and clinicians should be especially careful to respond to the emotional content of the discussion (Table 5).⁷⁵ The underlying principle is that the discussion should move back and forth from preferences to reasons and values to information and back, ensuring that the patient understands the implications of his or her stated preferences and that the physician understands the patients' values. Although little evidence exists to guide practice, it may be more effective for a physician to make a values-based recommendation, rather than offering a variety of choices without guidance.

Discussing Transitions in Focus From Anticancer to Palliative Care

For the purposes of this article, we define these transitions as the point when it becomes clear that disease-modifying anticancer therapy is no longer effective. These can be difficult conversations, because they provoke intense emotions from patients and families, and a sense of failure from oncologists.

Patient preferences for discussing transitions

Most patients and families want to discuss the transition to palliative care with their oncologists and report frustration when the conversations are not timely⁸³; the majority want to discuss dying and pal-

liative care with their oncologist.²² Studies also document dissatisfaction with the transition to palliative care, and cite physician's lack of knowledge and communication skills and reluctance to make referrals as barriers to effective transitions to palliative care.^{27,84-86} Other studies demonstrate that the importance of the relationship with the oncologist increases as the patient's illness progresses.⁸⁷ At the initial consult, patients want primarily cognitive information about their illness, but as early as the first follow-up visit, their preference shifts toward wanting support and reassurance, and discussing their fears and worries.⁸⁸ Thus transition discussions may span more than 1 visit. The literature identifies 3 aspects of a good discussion about the transition from curative to palliative care: clarity of information, grieving loss, and sustaining hope.

Clarity of information

Transitions often begin with a bad news conversation. In transition discussions, patients and their families want their oncologist to be sensitive to how information is affecting them, do not want a greater amount of detail than they are ready to hear, and want to be able to ask questions.^{22,26,89,90} Patients often ask about the availability and efficacy of further treatments, including alternative and complementary therapies, and prognosis when they are told that their cancer cannot be cured. Given that a subset of patients have misconceptions about the intent of palliative anticancer therapy as noted earlier, the oncologist will likely need to communicate that the cancer cannot be cured even if this has been done previously. Previously discussed recommendations for giving bad news are useful, particularly those for responding to emotion.

Grieving Loss

Qualitative studies about transitions identify loss as a central issue; when faced with a life-limiting illness, patients face the loss of family, hopes for the future, and life as they knew it.^{26,89,91-93} In survey studies, the concept of loss is captured in the category of psychosocial issues. Patients' fears and worries often focus on psychosocial and emotional issues, and in 1 study, 80% of patients wanted to discuss their family and social life with their physician.¹¹ Yet psychosocial issues were discussed 2.5 times less frequently than biomedical issues in 1 study of oncology visits.¹⁴ A focus group study indicated that patients at transitions want their oncologist to be open to talking about sensitive topics such as about dying.²⁵ However, patients often may not raise these issues unless invited to by their oncologist.^{13,94}

Because patients spontaneously express cues about their concerns (eg, "I'm worried about how this will affect my family"), oncologist responsiveness to cues using empathic communication skills is critical to building a therapeutic relationship. Experts suggest that attention to emotional cues may enable patients to more clearly understand cognitive issues such as incurability, and make clearer decisions. However, physicians often do not express empathy in response to expressions of emotion, and this blocks further discussion of the concern, possibly "training" patients not to bring these issues up in the future.^{65,90} The oncologist's commitment to face the future with the patient, sometimes called nonabandonment,⁹⁵ is especially important to express in transition discussions. Patients want to know that their oncologist will still be their physician even if they do not continue chemotherapy.^{88,92}

Physicians, as well as patients, often experience loss when a patient's disease progresses.⁹⁶ These feelings of sadness, loss, and impotence may be part of the reason that oncologists report that issues related to death and dying are so stressful for them. In addition, physicians' distress over their perceived impotence may lead them to redouble chemotherapeutic efforts. It is important for the clinician to recognize and deal with one's emotional reaction to disease progression before seeing the patient.⁹⁷

Supporting hope

Maintaining hope is essential to patients and their families at the end of life.^{26,84} Although many clinicians equate honesty about a poor prognosis with destroying hope, healthy coping continually generates hope, even in difficult life situations. Even under situations of severe stress, positive emotions are prominent, and are an integral part of the coping process.⁹⁸ Oncologists can help patients to redefine hope by exploring and reinforcing patients' hopes and talking about what can be done.²⁶

