Why Oncologists Should Refer Patients Earlier for Hospice Care

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In this article, prognostic data are summarized and a suggested approach for discussing hospice enrollment with patients is presented.

Introduction

Since 1982, when Congress created the Medicare Hospice Benefit, home hospice has been broadly available in the US for the care of patients with advanced illnesses who have about 6 months left to live. National guidelines have consistently suggested that referral for hospice care is the best approach for medical management of patients with end-of-life needs, yet only about half of all cancer patients who die are ever referred for such care.[1-3] Patients referred to hospice often live for only a few days, thereby undermining the potential benefits to patients and their families of a concerted approach to care by the hospice team over a lengthier period of time.[4]

How can it be that hospice care is beneficial for cancer patients nearing the end of life but remains underutilized? The purpose of this article is to examine this quality-of-care conundrum. First we will review the patterns of cancer care near the end of life in the US, focusing particularly on the behavior of oncologists. Then we will contrast this approach with what patients and their families say they want from their oncologists during this period. We will then review what an oncologist needs to know to determine the right time to refer a patient for hospice care and what this service can offer patients with cancer and their families. Finally, for oncologists who may need to hone this skill, we will describe an approach to structuring the physician-patient conversation regarding hospice care.

Patterns of End-of-Life Cancer Care in the US

The overall pattern of care at the end of life for patients with advanced cancer has not changed much since the war on cancer was first declared in the early 1970s.[5] While it is true that overall mortality from cancer has gradually declined in recent years, this improvement is mostly due to prevention (smoking), early detection of surgically removable malignancies (eg, breast cancer), or early detection of malignancies that, if left undetected, would not have affected mortality (eg, prostate cancer). For cancer that has recurred, or is surgically unresectable, the overall mortality curve is unchanged.[6]

What has changed is the amount of chemotherapy and the increased sophistication of radiotherapy administered to patients prior to death.[7] While a great number of newer chemotherapy agents can yield a temporary radiological response in a wide array of tumors, there has been little change in clinical status or overall mortality. The existence of those agents has increased the complexity of treatment-goal discussions for this patient group, however. Whereas there may have been only a single chemotherapy for certain clinical situations in the past, there may now be a series of "salvage" regimens available. These agents are often reported by the media or advertised to patients (on television, via the internet) as a promising new advance in cancer care. Even when their clinical status has begun to wane, patients will pursue salvage regimens with the hope of response. Sadly, for patients with extensive disease, there is generally a low response rate and no change in life expectancy with most salvage regimens. Some oncologists point out that the very act of delivering chemotherapy eases the psychological pain of many patients, and that patients will seek out a physician who will pursue their continued wish to fight cancer.[8] In other words, the path of least resistance for some oncologists may involve delivery of chemotherapy as a type of "placebo" rather than engaging in a lengthy, honest, and emotionally draining discussion about prognosis with the patient and family. Further, oncology training in the US lacks instruction about how to have these difficult conversations, though they are so common in routine practice. Patterns for the delivery of
radiotherapy near the end of life are similar. **TABLE 1**

## Cancer: Prognostic Factors and Median Survival, Assuming Maximal Medical Therapy

Many oncologists wait until the patient becomes "symptomatic" before discussing explicit aspects of end-of-life care, even when it is clear that the cancer will be life-limiting.[9] As shown in Table 1, for the majority of patients with chemotherapy-refractory solid tumors, the period between "becoming symptomatic" with poor performance status and the death of the patient is 4 to 6 weeks. These poor-prognosis patients have always been excluded from clinical trials. Patients appear to be unwilling to "give up" chemotherapy unless the oncologist is explicit about prognosis and the likelihood that chemotherapy or radiotherapy will change the prognosis.[10,11] When therapy risks might outweigh the benefits, patients say they want to know.[12,13] Patients need accurate information about whether the treatment will help them to achieve their goals near the end of life. Patients have described five domains of quality end-of-life care: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones.[14] These goals may be met only when the prognosis is fully disclosed. Cancer prognostic factors are not easy to find; the standard textbooks do not codify that information in predictable, easy-to-find ways. However, Table 1 includes prognostic facts about patients with advanced cancers.

