Making Difficult Discussions Easier
Using Prognosis to Facilitate Transitions to Hospice

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Abstract
Patients with advanced cancer face difficult decisions regarding their treatment, and many will need to make difficult choices about end-of-life care because although cancer-directed therapies are increasingly available, few provide a cure. High-quality cancer care includes access to palliative care throughout the cancer care continuum, and increasing evidence suggests that timely enrollment in hospice can increase quality of life for patients dying from cancer. Therefore, clinicians must learn to recognize patients who are hospice-eligible and to develop prognostication and communication skills that enable honest provider-patient dialogue about end-of-life options. In this article, the authors review available tools for prognostication in advanced cancer and present a method for discussing prognosis by using the SPIKES acronym. In addition, by using patient-identified goals and service needs, the authors recommend a method for making a hospice referral after disclosure of poor prognosis. CA Cancer J Clin 2009;59:250-263. ©2009 American Cancer Society, Inc.

Palliative Care in the Cancer Care Continuum
In 2009, an estimated 1,479,350 individuals in the United States will be diagnosed with cancer, and an estimated 562,340 cancer-related deaths will occur.¹ Although there are many life-prolonging treatments available to patients with metastatic cancer, including chemotherapy, targeted therapy, radiation, and surgery, most cannot be cured. Therefore, health care providers will need to support these patients and their families from the time of cancer diagnosis through the dying process by integrating palliative care and hospice into the cancer care continuum.

Fortunately, in the United States, the number of hospitals that have palliative care programs has grown substantially. For instance, the 2008 American Hospital Association survey by the Center to Advance Palliative Care (CAPC) found that 77% of hospitals with more than 250 beds have active palliative care programs.² In addition, many cancer patients use hospice at the end of life. In 2007, 41.3% of hospice patients, over 400,000 persons, had a cancer diagnosis.³

Despite increasing availability of palliative care and hospice, there are numerous barriers to their timely use. One of the most troubling of these is the persistent association of palliative care and hospice with imminent death. For patients with cancer who are seeking cure or life prolongation, and for physicians who seek to meet their...
patients’ needs, this perception can limit acceptance of appropriate palliative care interventions. Neither hospice nor palliative care programs are designed or restricted to those patients who are imminently dying.

For instance, palliative care can and should be delivered concurrently with anticancer treatments. The National Comprehensive Cancer Network guidelines define palliative care as:

- an organized, highly structured system for delivering care to persons with life-threatening or debilitating illnesses. Palliative care is patient and family centered care . . . . The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of disease or the need for other therapies. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care.4

Comprehensive palliative care programs may provide aggressive pain and symptom management, psychosocial support, spiritual care, nutritional support, music or art therapy, and other services depending on the patient’s needs. Palliative care can be provided in many health care settings, and there are currently no criteria that restrict access to palliative care services. In fact, national and international organizations, such as the Institute of Medicine, American Society of Clinical Oncology, and the National Comprehensive Cancer Network (NCCN), recommend integration of palliative care practices into the cancer care continuum.4-6 The NCCN guidelines for palliative care recommend that all cancer patients have access to palliative care beginning at the time of diagnosis and that patients be reassessed for palliative care needs throughout the course of their illness.4

Several models of simultaneous oncology and palliative care have been studied. The benefits of these programs include increased rates of hospice enrollment and earlier hospice utilization,7-10 decreased emergency room visits and hospitalization,11 improved quality of life,10,12 and possible cost savings.8,13

In contrast to hospital-based palliative care, hospice is a federally funded program of care based on the criteria outlined in the Medicare Part A Hospice benefit, established in 1983. Hospice care was designed for patients with terminal illness and a life expectancy of 6 or fewer months. To be eligible for hospice, patients must be willing to forgo treatment of the condition for which hospice was initiated (eg, a cancer patient cannot receive cancer-directed therapy, such as chemotherapy, while enrolled in hospice).14 Hospice provides services to reduce pain and suffering and to improve quality of life. Hospice includes typical palliative care services, such as pain and symptom management, and also offers more comprehensive services, such as medications for pain and symptom management, case management, respite care, and bereavement services. Hospice care is provided by an interdisciplinary team that includes a nurse, physician, social worker, chaplain, home health aide, and volunteers. An overview of eligibility requirements and typical services provided by hospice are listed in Table 1.

Ideally, patients with cancer would have access to palliative care while undergoing cancer treatments in the adjuvant setting. Traditionally, palliative care in this environment is provided by oncology clinicians and is often called supportive oncology. It includes management of symptoms due to cancer and its treatment, such as pain, chemotherapy-induced nausea and vomiting, treatment-related cytopenias, as well as general coping and psychosocial issues associated with cancer diagnosis and treatment. Referral to palliative care specialists may be necessary for complex cases or for refractory symptoms after adjuvant treatment has been completed (eg, severe chemotherapy-induced neuropathic pain). Some suggest that traditional palliative care for oncology patients falls under the umbrella of supportive oncology care.

