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"I'm Not Ready for Hospice": Strategies for Timely and Effective Hospice Discussions

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Hospice programs offer unique benefits for patients who are near the end of life and their families, and growing evidence indicates that hospice can provide high-quality care. Despite these benefits, many patients do not enroll in hospice, and those who enroll generally do so very late in the course of their illness. Some barriers to hospice referral arise from the requirements of hospice eligibility, which will be difficult to eliminate without major changes to hospice organization and financing. However, the challenges of discussing hospice create other barriers that are more easily remedied. The biggest communication barrier is that physicians are often unsure of how to talk with patients clearly and directly about their poor prognosis and limited treatment options (both requirements of hospice referral) without depriving them of hope. This article describes a structured strategy for discussing hospice, based on techniques of effective communication that physicians use in other "bad news" situations. This strategy can make hospice discussions both more compassionate and more effective.

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Hospice programs provide a unique set of benefits for dying patients and their families (1). For instance, hospice patients receive medications related to their hospice diagnosis, durable medical equipment, home health aide services, and care from an interdisciplinary team. Families also receive emotional and spiritual support and bereavement counseling for at least a year after the patient's death.

Growing evidence from case–control studies indicates that hospice is able to provide high-quality care with high levels of satisfaction (2–5). This evidence shows improved pain assessment and management, improved bereavement outcomes, better overall satisfaction, and lower mortality rates among family members of patients who received hospice care (2, 4–6). In addition, 1 randomized, controlled trial found greater satisfaction among families of patients referred to hospice (3).

However, hospice provides care for only one third of all dying patients in this country, and patients who enroll generally do so very late in the course of illness. The median length of stay in hospice is approximately 3 weeks, and 10% of patients enroll in their last 24 hours of life (7). It is not known what proportion of patients should enroll in hospice or what the optimal length of stay is. Nevertheless, there is widespread agreement among experts in the field (8–11) and physicians (12) that more patients could enroll in hospice and many of those who enroll should do so sooner.

In part, barriers to hospice referral arise from the way that hospice care is designed. The eligibility requirements—that patients must have a life expectancy of 6 months and must forgo curative treatment—are fixed by the Medicare Hospice Benefit (1). In addition, patients may delay enrolling because reimbursement rates make it difficult for many hospices to provide expensive palliative treatments.

However, other barriers are created by the challenges of hospice discussions. For example, some patients and families cannot accept that effective, disease-directed treatment is no longer available or that the patient has fewer than 6 months to live. In this article, we describe approaches to hospice discussions using 3 different scenarios: a patient with a limited life expectancy who still wants aggressive treatment, a patient whose goals are consistent with hospice but who has an uncertain life expectancy, and a patient for whom hospice appears to be the best option on the basis of both prognosis and patient goals. In the third scenario, we describe a structured discussion that is modeled on other discussions that involve breaking "bad news" (13).

WHEN A PATIENT HAS A LIMITED LIFE EXPECTANCY BUT WANTS AGGRESSIVE TREATMENT

It is not unusual for patients or families to have overly optimistic goals and expectations of treatment (14–16). In these cases, even the most careful and persistent communication efforts often fail to change patients' and families' goals, and a decision to enroll in hospice is unlikely. However, physicians should still discuss the patient's goals for care and can use these discussions to introduce hospice as an option for the future.

Mr. T. is a 71-year-old veteran with congestive heart failure (ejection fraction, 0.12) and dyspnea at rest. He has been admitted for intravenous dobutamine 3 times in the past 6 months. During his last admission, he required tracheal intubation and mechanical ventilation. Whenever his physicians have discussed treatment goals, Mr. T. has remained steadfast in his desire for aggressive life-sustaining treatment. He has said that he would be willing to endure any discomfort for a chance of living even a few days more,

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as long as he is still able to make health care decisions for himself.

Although Mr. T. will probably live fewer than 6 months if his illness runs the usual course, his treatment goals are inconsistent with hospice's requirement of a focus on palliative care. Moreover, his preferences are not unrealistic, because aggressive, disease-directed treatment may prolong his life. Therefore, hospice is not appropriate for Mr. T. at this time.

