

Facilitating Hospice Discussions: A Six-Step Roadmap

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Abstract

Hospice programs provide comprehensive, compassionate care to dying patients and their families. However, many patients do not enroll in hospice, and those who do generally receive hospice care only in the last weeks of life. Although patients and families rely on their physicians to discuss hospice, there is often inadequate communication between patients and physicians about end-of-life issues. We describe a Six-Step Roadmap for navigating discussions about hospice adapted from the SPIKES protocol for delivering bad news: setting up the discussion, assessing the patient's perception, inviting a patient to discuss individual goals and needs, sharing knowledge, empathizing with the patient's emotions, and summarizing and strategizing the next steps.

Case

Mr. C is a 54-year-old man with metastatic lung adenocarcinoma who presented 1 year ago with multiple lung nodules and hepatic metastases. His tumor responded to initial treatment with four cycles of carboplatin and pemetrexed, and he was treated with maintenance pemetrexed for 5 months before his liver lesions progressed. Despite treatment with docetaxel and then erlotinib, his liver and lung tumors progressed rapidly. He has lost 10 pounds in the last few weeks and is now so fatigued that he spends most of his day resting in his recliner. He has been admitted to the hospital twice in the last month for worsening dyspnea in the setting of progressive pulmonary metastases.

Introduction

Hospice programs provide high-quality, compassionate care to dying patients and their families through an interdisciplinary team specializing in pain and symptom management.^{1,2} These

patients also receive medications and supplies, durable medical equipment, and home health aide services. Patients and their families receive support from a chaplain, social worker, physician, nurse, and volunteer. Families are offered bereavement services for at least 13 months following the patient's death (Table 1).³

Families report high levels of satisfaction with hospice and are more likely to describe high-quality care.¹ Despite this, only 40% of people in the United States die while receiving hospice care.³ Although longer hospice stays are associated with better quality of life in patients and less depression in bereaved family members,^{4,5} many patients enroll very late in the course of illness. In fact, the median length of stay is just over 3 weeks, and a third of patients die or are discharged within 1 week of hospice enrollment.³ The result is that brief exposures to hospice at the end of life do not allow patients and families to take full advantage of the benefits.⁶

There are several explanations for why people enroll in hospice so late. The Medicare Hospice Benefit requires hospice patients to choose a plan of comfort care, which means that they must usually forgo disease-directed therapies unless they provide a specific palliative benefit. Furthermore, the financial per diem payment structure of hospice means that patients may need to forgo palliative treatments that cannot be covered under the typical hospice reimbursement (approximately \$150/day for routine home care). Patients

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Table 1**Hospice Services and Team Members**

Services	
• Pain and symptom management	
• 24-hour telephone access to a clinician	
• Assistance with personal care needs	
• Help with errands and light housework	
• Spiritual support	
• Companionship for the patient and family	
• Bereavement counseling before and after the patient's death	
• Patient and family education and counseling	
• Case management and coordination	
• Advance care planning	
• Medications and supplies related to the hospice diagnosis	
• Durable medical equipment	
• Child bereavement services	
• Respite services (up to 5 consecutive days of inpatient care to allow families a needed break)	
• Inpatient hospice (for treatment of severe symptoms that cannot be managed at home)	
Team members	
• Physician	
• Nurse	
• Social worker	
• Home health aide	
• Chaplain	
• Bereavement counselor	
• Physical therapist	
• Occupational therapist	
• Volunteer	

National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America.³

may not be willing to give up these therapies or may be reluctant to transition from a model of care focusing on disease-directed therapies to one with palliation as the goal.

Patients may also enroll in hospice later if their physicians do not discuss hospice or if they have these discussions in the last few weeks of the patient's life.^{7,8} Physicians may delay hospice discussions because they are unsure of the patient's prognosis,⁹ although the disease trajectory in patients with cancer is often more straightforward than in patients with non-oncologic diagnoses. Studies have documented deficiencies in doctor-patient communication regarding prognosis and end-of-life issues,¹⁰ and patients report inadequate communication with physicians about shared decision making at the end of life.¹ Another study found that about half of patients diagnosed with metastatic lung cancer reported not having discussed hospice with a provider within 4–7 months after diagnosis.¹¹

Although these discussions may be delayed or avoided altogether, seriously ill patients value the ability to prepare for the end of life.^{12,13} Patients rely on their physicians to discuss hospice and other end-of-life care options. Furthermore, most family caregivers report that communication with their oncologists was important in helping them to understand the

patient's prognosis and to see the role that hospice could play as a treatment alternative.⁷

These conversations are often difficult for patients and families and can also be challenging for physicians. Nevertheless, communication skills in discussing transitions to palliative care can be learned.^{14,15} Although these discussions are not nearly as straightforward as a medical or surgical procedure, one can approach them with the same methodical preparation and careful consideration of the steps involved.