For patients with advanced cancer who are still receiving disease-modifying cancer treatment but who are unlikely to be cured of their cancer, both clinic- and hospital-based palliative care should be

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**Table 1. Hospice Eligibility and Services**

| ELIGIBILITY                                      | SERVICES                                      |
|-------------------------------------------------|------------------------------------------------|
| Life expectancy 6 mo or less if the illness runs its usual course | Multidisciplinary team: physician, nurse, social worker, chaplain, volunteers, physical/occupational therapist |
| Willingness to accept a palliative plan of care  | Symptom management                            |
|                                                 | Patient and family education                   |
|                                                 | 24-h case management                           |
|                                                 | Counseling, care planning                      |
|                                                 | Durable medical equipment                      |
|                                                 | Inpatient care as needed                       |
|                                                 | Respite care as needed                         |
|                                                 | Medication and supplies                        |
|                                                 | Home health aide services                      |
|                                                 | Bereavement support                            |
available early in the palliative cancer care continuum. Oncologists and palliative care clinicians may need to explicitly address incorrect associations between palliative care and imminent death so that patients feel comfortable engaging in concurrent palliative and oncology care. The degree of palliative care staff involvement may depend on a patient’s service needs. For example, the palliative care team can assist in pain and symptom management related to cancer and continued cancer treatment. In addition, palliative care teams, by using a patient- and family-focused multidisciplinary approach, can provide expanded psychosocial and spiritual support to patients and caregivers who are beginning to come to terms with end-of-life issues. While patients are still pursuing anticancer therapies, collaboration between oncologists and palliative care clinicians should be viewed as a part of routine patient-centered oncologic care.

When patients have exhausted appropriate anticancer therapies, when oncologists have established that cancer-related prognosis is limited, or when patients have palliative care needs that only hospice can meet, providers can work with patients to transition to hospice. Ideally, discussions about hospice should be conducted by the patient’s care team as a part of routine oncology care.

Prognostication for the Transition to Hospice

Referral for palliative care services is generally based on actual or anticipated patient symptoms, whereas enrollment in hospice requires that patients meet specific criteria, including having a life expectancy of less than 6 months if his/her illness runs its usual course. Therefore, to determine when to discuss hospice, providers need to be able to estimate and communicate prognosis accurately. Although cancer may follow a variety of trajectories early in the course of disease, many patients with advanced cancer have a predictable course. In fact, most patients with advanced cancer undergo a gradual and predictable loss of function during the last year of life followed by a marked functional decline in the months immediately preceding death.

Clinical Predictions of Survival

Despite patients’ predictable pattern of functional decline, health care providers often have difficulty accurately determining survival. Clinical predictions of survival (CPS) are often wrong, and physician estimates tend to err in the optimistic direction. In a systematic review on the subject, Glare found that although clinical predictions of survival tend to overestimate actual survival, the 2 are correlated. Furthermore, clinicians’ predictions of survival add to data derived from functional status, lab tests, and other sources. Studies showing correlation between performance status, clinical predictions of survival, and actual survival are inconsistent. In particular, when a patient’s Karnofsky Performance Status (KPS) is low, the clinical prediction of survival may be a more accurate predictor of survival.

However, clinicians’ predictions are not perfect, and they tend to be particularly fallible for patients very near the end of life. This limitation of clinical predictions may reflect the variability of disease course in advanced cancer. For example, it is difficult to predict death from a catastrophic event such as hemoptysis, pulmonary embolism, or sepsis. However, it may be the result of factors, such as length of the physician-patient relationship, that limit recognition and/or acknowledgement of advanced disease or may reflect physical, psychosocial, emotional, or disease-related factors that are not yet clearly defined.

Additional Information that Can be Useful in Estimating Prognosis

CPS should be used with other clinical, laboratory, psychosocial, and disease-related factors to refine prognostic estimates in clinical settings. Table 2 provides a list of factors that can be used to estimate the prognosis of patients with advanced cancer. Information in Table 2 is based on several comprehensive literature reviews as well as on recent studies that discuss prognostic factors in advanced cancer patients. In its 2005 guidelines, the European Association for Palliative Care reported that the strongest evidence supports use of CPS and prognostic scores. In addition, some evidence supports the use of performance status, symptoms such as the cancer anorexia-cachexia syndrome (CACS), dyspnea, and delirium, as well as laboratory data, such as leukocytosis, lymphocytopenia, and high C-reactive protein (CRP) levels to aid in prognostication.
Performance status, often assessed by using the Karnofsky Performance Score (KPS) or the Eastern Cooperative Oncology Group (ECOG) Performance Scale, has been correlated with prognosis in multiple studies. High ECOG scores (≥2) and low KPS scores (≤50%) have been linked to shorter survival. In addition, rapid decline of performance status predicts shorter survival, underscoring the need for frequent, repeated assessments of performance over time.