### What Hospice Care Offers in the United States

**TABLE 2**

## Medicare Hospice Benefit

Hospice care is enhanced palliative care for patients with advanced cancer as they approach the end of their lives. In the US, this is conventionally defined as a likely life expectancy of 6 months, if the disease runs its usual course. In the US, about 80% of hospice care is paid for by Medicare, the federal system of healthcare coverage for the elderly and the disabled. The MHB pays for comprehensive medical, nursing, counseling, and bereavement services provided to patients living with advanced illness and to their families (**Table 2**). These services are provided by an interdisciplinary team which meets at least every other week to review the plan of care and its effectiveness in advancing the goals expressed by the patient, family, and other caregivers. As a generalization, about 95% of hospice care is provided where a patient lives (either at home or in a
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long-term-care facility). These services can also be provided in an inpatient hospice unit or a hospital. Although hospice provides end-of-life care, referral for hospice care does not shorten life expectancy. For certain diagnoses, hospice enrollment is actually associated with longer survival times. For instance, patients with newly diagnosed non–small-cell lung cancer show a longer median survival time, increased quality of life, decreased chemotherapy use, and longer hospice stay when palliative care is instituted early in their disease trajectory.[4]

In addition to benefits to patients, the Center to Advance Palliative Care (www.CAPC.org) summarizes benefits to physicians for referral of patients for hospice care. These include fewer disruptions to their schedules for the management of patients at home, reduced conflict with patients and families, and avoidance of the need to learn new codes and bill for the necessary prolonged medical services. Importantly, hospice care, with its special expertise, has been demonstrated to be superior to standard end-of-life care.[15]

**Referring Patients for Hospice Care**

The most common complaint from patients and families about hospice care is that they were not informed about the practical benefits; there was too much talk about the philosophy of care and not enough about who would help and how.[16] While managing symptoms and ensuring physical comfort are important, patients and families experience multiple issues that cause suffering and which lie in the practical, emotional, and spiritual domains.

When patients elect coverage using the MHB, the hospice coordinates and pays for all treatments and medications related to the primary hospice diagnosis. Patients can continue to receive care for diseases unrelated to the advanced illness (eg, continued dialysis for renal failure if the patient is dying of cancer) using regular Medicare coverage. Most Medicaid and commercial insurers use the Medicare Hospice Benefit Model for coverage of hospice care. Most Medicaid and commercial insurers use the Medicare Hospice Benefit Model for coverage of hospice care.

**Medicare hospice benefit eligibility**

To pay for hospice care, Medicare requires both the attending doctor and hospice doctor to certify that the patient has a life expectancy of 6 months or less if the disease or condition runs its normal course. The standard for certainty is “more likely than not”; in other words, the patient has a 51% or greater chance of dying in the next 6 months. If patients improve or resume disease-directed therapy with the primary goal of extending life-expectancy, they can be discharged and have their care paid for under the usual Medicare Part A, Part B, and Part D benefits. They can later elect the MHB and resume hospice services without penalty. Individual patients can continue to be eligible for hospice if they live longer than 6 months, providing that the doctor believes death is more likely than not within 6 months. The patient does not need a do-not-resuscitate (DNR) order to be eligible for hospice care. There is no limit to the number of days that a patient can receive hospice care. There is no penalty if the patient outlives the initial prognosis. For example, one of the authors (CvG) had a patient with refractory breast cancer live for 6 years while enrolled in hospice care. At each recertification period, it was clear that the patient was more likely than not to die within 6 months because of her underlying disease. It was unforeseeable that this patient would live much longer than average.

**Prognosis**

When compared with actual survival, doctors overestimate prognosis by a factor of three or greater.[17] For cancer, the most reliable indicator of prognosis is performance status—and this scientific fact has not changed in more than 40 years (Table 1).