When Is a Hospice Discussion Appropriate?

To be eligible for the Medicare Hospice Benefit, a patient must have a prognosis of 6 months or less if his or her illness runs its usual course; also, the patient needs to be willing to accept the hospice philosophy of comfort care. This second criterion is not formally defined but is generally accepted to mean that the patient must be willing to forgo disease-directed therapies related to the hospice admitting diagnosis.

These eligibility criteria should not be used to define the patients for whom a hospice discussion is appropriate however. When a patient's goals and values reflect a desire to focus on palliation, it is time for the physician to initiate a hospice discussion. Other triggers for early hospice discussions can include a change in clinical status, recent hospitalization, decline in performance status, new weight loss, or complication of treatment. Although these factors may prompt a discussion of options for care, including hospice,^{16,17} not all discussions will lead to a hospice enrollment decision. Nevertheless, earlier discussions that prompt conversations about a patient's needs, goals, and preferences can facilitate later decisions about hospice and other treatment options.

A Six-Step Roadmap

We provide a Six-Step Roadmap for navigating discussions about hospice adapted from the SPIKES protocol for delivering bad news.¹⁸ This strategy is comprised of six communication steps that can be remembered by using the mnemonic SPIKES: setting up the discussion, assessing the patient's perception, inviting a patient to discuss individual goals and needs, sharing knowledge, empathizing with the patient's emotions, and summarizing and strategizing the next steps.

STEP 1: SET UP THE DISCUSSION ABOUT HOSPICE

Before discussing hospice with a patient and family, it is important to communicate with other members of the medical team to ensure an understanding of the patient's prognosis and treatment options. It is also helpful to find out what the patient and family may have expressed to other providers regarding these issues and how they have been coping. Any provider who has been in contact with the patient may be able to contribute to this consensus, including the medical oncologist, radiation oncologist, palliative care physician, primary care physician, home nurse, and social worker. A clear, unified message from the team decreases confusion for the patient and family.

Once a common agreement has been established regarding the patient's prognosis and treatment options, physicians can schedule a time and arrange for a place to allow for an uninter-

Table 2**Useful Language for Hospice Discussions**

Invite other decision makers	"Who do you usually rely on to help you make important decisions?" "When we discuss your results, who would you like to be present?"
Assess understanding of prognosis	"Tell me about your understanding of the most recent tests/studies." "Can you share with me what you think is happening with your cancer and the treatments?"
Identify goals of care	"What is most important to you right now?" "What are your biggest concerns right now?" "What are your hopes for the coming weeks/months?" "What do you enjoy doing now?" "What is most important to you now?" "What are you worried about now? In the future?"
Reframe goals ("wish" statements)	"I wish I could promise you that you will be able to make it to your daughter's wedding, but unfortunately I can't. What do you think about writing a letter for her to read on her wedding day? We can also think about other ways to let her know that you will always be with her, even if you cannot physically be there." "I wish that we could find a new chemotherapy that could cure your cancer. Even though cure is not possible, I think that we can meet some of your other goals, like staying at home to spend time with your children."
Identify needs for care	"What has been hard for you and your family?" "What is your life like when you are at home? How are you and your family managing?" "Are you experiencing pain or other symptoms that are bothering you?" "Have you been feeling sad or anxious lately?" "Would it be helpful to have a visiting nurse come to your home to assist you with your medications?"
Introduce hospice	"One of the best ways to give you the help that you need to stay at home is through hospice." "The hospice team specializes in caring for seriously ill patients at home." "Hospice can provide you and your family with more services and support."
Recommend hospice	"From what you have shared with me today, I recommend hospice as a way of helping you meet the goals that are important to you." "I feel that hospice is the best option for you and your family. I know this is a big decision, and I want you to know that the decision is yours."