As with CPS, performance status is most effective when used with other factors to assist in prognostication. The Palliative Performance Scale (PPS), a modification of the KPS, uses ambulation, activity level, extent of disease, ability to perform self-care, oral intake, and level of consciousness to assess function. PPS scores are correlated with survival when the PPS is 50% or less. The PPS has been validated in palliative care populations and in acute inpatient hospital populations. Although there appears to be good inter-rater reliability in the outpatient oncology setting, this tool has not yet been validated for use in an outpatient oncology setting. Table 3 describes the ECOG, KPS, and PPS.

**Prognostic Tools**

Researchers have developed and validated many prognostic tools or aids that systematically combine clinical and laboratory values to provide estimates of survival in palliative care populations. Most are simple and can be scored without complex calculations after obtaining data from patient interviews and chart review. Several of these tools have been validated in hospitalized advanced cancer patients. Unfortunately, few of these tools have been tested in the outpatient oncology setting where they are needed most. Comprehensive reviews on this topic have been completed by Glare and Sinclair, and by Stone and Lund, and several tools are described here.

The Palliative Prognostic (PaP) Score uses the CPS, KPS, anorexia, dyspnea, white blood cell count (WBC), and lymphocyte percentage to predict survival in advanced cancer patients. This model was originally developed in the palliative care setting but has been validated for prognostic assessments in hospitalized advanced cancer patients. The model produces 3 prediction strata reflecting a >70% chance, a 30-70% chance, or a <30% probability of surviving at least 1 month.

The Palliative Prognostic Index (PPI) is useful in predicting short-term survival of advanced cancer patients in the palliative care setting. It uses the PPS, as well as presence of edema, delirium, dyspnea at rest, and oral intake to create a PPI score. The score predicts survival of <3 weeks, <6 weeks, or >6 weeks.

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**TABLE 2. Factors Associated with Poor Prognosis in Advanced Cancer**

| CATEGORY                  | PROGNOSTIC FACTOR                    |
|---------------------------|--------------------------------------|
| Estimates of function or prognosis | Clinical prediction of survival*     |
|                           | Poor performance status*             |
|                           | Prognostic scores*                   |
| Symptoms/Signs            | Anorexia*                            |
|                           | Asthenia                             |
|                           | Cognitive decline/delirium*          |
|                           | Dysphagia*                           |
|                           | Dyspnea*                             |
|                           | Pain                                 |
|                           | Tachycardia                          |
|                           | Weight loss*                         |
|                           | Xerostomia*                          |
| Patient characteristics   | Male                                 |
|                           | Multiple comorbidities               |
| Disease characteristics   | Brain metastasis                     |
|                           | Multiple metastatic sites            |
|                           | Visceral metastases, such as liver metastasis |
|                           | Primary tumor (lung)                 |
| Laboratory values         | Abnormal calcium level               |
|                           | Abnormal sodium level                |
|                           | Anemia                               |
|                           | High CRP*                            |
|                           | High LDH                             |
|                           | Hypoalbuminemia                      |
|                           | Leukocytosis*                        |
|                           | Lymphocytopenia*                     |

CRP indicates C-reactive protein; LDH, lactate dehydrogenase.

*Factors with the best evidence on the basis of 2005 Prognostic Factors in Advanced Cancer Patients: Evidence-based Clinical Recommendation—A Study by the Steering Committee of the European Association for Palliative Care.
Chow et al developed a survival prediction score (SPS) and a risk factor-based model to predict survival in an outpatient radiation oncology setting, but it has not been used to assess other patient populations or populations outside of Canada. Similarly, several other prognostic tools, including the Terminal Cancer Prognostic (TCP) Score, the Chuang Prognostic Score, and a “poor prognostic indicator” created by Bruera et al, have been developed and validated in advanced oncology patients, although few have been tested and validated in outpatient oncology settings before patient admission to hospital or hospice.

By using CPS, laboratory and examination data, patient functional status, and prognostic tools, clinicians can make reasonably accurate estimates of survival. Although tools can improve clinician estimates of prognosis, their estimates of prognosis remain imperfect. Therefore, clinicians need to convey prognostic information in a way that supports patients and families in making decisions without causing emotional harm.

TABLE 3. The Karnofsky and ECOG Performance Status Scales and the Palliative Performance Scale

| Karnofsky Performance Status Scale | Eastern Cooperative Oncology Group Performance Status | Palliative Performance Scale (PPSv2)* |
|-----------------------------------|------------------------------------------------------|-------------------------------------|
| 100%: Asymptomatic                | 0: Asymptomatic                                      | 100% Full                           |
| 90%: Few signs or symptoms        | 1: Symptomatic but capable of full self-care, ambulatory | Full Normal                       |
| 80%: Normal activity, more signs and symptoms | 2: Symptomatic, in bed or chair <50% of the time; not able to work | Normal activity and work; some evidence of disease |
| 70%: Capable of self-care but not normal activity | 3: In bed or chair >50% of the time, not bedbound, but requires assistance with some ADL | Normal activity with effort; some evidence of disease |
| 60%: Capable of most self-care, requires help with some activities | 4: Bedbound | Full |
| 50%: Requires frequent assistance and medical care | 5: Dead | Normal or reduced |
| 40%: Disabled | | Full or confusion |
| 30%: Severely disabled, hospitalization indicated | | |
| 20%: Very sick, urgently requiring hospitalization | | |
| 10%: Moribund | | |
| 0%: Dead | | |

ECOG indicates Eastern Cooperative Oncology Group; ADL, activities of daily living.