However, Mr. T.'s physician should still explore the choices that Mr. T. and his family will face in the future, including choices about hospice. His physician should also explain that Mr. T.'s heart failure is a progressive disease that will ultimately be fatal. In 1 prospective study, this acknowledgment was an independent predictor of subsequent hospice enrollment in patients with noncancer diagnoses (17). This discussion provides a valuable opportunity to introduce hospice as an option for the future. Although most hospice discussions occur very close to the time of enrollment (18), early discussions can promote more timely hospice enrollment and may improve satisfaction with end-of-life care (3).

Mr. T.'s physician acknowledges Mr. T.'s strong feelings about treatment but suggests that hospice might be the best option in the future if he becomes unable to make his own decisions. Mr. T. agrees and tells his wife that he would want hospice care if that happens.

Table 1. **Factors That Are Associated with a Limited Prognosis and That Should Trigger Consideration of Hospice in Selected Diagnoses***

- **Congestive heart failure**
  - New York Heart Association class IV (the existence of symptoms at rest) (21)
  - Serum sodium level <134 mmol/L or creatinine level >2.0 mg/dL attributable to poor cardiac output (22)
- **Chronic obstructive pulmonary disease**
  - Cor pulmonale (23, 24)
  - Intensive care unit admission for exacerbation (25)
  - New dependence in 2 ADLs (24)
  - Chronic hypercapnia (Pa_{CO_2} >50 mm Hg) (26)
- **Dementia**
  - Dependence in all ADLs, language limited to several words, and inability to ambulate (27)
  - Acute hospitalization (especially for pneumonia or hip fracture) (28)
- **Cancer**
  - Performance status
    - Karnofsky score <50 (29)
    - Eastern Cooperative Oncology Group score >2 (30, 31)
  - Signs and symptoms
    - Liver metastatic tumors (32)
    - Multiple tumor sites (≥5) (32)
    - Malignant bowel obstruction (33–35)
    - Malignant pericardial effusion
    - Carcinomatous meningitis

* ADLs = activities of daily living.

WHEN A PATIENT'S GOALS ARE CONSISTENT WITH HOSPICE BUT LIFE EXPECTANCY IS UNCERTAIN

Physicians find it difficult to predict survival accurately in patients with advanced illness (12) and often overestimate a patient's life expectancy at the time of hospice referral (19). As a result, many patients are never informed about hospice, and others are referred to hospice weeks or months after their goals make them eligible (17).

Mr. B. is a 75-year-old man with moderate Alzheimer disease and coronary artery disease who was recently admitted to a skilled care facility. He needs assistance with most activities of daily living and is often confused and disoriented. He is able to eat with some assistance, and his weight has been stable. Mr. B.'s wife understands that Alzheimer disease is progressive and ultimately fatal and will eventually result in a quality of life that would be unacceptable to her husband. She believes her husband would want a palliative approach to care.

Although a hospice approach seems ideal for Mr. B., Medicare regulations require that his physician and a hospice medical director certify that he has 6 or fewer months to live if his illness runs the usual course (1). To help determine prognosis, hospices use guidelines for noncancer diagnoses that are promulgated by Medicare's fiscal intermediaries (20). These criteria ultimately determine a hospice's decision about eligibility, but physicians do not need to use them in determining whether to initiate a hospice discussion. Instead, they should be alert for simple, easily ascertained clinical characteristics that are associated with a life expectancy of 6 months or fewer. The most valuable predictors of a limited life expectancy can be derived from available clinical and laboratory data and require no additional testing (**Table 1** [21–35]).

Mr. B.'s physician should recommend hospice if she identifies characteristics that are associated with a limited life expectancy (**Table 1**) or, more generally, if she suspects he may have a life expectancy of 6 months or less. In recommending hospice, she need not certify that Mr. B. will die within 6 months, but only that death is more likely than not within that period. A letter from former Centers for Medicare & Medicaid Services administrator Thomas Scully emphasizes that prognostication "is not an exact science" and that physicians are only expected to use their best clinical judgment (36).

Mr. B. does not have the common indicators of limited life expectancy in patients with dementia, such as recent hospitalizations for aspiration pneumonia or extremely limited verbal communication (27, 28), and Mr. B.'s physician believes that he is likely to live for another 2 to 3 years if his illness runs the usual course. Therefore, Mr. B.'s physician suggests that they institute a palliative approach to treatment now and that they reconsider a hospice referral in the future as his condition declines.