Adapted from Cassett et al⁸ and Baille et al¹⁵

rupted conversation. Scheduling a patient at the end of a clinic day or visiting a patient in the hospital during an admission are potential ways to do this. Before scheduling a meeting, however, it is essential to know who the patient would like to be present at the meeting. One approach may be to tell the patient that there are important options to discuss regarding the next steps in his or her care and find out who may be able to help the patient with such decisions (Table 2). Additionally, a palliative care physician may cofacilitate these discussions. If the patient already has a palliative care physician, it may be helpful to have him or her involved in the meeting. If the patient has not yet been evaluated by a palliative care team, it may be possible to consult a palliative care specialist who can attend the meeting or follow up with the patient afterward.

Mr. C's medical oncologist, Dr. A, contacted Mr. C's radiation oncologist as well as his primary care physician. They all agreed that his prognosis could be measured in weeks to months and that his performance status precluded any further chemotherapy. Dr. A also spoke with the hospital social worker who met Mr. C and his wife during his most recent hospitalization. The social worker said that Mr. C's wife has been very distressed, particularly about his increasing debility and her difficulty in caring for him at home. When Dr. A visited Mr. C during his hospitalization, Dr. A explained to Mr. C that they would be making some decisions about the next steps in his care and asked who might be able to help with these decisions. When Mr. C said his wife would be this person, Dr. A asked that she come to his next visit. Dr. A decided

to schedule Mr. C for an appointment at the end of his clinic session the following week.

STEP 2: ASSESS THE PATIENT'S PERCEPTION

The physician can begin this discussion by asking the patient to describe his or her current medical situation (Table 2). Although the physician may have provided this information on prior occasions, it is important to hear the patient's perception of the diagnosis and prognosis. Patients with advanced cancer often overestimate their prognosis and are more likely to favor life-extending therapies over hospice.¹⁹ These questions provide an opportunity to address any misconceptions or gaps in understanding that the patient may have. When the physician, patient, and family are in agreement with the patient's current medical situation it allows for further exploration of the patient's hopes and concerns.

This part of the discussion should rely on open-ended questions designed to elicit the patient's perspective. In particular, an invitation to "tell me more" encourages patients to explore how they are thinking or feeling and can yield more information than closed-ended or leading questions. This phrase can also help redirect the conversation when necessary ("You mentioned before that you are worried that the chemotherapy is not working anymore. Tell me more about your concerns.").

Dr. A asked Mr. C how he was doing overall and to describe his understanding of whether the erlotinib had been working. In response, Mr. C expressed his concern about his recent weight loss and lethargy. Dr. A

asked Mr. C to tell him more about these concerns, and Mr. C said that he thought his symptoms were a sign that the erlotinib was not helping him. He said he knew that the CT scans showed progression of disease, and he wondered whether chemotherapy could help. Dr. A confirmed there was progression of cancer in his lungs and liver. Dr. A also expressed his concern that more chemotherapy would not provide additional benefit for him and may harm him. Mr. C and his wife were tearful and agreed that he was too weak for more chemotherapy. Dr. A acknowledged that the disease had progressed quickly and must be very upsetting to them.

STEP 3: INVITE THE PATIENT TO DISCUSS GOALS OF CARE AND NEEDS FOR CARE

Before sharing information about hospice with a patient, it is important to understand the patient's hopes and fears about the future, goals of care, and needs for care. It is helpful to start with learning about the patient's perspectives on the future and linking that to the patient's goals of care. Once the goals are clear, it is easier to match the patient's needs with his or her goals.

One way to elicit patients' goals of care is by asking them to describe their hopes and fears about their cancer in the context of their life (Table 2). Patients may volunteer information about their hopes (eg, attending their daughter's wedding) or fears (eg, worrying about pain) that provide insight into their more global goals of care. Again, the "tell me more" phrase can be helpful ("Tell me more about what you mean when you say you are a burden on your family.").

Once the patient and family express their thoughts, it is useful to restate the patient's goals by asking a question that summarizes the patient's statements ("From what you and your family have just shared with me, I hear that the most important thing to you is . . . Did I understand you correctly?"). It is often challenging for patients to specifically articulate their goals of care. Asking a question allows the patient and family the chance to elaborate or offer corrections.

If a patient expresses unrealistic expectations (eg, a cure, years of life), "wish" statements can be helpful in providing gentle redirection. These statements express empathy while also communicating that the wished-for outcome is unlikely ("I wish that we could guarantee that . . . but unfortunately we can't."). These statements can explain the reality of the situation in a compassionate manner (Table 2). Patients and families who have unrealistic goals of care may need time to readjust their expectations, and in these cases it may be prudent to revisit the discussion of hospice at a later date.