*The Palliative Performance Scale (PPS) score assignment is based on assessment of the correct level of function and/or category in each column and by the determination of “best fit” horizontally. Leftward columns have more weight in the PPS determination. This tool is available for download at http://palliative.info/resource_material/PPSv2.pdf.
differ if a patient’s main goal is to be present at a wedding in 1 month versus to make a decision between hospice enrollment, early phase clinical trial enrollment, or off-label chemotherapy when no standard chemotherapy options are available. Acknowledging uncertainty about statistics and formulation of prognostic estimates during the conversation\textsuperscript{15,48} and providing general time frames (eg, days to weeks, weeks to months)\textsuperscript{15} may enable clinicians to feel more comfortable with the imprecise nature of prognostication while still providing necessary information to patients.

**Prognostic Disclosure**

In addition to challenges of determining prognosis accurately, physicians may also be reluctant to disclose prognosis.\textsuperscript{49} In 1 study of US oncologists, 98% would tell their patients that they have a life-limiting cancer, but fewer would provide direct prognostic information. When asked to choose 1 of 4 descriptions to characterize their prognostic disclosure practices, 42% of these oncologists stated they always provided a prognosis, whereas 33% provided a prognosis only after asking a patient whether they wanted the information and receiving a positive response. Only when patients asked, 16% talked about prognosis, and 0.4% never discussed prognosis. A few (9%) oncologists did not characterize their responses in these categories.\textsuperscript{50} Several additional small studies confirm that physicians may wait to be asked for prognostic information.\textsuperscript{51–53} For example, 43.7% of internists in 1 United States-based sample\textsuperscript{52} and 17% and 33% of oncologists practicing in Western and non-Western countries\textsuperscript{51} disclosed prognosis only when asked, indicating that physician specialty and cultural factors may influence disclosure practices. In general, physicians are more likely to disclose that they are unable to cure a patient than they are to disclose information about life expectancy or disease progression.\textsuperscript{50,53–55}

**Physician Barriers to Prognostic Disclosure**

Physicians report multiple barriers to communicating prognostic information. Some physicians feel uncomfortable disclosing prognosis because they fear their estimates may be inaccurate.\textsuperscript{49,53} For example, Lamont and Christakis found that physicians who were less than 50% sure about their prognostic estimates were more likely to favor nondisclosure to patients.\textsuperscript{49} Among internists, 50.2% feared that patients would lose faith in them if they made a prognostic error, potentially damaging the physician-patient relationship.\textsuperscript{52} In addition, oncologists may worry about successfully maintaining honesty and hope in prognostic conversations\textsuperscript{51,53} or may view patient death as personal failure and are, therefore, uncomfortable talking about it.\textsuperscript{56} Two studies of oncologist practices and beliefs about discussing prognosis or bad news showed that oncologists have high levels of discomfort talking about transitions from cancer treatment-directed care to palliative care.\textsuperscript{51,57} Furthermore, physicians may not have adequate strategies for coping with their own emotions,\textsuperscript{51,56} their patients’ emotions,\textsuperscript{51,53} or family reactions to bad news.\textsuperscript{51} Finally, physicians report lack of communication training\textsuperscript{50,52,57} and lack of time as barriers to prognostic disclosure.\textsuperscript{51,56,58} Notably, discussions about prognosis and goals of care can be time-intensive, resulting in less efficiency in clinics, and reimbursement for physician counseling time is not as good as reimbursement for chemotherapy treatment. These factors may create practical and financial disincentives for discussing prognosis and suggesting hospice enrollment.

**The Benefits of Prognostic Disclosure**

Provider and patient reluctance to openly discuss prognostic information may result in missed opportunities for appropriate goal setting and care planning. A pattern of incomplete disclosure may represent “necessary collusion”\textsuperscript{59} between patients and physicians that allows for pacing of bad news, but it may also create a more harmful scenario in which patients have inadequate time to prepare for death.

Patients confronting death often use general prognostic information to make medical, emotional, spiritual and practical plans for the future.\textsuperscript{60–64} They want to participate in their own funeral planning,\textsuperscript{63} complete advanced directives, and make decisions about end-of-life care.\textsuperscript{62,63} They also benefit from life review and attention to important relationships before death.\textsuperscript{60,61} Patients who are aware of their prognosis are less likely to choose aggressive medical interventions or to receive intensive care and more likely to enroll in hospice earlier.\textsuperscript{65–67} Physician fears about
inaccurate prognostication may be alleviated in this context, because prognostic precision is less important than honest and open discussions about a patient’s goals of care and end-of-life wishes.