WHEN HOSPICE SEEMS TO BE THE BEST OPTION

When patients have a poor prognosis and treatment options are limited, physicians should discuss hospice more directly and recommend it when appropriate (37). Physicians often find these hospice discussions difficult and uncomfortable because patients are being asked to "give up" on disease-directed treatment. However, just as they can with other "bad news" discussions, physicians can make hospice discussions more compassionate, and more effective, by following a structured approach similar to that first described by Buckman for breaking bad news (13). The overall aim of a hospice discussion that follows this approach is to define a patient's treatment goals and needs for care and then to present hospice as a way to achieve those goals and meet those needs.

Ms. M. is a 42-year-old woman with ovarian cancer and hepatic metastatic tumors. Her functional status is poor. She lives at home with her 2 adolescent children and her husband, who has become her sole caregiver. Her cancer has extensive peritoneal involvement, with tense ascites managed by a peritoneal catheter. She enrolled in a phase II trial, but diminished renal function required that she withdraw. During the previous month, she has spent almost the entire day in bed and has relied on her husband for most of her care needs. She was admitted to the hospital 3 days ago for malignant bowel obstruction, which has improved with bowel rest, intravenous fluids, and octreotide.

Metastatic ovarian cancer with poor functional status and malignant bowel obstruction is associated with a poor prognosis (30, 31, 33–35). No further options for curative treatment are available. Therefore, Ms. M.'s physician should discuss hospice as the best option for care. Although it is sometimes feasible to extend a hospice discussion over several follow-up visits, Ms. M.'s physician should initiate this discussion as soon as possible in light of Ms. M.'s limited life expectancy. An effective approach to hospice discussions has 8 steps that are similar to those of other discussions in which physicians must share bad news with a patient and family (13, 38).

Establish the Medical Facts

As with any important health care conversation, Ms. M.'s physician needs to be certain that Ms. M.'s other health care providers share his impression of her therapeutic options before meeting with the patient and her family. Mixed messages from health care providers make discussions particularly difficult. Therefore, communication with the patient's other health care providers is essential to ensure a coordinated approach.

Set the Stage

Ms. M.'s physician should identify a time and place for an uninterrupted conversation. Because hospice decisions are often shared with family members (18, 39), he should ensure that those with whom Ms. M. would share major decisions are present (**Table 2**). In this case, Ms. M. and her husband share her health care decisions.

Assess the Patient's Understanding of His or Her Prognosis

At the start of the discussion, Ms. M.'s physician should determine what she and her husband know about her disease status and prognosis (**Table 2**). Patients with serious illness may have an overly optimistic view of their prognosis (14–16), and physicians may contribute to this discrepancy by inflating the prognostic estimates that they provide (40). Therefore, it is useful to begin by asking patients to describe their current medical situation (**Table 2**). This question can identify gaps in patients' knowledge (misunderstanding) and in their ability to apply that knowledge to their own situation (denial) (41).

Ms. M. and her husband recognize that her cancer is very advanced and that it will progress in the near future. She volunteers that she has begun organizing her affairs and writing letters to leave to her children.

Define the Patient's Goals for Care

After clarifying Ms. M.'s understanding and expectations, her physician should help to define her goals for care (**Table 2**). In some situations, simply summarizing what those goals appear to be in the form of a question is sufficient ("From what you've told me, and the things we've talked about in the past, it seems like what's most important to you at this stage is. . . . Is that right?"). Under other circumstances, a patient's goals may be unclear or unrealistic, in which case, reconciliation with the physician's views is essential. At a minimum, it is important to inquire about patients' hopes and fears, which offer insights into their goals (for example, remaining at home, avoiding discomfort, living as long as possible) (38). Finally, "wish" statements can be helpful in keeping patients and physicians on the same page when patient's goals are unrealistic ("I wish we could guarantee that. . . . But we can't.") (42).

Patients and families with unrealistic goals need time to readjust their plans and expectations. In addition, physicians need to explain their positions with clarity, compassion, and support. It may take time to negotiate realistic treatment goals, and physicians should generally wait to recommend hospice until the patient's goals are consistent with a hospice approach.

Ms. M. says the current hospitalization has been difficult for her and has prevented her from spending time with her children, which is her foremost priority. She would like to avoid another hospitalization unless it would be necessary to relieve her symptoms. She realizes that no further curative treatments are available, but she wants to know whether surgery would be an option for treating the malignant bowel obstruction. Her physician explains that the ascites would make surgery technically difficult and would increase the risk for complications. Ms. M. and her husband accept this news tearfully.