Once the goals of care have been established, it is important to further explore the needs for care. Although some of these needs may have been mentioned during the goals discussion, it is helpful to directly ask the patient and family about their needs. General questions about what has been hard for the patient and the family can be useful in eliciting needs, as are questions about what life has been like at home and how they are managing (Table 2). It is also important to ask more specific questions that pertain to the patient's symptoms such as pain or depression and those that address the family's needs for help around the house (Table 2). Once this information has been shared, it is often useful to repeat a

summary back to the patient and family ("From what we have just discussed, it may be helpful to have a visiting nurse to assist with his medications and a home health aide to dress and bathe him . . . Does it sound like this could be helpful to you?"). Often, these needs can be addressed by the multidisciplinary hospice team, and it is important to understand what needs exist in preparation for a discussion about how hospice might be helpful.

Mr. C shares with you that his two hospitalizations for dyspnea have been frustrating because he feels that they have prevented him from spending quality time with his daughters. Although he did not want to be admitted to the hospital, he tearfully expressed that he was worried about "suffocating to death" and did not want to die at home in front of his wife and children. Mr. C's wife also shares that it has been harder to bathe and dress him because he is becoming so weak. Mr. and Mrs. C agree that it would be helpful to have the support of a visiting nurse and a home health aide.

STEP 4: SHARE KNOWLEDGE

Once the patient's goals and needs for care have been clarified, physicians can introduce hospice as a way of achieving their goals and meeting their needs. In presenting hospice in this transparent manner, patients and families can better understand how hospice is part of a plan of care that addresses their individualized goals and needs. Most family caregivers report that communication with their oncologists was critical in their understanding the patient's prognosis and hospice as a treatment alternative.⁷ In one survey, the majority of caregivers did not realize that their loved ones could benefit from hospice until their physicians first discussed it with them.⁷

A discussion of hospice should offer concrete information about the services provided to patients and their families (Table 1). Many patients and families do not understand the benefits, such as a visiting nurse for frequent symptom management or a home health aide to assist with daily patient care, until after enrollment. Many say they wish they had known sooner.²⁰ By providing this information earlier, patients and families may make more informed decisions about hospice. This description also makes clear to the patient and family that hospice is not simply a generic recommendation but rather the physician's recommendation of a program that is the best fit for their specific goals and needs.

Given the emotional nature of these discussions and the large amount of information involved, it is important to ask the patient to explain in his or her own words how hospice could help ("To make sure I did a good job of explaining things, can you tell me what we just talked about in your own words?" and "How do you think hospice might help you?"). This provides the opportunity to assess understanding and clarify any confusion.

Since not all patients are best served by hospice, the discussion may also be expanded to include other options for palliative care. For example, hospice is not equipped to care for debilitated patients at home who do not have a caretaker, nor is it usually able to absorb the costs of expensive palliative treatments. Sometimes, larger hospices may be able to make exceptions on a case-by-case basis, but it is helpful to be

Table 3**NURSE Statements for Expressing Empathy**

N = Naming	"It sounds like you are worried about how fast the cancer has been progressing." "Some people in this situation would feel frustrated."
U = Understanding	"My understanding of what you have told me is that you are worried about being able to live independently at home." "I can see how difficult this has been for you and your family."
R = Respecting	"It is very clear to me how supportive your family has been." "I can see how hard you have worked to understand the treatment options for your cancer."
S = Supporting	"I will support the decisions that you make, no matter what you decide." "I will always be your doctor."
E = Exploring	"Could you tell me more about what you mean when you say that you don't want to give up?" "I sense that you may be feeling anxious about stopping chemotherapy. Can you share with me what you are feeling?"

Adapted from Back et al^{15,23}

aware of other options for palliative care like bridge-to-hospice home care and outpatient palliative care programs.

Dr. A explained that hospice could provide intensive management of his dyspnea with the assistance of a visiting nurse and a 24-hour phone line to call for assistance. With these measures in place, Dr. A said that he hoped hospitalizations could be avoided, allowing him more time at home with his family. Dr. A addressed Mr. C's concern about dying at home and shared with him that he could be transferred to an inpatient hospice if death seemed imminent. Dr. A shared with Mrs. C that hospice could provide the services of a home health aide, which seemed to reduce her concerns about being able to care for her husband as he became weaker.