**An Individualized Approach to Prognostic Disclosure**

Although barriers to prognostic disclosure are significant, they can be overcome. Physician discomfort with prognostication and possible bias in conversations toward anticancer treatment may reflect habitual communication patterns within treatment-oriented oncology practices as well as a failure of physician education and support. Notably, educational interventions for oncologists in the United Kingdom and the United States have improved physician comfort and effectiveness in communication in these challenging settings. For example, Back and colleagues reported that oncology fellows who completed a communication skills course acquired a median of 6 new breaking bad news skills and 4 transitions to palliative care skills based on assessment during pre- and postintervention standardized patient encounters. Senior oncologists enrolled in a communication skills course reported a statistically significant shift toward patient-centered attitudes (\(P = 0.03\)), subjectively reported more awareness of communication tasks, more confidence in communication tasks that had previously worried them, and 76% of those who had educational responsibilities had or were creating new communication teaching initiatives.

One useful guide to disclosing information is what patients themselves want and expect from their health care providers. Studies suggest, for instance, that in receiving prognostic information, patients favor physicians who are realistic. They also want physicians to listen well, and to communicate in a straightforward and clear manner. Patients expect physicians to be sensitive and empathic in their delivery of a poor prognosis, and to allow time for questions. Finally, they expect that physicians will not abandon them, and that they will appropriately pace the transition to palliative care.

Patients prefer prognostic information to come from an “expert,” such as an oncologist or a physician with whom they have an established relationship. For instance, Friedrichsen found that the demeanor of the physician, the method of disclosure, and the prior relationship with the patient all influence metastatic cancer patients’ perceptions of information during decision making at times of transition. Indeed, this preference for an empathic provider is noted in multiple studies of communication between physicians and patients with advanced cancer.

Common themes emerge among advanced cancer patients and their families regarding the content and style in which prognostic information is discussed. However, preferences are not uniform, and a flexible patient-oriented approach should be developed after assessing the specific needs and concerns of each patient and family.

Age and culture may be important factors to consider when addressing prognostic disclosure with patients and their families. Several studies suggest that younger patients may want more prognostic information than older patients. A 2003 study of older adults with life-limiting illnesses revealed that only 55% of those who had not received information on life expectancy wanted this information. However, most participants in a recent study of 260 cancer patients, regardless of age greater than or less than 65 years, wanted as much information as possible regarding their prognosis. It is not clear how a patient’s age contributes to desires for prognostic information. Although patients of all ages may have decreased recall of bad news conversations, older patients given a poor prognosis and large amounts of information during physician consultations were less likely than younger patients to recall the information.

While a comprehensive review of specific cultural beliefs regarding disclosure of prognosis and discussion of death is not possible within this article, it is important to acknowledge that cultural beliefs may impact patient and family desires for and receptivity to prognostic information. Several reviews on this topic suggest that patients from English-speaking or Western countries desire comprehensive information about prognosis and that patients in other parts of the world may vary significantly in their information needs, often wanting less prognostic information during medical conversations. Cultural attitudes may influence the degree to which families should be involved in making health care decisions. In addition, acculturation may change patient and family
beliefs regarding their involvement in making health care decisions and seeking prognostic information.\textsuperscript{83,86} For example, in 1 study of Japanese-speaking Japanese Americans and English-speaking Japanese Americans, increased acculturation was associated with stronger preferences for full prognostic disclosure. However, desire for family involvement in making decisions persisted in all 3 groups.\textsuperscript{86} Finally, it is important to recognize that physicians’ cultural beliefs may influence their information disclosure and prognostication practices.\textsuperscript{51,58}

Practitioners should not make assumptions about patient or family preferences based on age or cultural beliefs. Instead, providers should create an individualized approach to prognostic disclosure after asking patients and their caregivers how to proceed. In many cultures, including family members in conversations about prognosis may serve several purposes, such as supporting patients in recall of complex information and acknowledging the importance of the family unit in sharing health care decision making.

Most patients with advanced cancer want information on their disease, treatment, and chance of cure, although fewer want direct estimates of survival or information about death or palliative care.\textsuperscript{60,73,74,77,87,88} In addition, many patients seem to prefer a qualitative prognosis (“You are likely to live/die from your cancer.”) rather than a quantitative prognosis (“You are likely to die in 6 months.”). For example, Kaplowitz and colleagues studied cancer patients’ desire for prognostic information. Among their surveyed patients, 80% wanted a qualitative prognosis, whereas only 53% wanted a quantitative prognosis; 66% of patients asked for qualitative and 35% asked for quantitative prognostic information. Despite patients’ requests, physicians were more likely to provide qualitative data (89% qualitative versus 30% quantitative).\textsuperscript{79} These data highlight the discrepancy between what patients want and ask for as well as what physicians are willing to disclose. It is clear that physicians must ask patients for direction on how much information to provide.