**Plan of care (POC)**

The hospice program approves, coordinates, and pays for services that are reasonable and necessary for palliation and for management of the advanced illness. The POC is based on the patient's diagnosis, needs, goals of care, orders of the attending doctor, and, as necessary, collaboration with the hospice medical director. It includes caregiver education and support for the patient and family as the unit of care. It is surprising to many doctors that the hospice team can spend considerable time with the patient's family members to address their concerns and help in decisions that can significantly affect the wellbeing of the patient. The POC is quite specific to individual hospice programs. Some care plans will include chemotherapy, radiotherapy, blood transfusions, antibiotics, laboratory testing, radiological imaging, and total
parenteral nutrition (TPN), among other interventions when they are likely to make the patient feel better. Other, usually smaller, hospice programs will not be able to provide these interventions as part of the plan of care because of availability and cost. The MHB includes no rules about what may or may not be incorporated into the plan of care.

Doctor role

The attending doctor is indicated by the patient at the time of enrollment. This can be the patient's oncologist. Sometimes the patient will select a hospice doctor for this role. Sometimes the oncologist will request that the hospice doctor be the attending physician for the purposes of hospice enrollment, to deal with ordering and renewing medications; other oncologists prefer to retain this role.

The attending doctor is responsible for working with the hospice team to direct care. Direct patient care services by the attending doctor are billed to Medicare in the usual fashion using the standard Evaluation and Management codes.

Places of care

Home. The majority (95%) of hospice care days take place in the home because that is where patients say they want to be. Hospice team members visit the patient and family on an intermittent basis. Care continues as long as the patient remains eligible and wants the care. Medicare rules do not require a primary caregiver to be in the home; many patients live alone and like it that way! Nursing home or other long-term care facility. This is the patient's home, and the patient's "family" frequently includes the staff. Hospice care is specialty care provided in addition to usual nursing home care.

Hospice inpatient unit. Dedicated units are sometimes available which are free-standing or located within other facilities such as nursing homes or hospitals. Permitted length-of-stay varies, as some units are for residential care and others are for short-term acute palliative care.

Hospital. Occasionally pain and other symptoms or other conditions related to the advanced illness cannot be managed at home and the patient is admitted to an inpatient hospital or other contracted inpatient facility for more intensive management. The inpatient facility must have a contract with the hospice program.

Payment to the hospice

Medicare pays for covered services using a per diem capitated arrangement in one of four categories:

- **Routine home care:** Care at home or in a nursing home.
- **Inpatient respite care:** Care in an inpatient setting (usually a nursing home or inpatient hospice unit) for up to 5 days, to give family caregivers a break when the patient is otherwise clinically stable.
- **General inpatient care:** Acute inpatient care for conditions related to the advanced illness (eg, pain and symptom control, caregiver breakdown, impending death and the patient does not want to die at home).
- **Continuous home care:** Provides short-term acute care at home with around-the-clock care for a crisis that might otherwise lead to inpatient care. Many hospice programs find this type of care challenging to provide, because of the staffing requirements.

Payment to attending and consulting doctors

Direct patient care services by the attending doctor for care related to the advanced illness are covered by Medicare, but not under the MHB.

If the attending doctor is not associated with the hospice program, the doctor bills Medicare Part B in the usual fashion. The bill must indicate that the doctor is not associated with the hospice program, or the claim may be denied. If the attending is associated with the hospice program or is a consultant, the doctor submits the bill to the hospice program, which in turn submits the claim to Medicare under Part A. The doctor is reimbursed based on a contract with the hospice program.

What do patients and families want to know about hospice care?

Patients and their families are most interested in "what [they] get" from enrolling in home hospice care.[16] They do not usually learn about these benefits from their doctor; rather, they are told about them by a representative from the hospice, or from a friend or someone who has used hospice
services before. They do not need to know about the "philosophy" of hospice care; they need to know practical assistance will be provided in the tasks of caring and in terms of case management; and that medications related to the treatment of the advanced illness, as well as supplies and equipment, are provided without cost to the patient.