Patients and families often remain hopeful, even after they have been given a life-threatening diagnosis.^{56,99} Although many continue to hope for a miracle, or to be cured, studies show that patients also have other concurrent hopes. In an Australian study, cancer patients and healthcare providers described a spectrum of hopes: being cured, living longer, finding meaning in life, having special time with loved ones, finding spiritual meaning, and having a peaceful death.²⁶ An American study described patients' hopes for a good death: freedom from pain and other symptoms, clear decision making, preparation for death, having a sense of completion, contributing to others, affirmation of the whole person, being at

TABLE 6
Discussing Transitions From Curative to Palliative Care

Recommendations
Discuss anticancer treatment failure in a timely manner
Use bad news recommendations to establish shared understanding of the clinical situation
Be prepared to acknowledge and grieve losses
Explore hopes other than cure, support realistic hopes
Allow patients to hold private hopes and avoid attacking these hopes
Emphasize what can be done for the patient and family
Reaffirm commitment to the patient and family

peace with God, being in the presence of family, being kept clean, and trusting one's physician.¹⁰⁰

Patients want their oncologists to explore new hopes with them, to help them set realistic goals for the future, and to discuss the practicalities of day-to-day living.²⁶ Within that relationship, patients say their oncologists can nurture hope by emphasizing what can be done: pain and symptom control, emotional and practical support, having dignity, and being in a caring environment.²⁶ Common pitfalls when discussing the transition from curative to palliative care are focusing on hope for cure to the exclusion of other hopes and viewing anticancer therapies as the only thing that an oncologist can offer a patient. One empirical study focusing on the transition to hospice care, involving a survey of bereaved family members of cancer patients who had died in an inpatient hospice unit, indicated that a substantial proportion felt that communication needed to be improved and that family distress correlated with the family being told that "nothing more could be done."¹⁰¹

Recommendations for transition discussions

Although existing literature on transition discussions is largely descriptive, these studies suggest that improving communication about palliative care for cancer patients should involve a discussion of patient values, and a clear statement about nonabandonment with specific care plans (rather than a statement that "nothing more can be done") (Table 6).¹⁰² Knowledge of the elements of a good death may help guide a productive conversation. An expert approach described as "Hope for the Best, Prepare for the Worst" is a useful framework for discussing planning for the future while still embracing a patient's hope to be cured.¹⁰²

Preparing for Dying and Death

Many cancer clinicians observe their patients through the trajectory of illness, yet preparing patients for dying and death requires a shift in the

oncologist's mindset. Discussions about prognosis, anticancer treatment choices, and treatment side effects, in general, give way to discussions about the physical, psychosocial, spiritual, and practical aspects of preparing for death. The discussions, however, are often asymmetric; the literature describes patients and caregivers' desire to talk about psychosocial concerns at the end of life, and physicians' struggle to talk about CPR.

Patient and caregiver views on end-of-life discussions

In descriptive studies, the majority of patients and caregivers report wanting information about the disease process, likely future symptoms and how these symptoms could be managed, and life expectancy.^{25,103} Patients want to talk about these issues with a health professional with whom they have an established level of trust, and who have shown empathy, honesty, and sensitivity to different levels of understanding.¹⁰⁴ Patients are also concerned about pain control, nonabandonment, and information about hospices.¹⁰⁵ Interestingly, patient and caregiver information needs showed a tendency to diverge as the illness progressed, with caregivers needing more and patients wanting less information.¹⁰⁴ In 1 study, patients and caregivers agreed that the following communication practices were desirable: 1) consistency among different health professionals and openness to questions and discussion, 2) provision of specific information needed to care for the patient, and 3) separate discussions with patient and caregiver.¹⁰⁶ Qualitative studies have identified the following content issues to be discussed: good pain and symptom control, avoiding inappropriate prolongation of dying, strengthening important relationships, achieving a sense of control, and finding a sense of closure.¹⁰⁷⁻¹⁰⁹

Current practice in end-of-life discussions

Interestingly, the empirical literature describing end-of-life discussions from the clinician's viewpoint does not mirror the patient studies described above and is largely centered around discussions of CPR. In a large study of seriously ill hospitalized patients that included over 800 patients with cancer, physicians misunderstood patients' wishes about CPR nearly half the time, suggesting that communication about CPR had been inadequate.¹¹⁰ Only 23% of patients reported discussing CPR with their physician, and importantly, of those who had not discussed CPR, 58% were uninterested in doing so; this group did not consider CPR to be a pressing concern.¹¹¹ In a more recent Canadian study of hospitalized patients with advanced disease including cancer, only 3% reported discussing CPR with their physician, and

patients who felt that end-of-life issues were relevant to them were 5.5 times more likely to want a discussion with their physician.¹¹² These studies suggest the difficulty of raising CPR for patients who are not prepared to talk about dying, and raise a question about whether CPR discussions might be more successful if they occur after better discussions of prognosis and goals of care.