Clarity and empathy are important in patient-physician communication, but even when clear and emotionally respectful conversations occur, needs for prognostic information change over time, and patients and families adjust to difficult news at different speeds. Some patients want regular and repeated opportunities to talk about prognostic information,\textsuperscript{72} and they may want physicians to pace the transition to palliative care after assessing patient readiness for these types of conversations.\textsuperscript{48,70} Appropriate conversational pacing may result in improved comprehension and ability to cope with challenging prognostic information.

**SPIKES: A Framework for Prognostic Discussions**

The SPIKES protocol provides an organized framework for prognostic conversations, and indeed for many other examples of “bad news” conversations. In addition, in 2007 the *Journal of the Australian Medical Association* published the Clinical Practice Guidelines for Communicating Prognosis and End-of-life Issues with Adults in the Advanced Stages of Life-Limiting Illness and Their Caregivers, which has expanded communication guidelines similar to those proposed in SPIKES, but also includes recommendations for addressing the issue of hope.\textsuperscript{15} Recommendations for prognostic disclosure, based on studies of patient preferences, guidelines, and expert opinion are described below, following the SPIKES format (Table 4).

**Step One. Setting**

Little research describes the optimal setting for disclosure of poor prognosis, although expert guidelines on delivery of bad news suggest that attention to the physical environment is important. Best practices include identification of appropriate participants and inviting them to attend (eg, patient, family, staff, and consultants), using a quiet room with plenty of chairs so that all conversation participants can be seated, and limiting interruptions such as pager or telephone calls.\textsuperscript{15,89,90}

**Step 2. Perception**

Guidelines suggest asking patients open-ended questions to assess what they already know about their disease. General questions, such as “How do you think things are going with your cancer treatment?,” “What’s your understanding of the reason we ordered the most recent PET/CT?,” or “What do you understand about your progress during this hospitalization?,” may help identify the appropriate starting point for a discussion about prognosis.

**Step 3. Invitation/Information**

As noted previously, few demographic, emotional, or disease-related factors consistently predict patients’ disclosure preferences and their needs for information about survival and prognosis. Instead, patients
want individualized information from physicians who take the time to ask what the patient wants to know and how he or she wants to use the information.60,69 Also, there is little consensus on the best delivery method for prognostic information, although in 1 qualitative study of patients, caregivers, and health care providers, participants suggested “avoiding being too exact.”64 Prognostic content can be provided with probabilities, averages, or temporal ranges rather than absolute timeframes,30, 64 and in 1 study, participants preferred words, percentages, and fractions to pictorial representations of prognostic data.60 Patient characteristics, such as age, race, and psychiatric comorbidity, may also affect the amount and type of information patients want.60 Asking patients and families directly about their preferred delivery method, content, and amount of information desired may improve communication efforts around prognostication. In addition, it is possible that patients and their families may want different information, and, therefore, individual preferences may necessitate different discussions depending on information preferences.15 Simply asking how much information patients want and how information will be used can help plan the next step in the discussion.

**Step 4. Knowledge**

By using clear, straightforward, nontechnical, and education-appropriate language to describe clinical information is key to effective communication.48,64,70,72 Patients and families prefer jargon-free70 and euphemism-free language.69 Patients also want their physicians to check comprehension after disclosure of prognostic information.72 Notably, in 1 series of audiotaped patient-oncologist interactions, only 10% of consultations included assessments of patient understanding.87

### TABLE 4. SPIKES: Six-Step Protocol for Breaking Bad News89,90

| SPIKES | PROTOCOL |
|--------|----------|
| **S: Setting** | Prepare yourself emotionally for the anticipated conversation. Obtain all relevant laboratory, pathology, and radiologic data, and speak with collaborating providers. Formulate your prognostic estimate. Include pertinent persons such as the healthcare proxy and family or friends; also consider inviting collaborating providers. Prepare the physical environment. (Are there enough chairs, and are tissues available?) Limit interruptions. |
| **P: Perception** | Find out what the patient understands about his or her disease and situation.15 "What is your understanding of your health situation?" the current state of your cancer? the reason we ordered the recent PET/CT?" your progress during this hospitalization?" your biggest concern at the moment?" |
| **I: Invitation/Information** | Ask the patient what kind of information they would like to receive. "Are you the type of person who likes to know details or numbers, or do you prefer more general information?" "How much would you like to know?" |
| **K: Knowledge** | Provide information in clear, nonmedical language targeted to the patient’s educational level and information preferences. Acknowledge limitations of prognostic estimates.15,48,85 "Every person is different. I can only tell you what usually happens to patients in your situation, not exactly what will happen to you."15 Check for patient understanding.72 |
| **E: Emotion/Empathy** | Acknowledge patient emotions. Use NURSE acronym to remember ways to respond to emotion. N: Name U: Understand R: Respect S: Support E: Explore Answer questions. |
| **S: Summarize/Strategize** | Summarize and check for patient understanding. Assess patient goals. Avoid abandonment by establishing a follow-up plan for patients and caregivers that ensures regular contact.108 |
Step 5. Empathic Communication/Acknowledge Emotions

Patients want information about changing goals of care and poor prognosis to be presented sensitively, and they want clinicians to respect patients’ and families’ emotional responses. Patients and families prefer physicians who spend time listening to their concerns. Many studies suggest that patients and families also need adequate time to ask questions about new prognostic information, and this is a critical element to patient satisfaction with sensitive information exchange.