STEP 5: EMPATHIZE WITH THE PATIENT'S EMOTION

In discussions regarding end-of-life care, patients and families value empathy, compassion, and honesty balanced with sensitivity and hope.²¹ Throughout the conversation, it is likely that the patient and family will express a range of emotions. Rather than providing immediate reassurance or trying to "fix" the emotion, it can be helpful to use an empathic statement to let the patient know that his or her emotions are recognized.¹⁵ Empathic responses address and validate a patient's emotions and encourage further disclosure.²² The NURSE mnemonic summarizes ways in which to respond to emotions: naming, understanding, respecting, supporting, and exploring the feelings the patient has shared (Table 3).^{15,23}

Some of the emotions arising during a hospice discussion may stem from preconceived notions or a prior experience. Therefore, it may be helpful to specifically ask patients and families about these perceptions and experiences. Common

misperceptions may include the concern that hospice hastens death. Other patients view hospice as "giving up" and worry about being abandoned by their physicians. A hospice discussion provides the opportunity to directly address these concerns and provide clarification ("No, hospice does not hasten death. Hospice helps you have the best quality of life for whatever time you have.").

Ultimately, some patients and families may decide that hospice is not the right choice for them. It is important to recognize that the time invested has not been wasted. Instead, if done well, these discussions offer an opportunity for the physician to align his or her goals and understanding with those of the patient and family. Specifically, these discussions are a chance to demonstrate a desire to understand the patient's individualized goals and to share concerns about disease progression. In essence, it is a valuable opportunity to establish a collective understanding about the patient's current situation while also laying important groundwork for future discussions.

Mr. C tearfully shared his concern about being a burden to his wife and about how his daughters would handle his progressive decline. Dr. A sat quietly, allowed Mr. C to fully detail his worries, and then said, "I can see how worried you are about your family and understand that you want to make sure that their needs are also addressed."

STEP 6: SUMMARIZE THE DISCUSSION AND STRATEGIZE NEXT STEPS

In all stages of cancer, patients and families rely on their oncologist for information about treatment options. This is particularly important when a patient's cancer has progressed despite therapy and when the focus of care may be shifting from disease-directed therapies to palliation. Just as a physician may have previously recommended a chemotherapeutic option for a patient, so should he or she recommend the therapeutic option of focusing on quality of life. If hospice appears consistent with the patient's and family's goals and needs, the physician should make this recommendation. It may be helpful for the patient and family to hear a summary of how hospice will meet their needs. If the patient is amenable to learning more about hospice but is not yet ready to enroll, the physician can arrange for an informational visit with the hospice team.

Dr. A recommends hospice and emphasizes that hospice would provide services that meet Mr. C's goals of symptom management, avoiding hospitalizations, and providing support for his family. Mr. C and his wife agree that hospice is the best option for them. They would like to enroll after they have spoken with their children about their decision.

Conclusion

Discussions about goals of care and hospice are not easy. They are rarely as straightforward as presented in this case, and an oncologist may face numerous barriers when attempting to have these discussions. For instance, treating physicians may have differing opinions on therapeutic options. Patients and family members may have different goals and may be in

different stages of accepting a life-limiting cancer diagnosis. Additionally, these discussions take preparation, time, and skill. Although there are no easy solutions to these issues, the general guidance provided in this article focuses on suggesting tools and techniques that can make these discussions easier for oncologists, patients, and families. By increasing our competence and comfort with these conversations, we can reduce delays in offering patients the benefits of hospice as they near the end of life.

Although no algorithm will fully address the complexities and nuances of these conversations, this approach provides a general framework and offers tools to use while speaking with patients and families. Conversations about hospice do not begin with the recommendation of hospice but rather with an honest discussion of the goals and needs of a patient and family. If these goals and needs can be met with the services that hospice can provide, the physician has the opportunity to

educate the patient and to make the recommendation as they would for any other therapeutic option.

Patients and families consider communication to be one of the most important facets of end-of-life care.²⁴ Seriously ill patients value being able to prepare for death,¹³ and physicians have the duty to help patients and families prepare for the end of life.²⁵ Physicians can help increase the time patients have to plan for the last phase of their lives by having honest and open discussions about hospice and other alternatives. Oncologists have the responsibility to present patients with the benefits and burdens of therapies throughout the trajectory of their illness, and it is critically important during the transition from disease-directed to palliative care. By exploring the option of hospice, patients and families can make informed decisions about whether hospice may meet their needs. Equally important, patients are given the control to choose how they would like to live the final phase of their lives.

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