The only observational study of CPR discussions that studied actual conversations involves medical house staff and hospitalized patients (including cancer and noncancer diagnoses). These conversations demonstrated that physicians often provided incomplete information about what CPR involved, how often it was successful, and likely patient outcomes. For example, only 13% of physicians mentioned the patient's likelihood of survival after CPR, and no physician used a numerical estimate.¹¹³ Given that other studies indicate that the likelihood of a patient with metastatic cancer surviving CPR is between 0% and 20%,¹¹⁴ this study raises troubling questions about what physicians do or do not communicate in these situations. House staff initiated discussions about values or goals of care in <10% of the conversations, yet 90% rated their own performance highly and 77% reported feeling comfortable with the discussion. One third of these house staff had never been observed by a more senior physician while conducting a CPR discussion, suggesting little effective training in communication skills.¹¹³

Discussions about hastening death

Although a considerable proportion of patients tend to avoid discussions about end-of-life care, a small proportion of patients present a different issue for clinicians—they want to hasten death, and try to initiate discussions about assisted suicide or euthanasia. A longitudinal qualitative study of patients pursuing hastening death found that for these patients, talking about assisted suicide was a gateway to talking about dying, and patients were frustrated at being rebuffed by physicians. Importantly, physicians who presented scenarios of future suffering without effective treatment may have inadvertently encouraged patients to seek hastened death.¹¹⁵

Preparing caregivers for the patient's death

Preparing caregivers for the patient's death is often not a focus of communication.¹¹⁶ In a national sample, 23% of informants contacted reported that the death of their loved one was "extremely" unexpected.¹¹⁷ Communication between caregivers and healthcare providers is likely a major predictor of preparedness.^{11,118} Observational studies suggest that

TABLE 7
Preparing for Dying and Death

Recommendations

For patient:

Arrange discussion with a clinician who has an established relationship with the patient, if possible

Ask about concerns related to disease progression or dying

Offer to talk about life expectancy and last hours of life

Be prepared to discuss components of a good death:

Pain and symptom control

Avoiding inappropriate prolongation of dying

Strengthening important relationships

Achieving a sense of control

Minimizing burden on family

Finding a sense of closure or peace

If consistent with patient goals, physicians may recommend withholding cardiopulmonary resuscitation as part of this discussion

For caregiver:

Provide specific instructions for caring for patient

Consider a separate discussion for caregiver if patient gives permission

Recognize work caregiver does in caring for patient

Acknowledge and empathize with caregiver grief

Prepare caregiver when death is imminent

inadequate information and unpredictable situations contribute to caregiver uncertainty, and also that caregiver uncertainty is associated with poorer caregiver health outcomes.^{119,120} Studies of caregivers demonstrate that when they perceive that their questions have been answered, they experience fewer depressive symptoms, fewer economic and other burdens, and improved satisfaction and quality of life.¹²¹ The components of communication that could contribute to death preparedness have been outlined but not tested in intervention studies.^{120,122} However, a French study that randomized caregivers of dying patients in intensive care units (including cancer and noncancer diagnoses) to a communication intervention demonstrated lower rates of post-death post-traumatic stress disorder.¹²³

Finally, communication before death continues to have an impact on family caregivers after death. Studies indicate that preparedness impacts the caregiver's bereavement in physical health, depression, substance abuse, and even the caregiver's own death.^{121,124,125}

Recommendations for preparing patients and family caregivers for dying and death

Communication designed to prepare patients and family caregivers should start with a broad framework of patient goals and values before addressing specific interventions such as CPR (Table 7). If consistent with patient goals, physicians may recommend withholding CPR as part of this discussion.