Table 2. **Useful Language for Hospice Discussions**

Identify other decision makers	"Is there anyone you rely on to help you make important decisions?" "Who in the family should be there with us when we discuss the results?"
Assess understanding of prognosis	"What have your other doctors told you about your condition?" "Have they talked to you about what this latest problem might mean for you?" "From what you know, do you think that over the next month your cancer will get better, worse, or stay the same?"
Define the patient's goals for care	"What do you hope for most in the next few months?" "Is there anything that you're afraid of?"
Reframe goals	"I wish we could guarantee that we could keep you alive until your daughter's graduation, but unfortunately we can't. Perhaps we can work together on a letter for her to read on that day, so she will know you are there in spirit in case you cannot be there."
Identify needs for care	"It can be very difficult to care for a family member at home, and no one can do it alone. Have you thought about what kinds of help you might need?" "Would it help if we could find a way to deliver your medications to you?" "Would it reassure you if we could send a nurse out to your home to check on you?"
Summarize and link goals with care needs	"So I think I understand that your main goal is to stay at home and spend time with your family. To do that, we will need to help you in several ways, for instance, by sending a nurse out to your home and giving you both some help around the house. Is that right?"
Introduce hospice	"One of the best ways to give you the help that you will need to stay at home with your family is a program called hospice. Have you heard of hospice?" "Hospice is able to provide more services and support at home than most other home care programs." "The hospice team has a lot of experience caring for seriously ill patients at home."
Respond to emotions elicited and provide closure	
Acknowledge response	"You seemed surprised to learn how sick you are." "I can see it's not easy for you to talk about hospice."
Legitimize reaction	"Many people are understandably upset when they learn how ill their loved one is and that hospice is a possibility."
Empathize	"I can imagine how hard this is for both of you; you care about each other so much."
Explore concerns	"Tell me what's upsetting you the most."
Explain hospice goals	"Hospice doesn't help people die sooner. Hospice helps people die naturally, in their own time." "Hospice helps people live as well as they can for as long as they can."
Reassure	"Hospice's goal is to improve your quality of life as much as possible for whatever time you have left." "Hospice can help you and your family make the most of the time you have left."
Reinforce commitment to care	"Let's think this over for a day or two; you know I will continue to care for you whatever decision you make."
Recommend hospice	"I think that hospice would be your best choice right now, but of course, the final decision is yours." "Hospice could be very helpful to you in the ways that we've talked about, but I realize it's a big decision. I'd like to arrange for a hospice nurse to visit you so you can decide for yourself whether hospice is right for you."

Identify Needs for Care

Next, her physician should identify Ms. M. and her husband's needs and help them determine which needs could be met by hospice services. For instance, Ms. M.'s physician should identify symptoms and other sources of distress that could be alleviated by the intensive home care services that hospice can provide (**Table 3**). This discussion should be tailored to the patient's underlying illness, but symptoms like pain, fatigue, and constipation are common and should be assessed for most patients (43–46). In addition, it is important to identify other problems that respond particularly well to the multidimensional treatment that hospice can provide, such as dyspnea, depression, anxiety, and existential distress.

Ms. M.'s physician should also identify needs for practical assistance at home, because the care provided by informal caregivers may not be sufficient to meet the patient's needs (47). Ms. M.'s physician can also inquire about the need for financial help and spiritual or emotional support. Suggestions of specific services can be particularly useful in clarifying needs (**Table 2**).

Ms. M. and her husband identify several needs for care, including a visiting nurse to help her with the peritoneal catheter and with symptom management. Her husband also says he would welcome having someone to help around the house and to stay with his wife while he runs errands. They both wonder about how to prepare their children.

Introduce Hospice

At this point in the discussion, Ms. M.'s physician can introduce hospice as a way to achieve Ms. M.'s goals and meet their needs. Ideally, this part of the discussion should connect the patient's understanding of her illness, goals, and needs for care in a logical way. This helps physicians to present hospice as 1 part of a coherent plan of care that makes sense to patients and families (**Table 2**).

A discussion of hospice should take into account other programs for care that might be available, since hospice is not always the best option. For example, home hospice is poorly equipped to meet the needs of debilitated patients without informal caregivers who want to remain at home, unless they can pay for help. Similarly, frail older adults who require extensive supervision may receive more home care services from a Program of All-inclusive Care for the Elderly (PACE) (48, 49).