Step 6. Summarize and Strategize

Summarizing information and ensuring patient understanding are important when concluding a discussion of new prognostic information. If patients understand their prognosis and treatment options and providers understand patient goals, even when news is bad, it is possible to provide hope, limit patients’ sense of abandonment at times of transition, and help patients develop appropriate treatment plans. One strategy is to summarize the content of the discussion and ask for questions. After the summary, if a decision has been made to stop cancer-directed therapy, for example, it is important to reassure a patient that their former treatment team will remain active and accessible during the patient’s care (if this is true) and agree upon a next step, such as a telephone call or an office appointment within an appropriate timeframe.

When a discussion about prognosis does not result in a firm decision regarding a treatment plan, as may be the case when transitions are suggested and patients and families need more time to process new information, agreeing upon a time to review questions and revisit the issues is important as well. When clinicians believe no further therapies are indicated and have communicated this to patients and their families effectively, the final portion of the conversation should include discussion of patient goals and service needs. If hospice is indeed an appropriate option, understanding these goals and needs will enable clinicians to introduce hospice as a patient- and family-oriented program designed to meet the specific needs of the patient, and not a service just for patients who are dying.

The Transition from Cancer-Directed Treatments to Hospice

Communication about prognosis and transitions in goals of care should be a part of the overall oncologic care plan. Each clinical change represents an opportunity to clarify patients’ understanding of their disease, assess for acceptance of their terminal status, evaluate quality of life, treat symptoms, and appropriately alter goals of care. Patients with advanced cancer are likely to reach a point when symptoms and care needs can no longer be met by available hospital- or clinic-based palliative care services and their prognosis is poor enough that hospice eligibility criteria are met. When prognosis has been discussed and a clinician believes a transition from cancer-directed therapy to hospice is warranted, the last phase of the conversation should include 3 steps: (1) assessing patient goals, (2) determining service needs (symptom management, skilled nursing, nutrition, spiritual, emotional, financial counseling, etc), and (3) aligning prognosis, goals, and care needs to create a comprehensive treatment plan that includes hospice.

Assessing Patient Goals and Hope

Research suggests that patients may be able to maintain hope for cure while acknowledging the terminal nature of their cancer. Patients want to maintain hope, even when they recognize their disease is terminal. Their desire for honest and hopeful communication may seem illogical when prognosis is limited, although literature suggests that honoring both preferences is possible. Physicians can help patients reorient their goals and foster hope by exploring goals appropriate for a patient’s level of function and stage of disease. For example, frank prognostic discussions may help patients acknowledge that prolonged life (survival) is unrealistic, but participation in important events, such as a wedding or party, or completing important planning activities, such as creating a will, may be possible.

Common themes identified in interviews and surveys with advanced cancer patients and their families with regard to hopefulness and appropriate goal setting are provided in Table 5.

Determining Service Needs

Patients with advanced cancer and poor prognosis may need durable medical equipment, spiritual coun-
saling, or support from social workers, increased home care for symptom or medication management, or may have such severe symptoms that an inpatient hospice setting is appropriate. In addition, the burden on caregivers of terminal cancer patients is often high, and it is important to talk with caregivers about how they are managing care of their loved ones. By asking caregivers directly (eg, "It can be very difficult to care for a family member at home. Have you thought about what kinds of help you might need?"), it may be possible to identify service needs that could be met by hospice.

Introducing and Referring to Hospice

Once a patient’s goals and service needs are well understood and a clinician believes that hospice is appropriate based on prognosis, the clinician is well positioned to introduce hospice as a set of services designed to optimize services and support for a patient and his/her family. For example, if a patient has expressed the desire to spend time at home with friends and family, and the patient’s caregiver would like increased assistance with personal care and symptom management, hospice should be introduced as a program of home services, including visiting nurses and aides, who can provide regular home-based services and can be available by telephone at all times to address symptom-related questions. Sample language for suggesting hospice may include the following:

“You’ve told me you’d like to spend as much time as possible at home, and it’s important for you to have your pain and shortness of breath controlled. Your wife would like some help organizing your medications and your day-to-day care. A program called ‘hospice’ provides symptom management and personal care services for patients like you. Have you heard about hospice?”

Introducing hospice in the context of a patient’s goals and needs may help patients understand the services available through hospice and limit their misconceptions (eg, being referred because death is imminent). In addition, talking with patients about their perceptions of hospice enables providers to address misconceptions early in the process of hospice referral.