Because caregivers have distinct informational and emotional needs, they need conversations separate from the patient. Although there are suggestions about how to talk about a clinician-patient relationship that is ending because of death, these have not been empirically tested.¹²⁶

Conclusions

Talking with cancer patients who are approaching death represents a significant clinical challenge. Empirical research on how patients and oncologists discuss these issues has defined a few best practices, but further research should continue to link identified needs to communication practices that influence patient outcomes such as quality of life, quality of dying, and decision making, and to training that will enable oncologists to use these practices effectively.

REFERENCES

1. Epstein RM, Street RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Publication No. 07-6225. Bethesda, MD: National Institutes of Health; 2007.
2. [No authors listed]. Cancer care during the last phase of life. *J Clin Oncol*. 1998;16:1986-1996.
3. Foley KM, Gelband H. Improving Palliative Care for Cancer: Summary and Recommendations. Washington, DC: Institute of Medicine and National Academies Press; 2001.
4. Hewitt M, Simone JV. Ensuring Quality Cancer Care. Washington, DC: National Academies Press; 1999.
5. Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ*. 2004;328:864.
6. Molleman E, Krabbendam PJ, Annyas AA, Koops HS, Sleijfer DT, Vermey A. The significance of the doctor-patient relationship in coping with cancer. *Soc Sci Med*. 1984;18:475-480.
7. Davis C, Williams P, Parle M, Redman S, Turner J. Assessing the support needs of women with early breast cancer in Australia. *Cancer Nurs*. 2004;27:169-174.
8. Heaven CM, Maguire P. The relationship between patients' concerns and psychological distress in a hospice setting. *Psychooncology*. 1998;7:502-507.
9. Frankel RM, Stein T. Getting the most out of the clinical encounter: the 4 habits model. *J Med Pract Manage*. 2001;16:184-191.
10. Heaven CM, Maguire P. Disclosure of concerns by hospice patients and their identification by nurses. *Palliat Med*. 1997;11:283-290.
11. Detmar SB, Aaronson NK, Wever LD, Muller M, Schornagel JH. How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. *J Clin Oncol*. 2000;18:3295-3301.
12. Merckaert I, Libert Y, Delvaux N, et al. Factors that influence physicians' detection of distress in patients with cancer: can a communication skills training program improve physicians' detection? *Cancer*. 2005;104:411-421.
13. Ryan H, Schofield P, Cockburn J, et al. How to recognize and manage psychological distress in cancer patients. *Eur J Cancer Care (Engl)*. 2005;14:7-15.
14. Ford S, Fallowfield L, Lewis S. Doctor-patient interactions in oncology. *Soc Sci Med*. 1996;42:1511-1519.
15. 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.
16. Heritage J, Robinson JD, Elliott MN, Beckett M, Wilkes M. Reducing patients' unmet concerns in primary care: the difference one word can make. *J Gen Intern Med*. 2007;22:1429-1433.
17. Levinson W, Gorawara-Bhat R, Lamb J. A study of patient clues and physician responses in primary care and surgical settings. *JAMA*. 2000;284:1021-1027.
18. Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview. *JAMA*. 1997;277:678-682.
19. Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology*. 2002;11:47-58.
20. Anderson WG, Alexander SC, Rodriguez KL, et al. "What concerns me is..." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer*. 2008;16:803-811.
21. Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol*. 2007;25:5748-5752.
22. Hagerty RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol*. 2004;22:1721-1730.
23. Gattellari M, Voigt KJ, Butow PN, Tattersall MH. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *J Clin Oncol*. 2002;20:503-513.
24. Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MH. Lay constructions of decision-making in cancer. *Psychooncology*. 2002;11:295-306.
25. Wenrich MD, Curtis JR, Shannon SE, Carline JD, Ambrozio DM, Ramsey PG. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. *Arch Intern Med*. 2001;161:868-874.
26. Clayton JM, Butow PN, Arnold RM, Tattersall MH. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*. 2005;103:1965-1975.
27. Back AL, Arnold RM, Baile WF, Tulskey JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. *CA Cancer J Clin*. 2005;55:164-177.
28. Schofield PE, Butow PN, Thompson JE, Tattersall MH, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol*. 2003;14:48-56.
29. Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L. Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol*. 2001;19:2049-2056.
30. Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncol*. 1999;17:371-379.
31. Roter DL, Hall JA, Kern DE, Barker LR, Cole KA, Roca RP. Improving physicians' interviewing skills and reducing patients' emotional distress. A randomized clinical trial. *Arch Intern Med*. 1995;155:1877-1884.
32. Egan G. The Skilled Helper: A Problem-Management and Opportunity-Development Approach to Helping. 8th ed. Boston, MA: Thomson Learning; 2002.