If Ms. M.'s physician feels that hospice is her best option, he should introduce it now. There are 2 advantages to introducing hospice at this point in the discussion, rather than at the beginning. First, the delay can help physicians address common misconceptions about hospice. Some people initially view hospice as a sign of "giving up." Others believe that hospice is only for patients who are imminently dying or who have cancer or that hospice is a place where one goes to die rather than a home-based program (50, 51).

By delaying the discussion of hospice, physicians can ensure that patients and families are informed about the benefits of hospice before their preconceptions can color their response. Second, by introducing hospice late in the discussion, physicians can show that they understand the patient's goals and needs and that they are recommending hospice on the basis of this common understanding. This element of transparency is a key feature of both informed consent and good communication (52).

Ms. M.'s physician describes hospice as a program of care that is consistent with her goals and can meet the needs that they have identified together. Ms. M. and her husband respond positively, although tearfully, and she asks if a hospice referral means that she will only have "a few days" to live.

Respond to Emotions Elicited and Provide Closure

Throughout this discussion, it is essential to recognize and respond to the feelings of the patient and the family (**Table 2**). It can be useful to begin this process by asking about their experiences with hospice, so that negative experiences can be addressed and positive experiences can be integrated into the discussion. Physicians should fully explore and define any concerns raised before offering reassurance. Ms. M.'s physician can also anticipate common questions about hospice. For example, patients and families often want to know about payment for hospice care and what home care services hospice provides (18, 39). Her physician should conclude the conversation by reinforcing his commitment to care for Ms. M. and her family regardless of their decision.

Recommend Hospice and Refer

Ms. M.'s physician can arrange an enrollment visit if she and her husband decide that hospice is the best option, or he can suggest an "informational visit" if they are unsure. Before initiating a referral, physicians should be aware that some hospices are unwilling to accept a patient who is receiving expensive palliative treatments, such as octreotide for malignant bowel obstruction, or palliative radiation therapy. Hospices typically receive approximately $130 per day for home care, which is not adequate to cover the costs of such treatments. Hospices that care for large numbers of patients can absorb excess costs, but smaller hospices cannot. Some hospices may offer "open access" to all patients regardless of treatment, but this is not yet typical.

This barrier to hospice is arguably unethical and should be eliminated by changes to the Medicare Hospice Benefit. In the meantime, physicians should advocate on the patient's behalf and should press the hospice to act in the patient's best interests. If these negotiations are unsuccessful, physicians can consider an independent palliative care program or a hospice's "bridge" program as an alternative (53).

Table 3. **Hospice Services and Interdisciplinary Hospice Team Members**

- Services
  - Symptom management
  - Patient and family education
  - 24-hour case management
  - Patient and family counseling
  - Advance care planning
  - Identification of additional community resources
  - Assistance with personal care needs
  - Help with light housework
  - Spiritual support
  - Bereavement assessment and counseling after patient's death
  - Companionship for patient and family
  - Assistance with errands
  - Durable medical equipment
  - Medications and supplies related to admitting diagnosis
- Team members
  - Nurse
  - Physician or medical director
  - Social worker
  - Home health aide
  - Chaplain
  - Bereavement counselor
  - Volunteer

Ms. M. and her husband would like to learn more about hospice, so her physician arranges an informational visit in the hospital for the following day. At that visit, Ms. M. and her husband decide that hospice could help with the transition home and agree to hospice enrollment at the time of discharge.

CONCLUSION

Physicians who initiate discussions about hospice face several challenges. For example, they must determine whether hospice is appropriate, given a patient's goals and prognosis. Furthermore, even if hospice is clearly appropriate, the initial discussion can be uncomfortable for everyone. Although there are clear benefits to timely hospice referral for many patients, the introduction of hospice is frequently perceived by patients and families as bad news. Given these challenges, it is not surprising that hospice discussions happen very late in the course of illness and that most patients receive hospice care for only a short period. Physicians can overcome many of these challenges by considering indicators of a limited prognosis, framing the hospice discussion in terms of the patient's goals and needs for care, and recommending hospice when they think it is the best option. This approach, which has much in common with other "bad news" discussions, can provide structure for what can be a difficult conversation. Moreover, this approach can help physicians to deal with misperceptions and strong emotions and to present hospice as the best way to meet the needs of patients and their families in light of their clinical circumstances, prognosis, goals, and values.

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