Despite clinicians’ best efforts to communicate information on prognosis and transitions to hospice care, there will always be patients who are not interested in hospice services or those who are interested but ineligible because of desire for services not typically covered by the Medicare Hospice Benefit. For example, patients who want total parenteral nutrition or blood transfusions or those who need palliative radiation for painful bony metastases may be denied access to hospice because of high cost or complexity of providing these services. For example, 1 study of California hospice admission practices revealed that admission was denied to 48% of patients on chemotherapy, 36% of patients receiving radiation, and 25% of those requiring blood transfusions. Larger hospices and those a part of a hospice chain were less likely to have admission restrictions based on medically complex or expensive treatments. With regard to palliative radiation in hospice, a 2004 survey of National Hospice and Palliative Care Organization members revealed that although radiation was considered an important intervention, only 3% of patients received radiation treatments while getting hospice care from surveyed institutions. Cost was a notable barrier to provision of radiation services. Another study of freestanding Medicare-certified hospices revealed that only 23% of patients received palliative radiation. Larger hospice size, longer

### TABLE 5. Goal Setting and Maintenance of Hope After Disclosure of Poor Prognosis

| Physician Protocol |
|-------------------|
| Emphasize appropriate goal setting.93,95,109 |
| Attempt to reframe patient goals when they are unrealistic.95 |
| "Are there things you want to accomplish in the time you have left?"91 What are your most important hopes for the future?" |
| "I wish" statements may be useful to acknowledge the limits of medical care.110 |
| "Hope for the best and prepare for the worst."93 |
| Emphasize active interventions, not "there’s nothing more we can do."69,73,81 |
| Identify symptom management, emotional and practical service needs, and refer appropriately (eg, hospice care, chaplain, social worker). |
| Do not promise interventions that cannot be guaranteed (eg, you may not be able to eliminate patients’ symptoms completely).15 |
| Discuss quality of life, not length of life. Patients want information about symptoms and quality of life as their disease progresses.60,70 |
| Be prepared to discuss death if patients and families are interested.70 |
| Avoid abandonment. Provide a plan that continues the health care provider’s involvement during end-of-life care.98,108 |
length of hospice stay, and not-for-profit status were linked to palliative radiation provision.\textsuperscript{98} In the hospices with more patients or longer lengths of stay, cost for expensive services, such as palliative radiation, may be absorbed more easily.

For those patients who want aggressive anticancer therapy despite a poor prognosis and a clinician recommendation of hospice, a care plan may involve continued anticancer therapy (if any reasonable treatment option exists) and simultaneous palliative care or enrollment in hospice bridge program, if available. Decisions to continue use of disease-modifying therapies must be balanced with knowledge of a patient’s performance status and ability to tolerate therapy, treatment efficacy and toxicity, and preferences regarding quality versus length of life.

As noted previously, some patients may never want to talk about poor prognosis, survival, or death and dying\textsuperscript{60} and have a strong desire to receive treatment even when there is limited evidence of benefit.\textsuperscript{99,100} For these patients, frequent revisions in the goals of care are necessary, as these patients are likely to have steep functional declines and rapid changes in care needs. As more palliative treatment options are available for patients with metastatic cancer,\textsuperscript{101-103} it is important to repeatedly assess patient prognosis and goals and to be mindful of the pace at which patients with aggressive goals of care can accept that they are dying. Unfortunately, for some portion of this patient population, late hospice referrals or lack of hospice referral may be unavoidable.

Strong evidence that patients with advanced cancer and their caregivers benefit from discussing their end-of-life wishes with their oncologists has been generated from the findings of the Coping with Cancer (CWC) study. In this study, patients who talked with their oncologists about end-of-life wishes had better quality of life at the end of life, and their caregivers had better quality of life in the bereavement period. In addition, these patients used fewer intensive health care interventions at the end of life and were more likely to be enrolled in hospice for greater than 1 week.\textsuperscript{65} Furthermore, an analysis of cost differences between patients in the CWC cohort who had discussed end-of-life care and those who had not revealed a 35.7% decrease in cost of care for the last week of life.\textsuperscript{104} Given these potential benefits, it is important to consider earlier discussion about end of life with cancer patients. With earlier conversations, transitions near the end of life may be less daunting for patients, families, and their health care teams, and patients may have a better chance of having the type of death they desire.

**Conclusion**

Integrating palliative care upstream in the cancer care continuum should be considered the standard of care for patients with advanced or metastatic disease.\textsuperscript{4,6} In addition, hospice care is an important program of care for people dying from cancer and can be offered as part of comprehensive plan of high quality cancer care. Among cancer patients, hospice use has increased over time, but the percentage of patients who use hospice in the last 3 days of life is also increasing.\textsuperscript{103} The 2007 median and average hospice length of stay was 20.0 days and 67.4 days, respectively.\textsuperscript{3}

Late hospice referral and short hospice length of stay are concerning because the benefits of hospice are tied to longer lengths of stay.\textsuperscript{65} To provide optimal access to timely hospice services, conversations should occur within the context of honest prognostic disclosure, discussion of patient goals, and identification of service needs. By following the steps outlined in this article, providers will have an opportunity to improve the end-of-life experience for patients dying from cancer.
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