33. Smith RC, Hoppe RB. The patient's story: integrating the patient- and physician-centered approaches to interviewing. *Ann Intern Med.* 1991;115:470-477.
34. 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.
35. Oken D. What to tell cancer patients. A study of medical attitudes. *JAMA.* 1961;175:1120-1128.
36. Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *JAMA.* 1979;241:897-900.
37. Baile WF, Buckman R, Lenzi R, Globler G, Beale EA, Kudelka AP. SPIKES-A 6-step protocol for delivering bad news: application to the patient with cancer. *Oncologist.* 2000;5:302-311.
38. Hoffman M, Ferri J, Sison C, Roter D, Schapira L, Baile W. Teaching communication skills: an AACE survey of oncology training programs. *J Cancer Educ.* 2004;19:220-224.
39. Ptacek JT, Fries EA, Eberhardt TL, Ptacek JJ. Breaking bad news to patients: physicians' perceptions of the process. *Support Care Cancer.* 1999;7:113-120.
40. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med.* 1980;92:832-836.
41. Salander P. Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. *Soc Sci Med.* 2002;55:721-732.
42. Ptacek JT, Ptacek JJ. Patients' perceptions of receiving bad news about cancer. *J Clin Oncol.* 2001;19:4160-4164.
43. 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.
44. Barclay JS, Blackhall LJ, Tulsy JA. Communication strategies and cultural issues in the delivery of bad news. *J Palliat Med.* 2007;10:958-977.
45. Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA.* 1995;274:820-825.
46. Costantini M, Morasso G, Montella M, et al. Diagnosis and prognosis disclosure among cancer patients. Results from an Italian mortality follow-back survey. *Ann Oncol.* 2006;17:853-859.
47. Surbone A. Cultural aspects of communication in cancer care. *Support Care Cancer.* 2008;16:235-240.
48. Robinson K, Sutton S, von Gunten CF, et al. Assessment of the Education for Physicians on End-of-Life Care (EPEC) project. *J Palliat Med.* 2004;7:637-645.
49. Mackillop WJ, Stewart WE, Ginsburg AD, Stewart SS. Cancer patients' perceptions of their disease and its treatment. *Br J Cancer.* 1988;58:355-358.
50. von Gunten CF, Ferris FD, Emanuel LL. The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. *JAMA.* 2000;284:3051-3057.
51. Egely S, Penner L, Albrecht TL, et al. Discussing bad news in the outpatient oncology clinic: rethinking current communication guidelines. *J Clin Oncol.* 2006;24:716-719.
52. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA.* 1998;279:1709-1714.
53. Annas GJ. Informed consent, cancer, and truth in prognosis. *N Engl J Med.* 1994;330:223-225.
54. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br J Cancer.* 2001;84:48-51.
55. Delvecchio Good MJ, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Cult Med Psychiatry.* 1990;14:59-79.
56. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol.* 2007;25:5636-5642.
57. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation. Benefit or harm? *JAMA.* 1995;274:826-829.
58. Frank G, Blackhall LJ, Michel V, Murphy ST, Azen SP, Park K. A discourse of relationships in bioethics: patient autonomy and end-of-life decision making among elderly Korean Americans. *Med Anthropol Q.* 1998;12:403-423.
59. Clayton JM, Butow PN, Tattersall MH, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol.* 2007;25:715-723.
60. Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007; 186(12 suppl):S77, S79, S83-S108.
61. Gordon EJ, Daugherty CK. "Hitting you over the head": oncologists' disclosure of prognosis to advanced cancer patients. *Bioethics.* 2003;17:142-168.
62. Wallace JA, Daugherty CK. Emotional responses of oncologists when disclosing prognostic information to patients with terminal disease. *J Clin Oncol.* 2006;24(18 suppl):8520.
63. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med.* 2001;134:1096-1105.
64. The AM, Hak T, Koeter G, van Der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ.* 2000;321:1376-1381.
65. Robinson TM, Alexander SC, Hays M, et al. Patient-oncologist communication in advanced cancer: predictors of patient perception of prognosis [online]. *Support Care Cancer.* 2008. DOI: 10.1007/s00520-007-0372-2.
66. Back AL, Arnold RM. Discussing prognosis: "how much do you want to know?" Talking to patients who do not want information or who are ambivalent. *J Clin Oncol.* 2006; 24:4214-4217.
67. Back AL, Arnold RM. Discussing prognosis: "how much do you want to know?" Talking to patients who are prepared for explicit information. *J Clin Oncol.* 2006;24:4209-4213.
68. Matsuyama R, Reddy S, Smith TJ. Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. *J Clin Oncol.* 2006;24:3490-3496.
69. Beadle GF, Yates PM, Najman JM, et al. Beliefs and practices of patients with advanced cancer: implications for communication. *Br J Cancer.* 2004;91:254-257.
70. Horstmann E, McCabe MS, Grochow L, et al. Risks and benefits of phase I oncology trials, 1991 through 2002. *N Engl J Med.* 2005;352:895-904.
71. Meropol NJ, Weinfurt KP, Burnett CB, et al. Perceptions of patients and physicians regarding phase I cancer clinical trials: implications for physician-patient communication. *J Clin Oncol.* 2003;21:2589-2596.
72. 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.
73. Koedoot CG, Oort FJ, de Haan RJ, Bakker PJ, de Graeff A, de Haes JC. The content and amount of information given

- by medical oncologists when telling patients with advanced cancer what their treatment options are. Palliative chemotherapy and watchful-waiting. *Eur J Cancer*. 2004;40:225-235.
74. Brown RF, Butow PN, Butt DG, Moore AR, Tattersall MH. Developing ethical strategies to assist oncologists in seeking informed consent to cancer clinical trials. *Soc Sci Med*. 2004;58:379-390.
 75. Tulsky JA. Beyond advance directives: importance of communication skills at the end of life. *JAMA*. 2005;294:359-365.
 76. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care—a case for greater use. *N Engl J Med*. 1991;324:889-895.
 77. Lamont EB, Siegler M. Paradoxes in cancer patients' advance care planning. *J Palliat Med*. 2000;3:27-35.
 78. Fried TR, Byers AL, Gallo WT, et al. Prospective study of health status preferences and changes in preferences over time in older adults. *Arch Intern Med*. 2006;166:890-895.
 79. True G, Phipps EJ, Braitman LE, Harralson T, Harris D, Tester W. Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med*. 2005;30:174-179.
 80. Ganti AK, Lee SJ, Vose JM, et al. Outcomes after hematopoietic stem-cell transplantation for hematologic malignancies in patients with or without advance care planning. *J Clin Oncol*. 2007;25:5643-5648.
 81. SUPPORT: Study to understand prognoses and preferences for outcomes and risks of treatments. Study design. *J Clin Epidemiol* 1990;43(suppl):1S-123S.
 82. Roter DL, Larson S, Fischer GS, Arnold RM, Tulsky JA. Experts practice what they preach: A descriptive study of best and normative practices in end-of-life discussions. *Arch Intern Med*. 2000;160:3477-3485.
 83. Royak-Schaler R, Gadalla S, Lemkau J, Ross D, Alexander C, Scott D. Family perspectives on communication with healthcare providers during end-of-life cancer care. *Oncol Nurs Forum*. 2006;33:753-760.
 84. Shiozaki M, Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y. Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. *Palliat Med*. 2005;19:319-327.
 85. Miyashita M, Sanjo M, Morita T, et al. Barriers to providing palliative care and priorities for future actions to advance palliative care in Japan: a nationwide expert opinion survey. *J Palliat Med*. 2007;10:390-399.
 86. Feeg VD, Elebiary H. Exploratory study on end-of-life issues: barriers to palliative care and advance directives. *Am J Hosp Palliat Care*. 2005;22:119-124.
 87. Graugaard PK, Holgersen K, Eide H, Finset A. Changes in physician-patient communication from initial to return visits: a prospective study in a haematology outpatient clinic. *Patient Educ Couns*. 2005;57:22-29.
 88. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol*. 1997;8:857-863.
 89. Clayton JM, Butow PN, Arnold RM, Tattersall MH. Discussing life expectancy with terminally ill cancer patients and their carers: a qualitative study. *Support Care Cancer*. 2005;13:733-742.
 90. Tattersall MH, Gattellari M, Voigt K, Butow PN. When the treatment goal is not cure: are patients informed adequately? *Support Care Cancer*. 2002;10:314-321.
 91. Jefford M, Milne D, Aranda S, Schofield P. Further considerations regarding discussions around the transition to palliative care. *Palliat Med*. 2007;21:651.
 92. Schofield P, Carey M, Love A, Nehill C, Wein S. "Would you like to talk about your future treatment options?" Discussing the transition from curative cancer treatment to palliative care. *Palliat Med*. 2006;20:397-406.
 93. Lobb EA, Clayton JM, Price MA. Suffering, loss and grief in palliative care. *Aust Fam Physician*. 2006;35:772-775.
 94. Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. The patient-physician relationship. Patient-physician communication during outpatient palliative treatment visits: an observational study. *JAMA*. 2001;285: 1351-1357.
 95. Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med*. 1995;122:368-374.
 96. Shanafelt T, Adjei A, Meyskens FL. When your favorite patient relapses: physician grief and well-being in the practice of oncology. *J Clin Oncol*. 2003;21:2616-2619.
 97. Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA*. 2001;286:3007-3014.
 98. Folkman S, Moskowitz JT. Positive affect and the other side of coping. *Am Psychol*. 2000;55:647-654.
 99. Sardell AN, Trierweiler SJ. Disclosing the cancer diagnosis. Procedures that influence patient hopefulness. *Cancer*. 1993;72:3355-3365.
 100. Steinhilber KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476-2482.
 101. Morita T, Akechi T, Ikenaga M, et al. Communication about the ending of anticancer treatment and transition to palliative care. *Ann Oncol*. 2004;15:1551-1557.
 102. Evans WG, Tulsky JA, Back AL, Arnold RM. Communication at times of transitions: how to help patients cope with loss and re-define hope. *Cancer J*. 2006;12:417-424.
 103. Kutner JS, Steiner JF, Corbett KK, Jahnigen DW, Barton PL. Information needs in terminal illness. *Soc Sci Med*. 1999;48:1341-1352.
 104. Parker SM, Clayton JM, Hancock K, et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage*. 2007;34: 81-93.
 105. Pentz RD, Lenzi R, Holmes F, Khan MM, Verschraegen C. Discussion of the do-not-resuscitate order: a pilot study of perceptions of patients with refractory cancer. *Support Care Cancer*. 2002;10:573-578.
 106. Clayton JM, Butow PN, Tattersall MH. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. *Cancer*. 2005;103:1957-1964.
 107. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. 1999;281:163-168.
 108. Steinhilber KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med*. 2000;132:825-832.
 109. Block SD. Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA*. 2001;285:2898-2905.

110. Hofmann JC, Wenger NS, Davis RB, et al. Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. *Ann Intern Med.* 1997;127:1-12.
111. Puchalski CM, Zhong Z, Jacobs MM, et al. Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project. *J Am Geriatr Soc.* 2000;48(5 suppl): S84-S90.
112. Heyland DK, Frank C, Groll D, et al. Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members. *Chest.* 2006;130:419-428.
113. Tulsy JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med.* 1995;10:436-442.
114. Reisfield GM, Wallace SK, Munsell MF, Webb FJ, Alvarez ER, Wilson GR. Survival in cancer patients undergoing in-hospital cardiopulmonary resuscitation: a meta-analysis. *Resuscitation.* 2006;71:152-160.
115. Back AL, Starks H, Hsu C, Gordon JR, Bharucha A, Pearlman RA. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med.* 2002;162:1257-1265.
116. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: "they don't know what they don't know." *JAMA.* 2004;291:483-491.
117. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA.* 2004;291:88-93.
118. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *J Palliat Med.* 2005;8:1176-1185.
119. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage.* 2001;22:727-737.
120. Hebert RS, Prigerson HG, Schulz R, Arnold RM. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *J Palliat Med.* 2006;9:1164-1171.
121. Valdimarsdottir U, Helgason AR, Furst CJ, Adolfsson J, Steineck G. Awareness of husband's impending death from cancer and long-term anxiety in widowhood: a nationwide follow-up. *Palliat Med.* 2004;18:432-443.
122. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. *J Gen Intern Med.* 2001;16:41-49.
123. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med.* 2007;356:469-478.
124. Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "all the doctors just suddenly go" *JAMA.* 2001;286:1369-1376.
125. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med.* 2006;354:719-730.
126. Back AL, Arnold RM, Tulsy JA, Baile WF, Fryer-Edwards KA. On saying goodbye: acknowledging the end of the patient-physician relationship with patients who are near death. *Ann Intern Med.* 2005;142:682-685.