**How to discuss hospice care**

One of the biggest barriers to timely referral for hospice care is doctor discomfort with, and the length of time needed for, the discussion. It is helpful to discuss hospice care in the context of the larger goals of care, using a step-wise approach.[18]

**Establish the setting.** Ensure comfort and privacy. Sit down next to the patient. Ask if family members or others should be present. Introduce the subject with a phrase such as, "I'd like to talk with you about overall goals for your care."

**What does the patient understand?** Ask open-ended questions to elicit patient understanding about his or her current health situation. It is important to get the patient talking; if the doctor does more than 50% of the talking, it is unlikely that the rest of the conversation will go well. A ratio of 20% doctor: 80% patient/family is better. Consider starting the discussion with phrases such as: "What do you understand about the cancer and how things are going?" or "What have the doctors told you about your cancer?"

Listen for phrases like: "I know I'm going to die of this cancer," or "I know I don't have much time left," or "I know the cancer is getting worse." If the patient does not know/appreciate his/her current status, this is the time to review the information.

**What does the patient expect?** Next, ask the patient to consider the future. Examples of ways to start this discussion are: "What do you expect in the future?" or "What are you hoping for in the time you have left; what is important to you?" This step allows you to listen while the patient describes a real or imagined future. Most patients with advanced cancer use this opening to voice their thoughts about dying—typically mentioning comfort, family, and home, as their goals of care. If there is a sharp discontinuity between what you expect and what the patient expects, this is the time to clarify.

Listen carefully to the patient's responses; most patients have thought a lot about dying, so they only need permission to talk about what they have been thinking. Setting up the conversation in this way permits the doctor to respond with clarifying and confirming comments such as: "So what you're saying is, you want to be as independent as possible and stay out of the hospital." or "What you've said is, you don't want to be a burden on your family."

Use the opportunity to teach patients about what to expect if they express inaccurate or exaggerated fears: hospice is not a place to go to die, it does not mean 'giving up,' pain can be controlled, and they can avoid returning to the emergency department or hospital. Consider asking patients what other experiences they have had. Some have seen (or read/heard about) "bad" deaths that can be prevented by modern care.

**Discuss hospice care.** Present hospice care as a way to achieve the goals you just elicited. Use language that the patient will understand, and give information in small pieces. Never say, "There's nothing more we can do." "Nothing" is euphemistic and easily misinterpreted. To a patient, the word "nothing" means abandonment. While there may be nothing more that can make the cancer better, there is always something that can be done to help achieve overall goals of comfort and support at this stage of illness.

Consider summarizing the patient's goals as part of introducing a discussion of hospice care. For example, you can say: "You've told me you want to be as independent and comfortable as possible without being a burden to your daughter. Hospice care is the best way I know to help you achieve those goals."

Listen carefully to the response. Many patients have distorted views of hospice care. Others have never heard the term. Ask what the term means to them. Patients frequently describe hospice as a place to go to die, or when you give up hope. Respond by asking why they think that. Probe for previous experiences or how they developed their point of view. Respond by describing hospice as a team of people who help the doctor meet the patient's and family's physical, psychological, social, and spiritual needs. Offer to ask someone from the hospice to come by to give information. You do not have to be the expert. Tell patients that you can talk with them again after they have more information.

Offer your recommendation by saying something like: "From what you've told me, I think it would be best if we got the hospice involved" or "I always recommend that the hospice get involved with my patients at this stage of their illness." Reassure patients and families that, if the patient gets better,
or if there is a new treatment discovered, he or she can be discharged (or graduate) from hospice to receive that care. Nationally, 10% of hospice patients are discharged alive.

**Respond to emotions.** Strong emotions are expected when discussing advancing illness and death. Typically the emotional response is brief (less than 5 minutes). The most profound initial response that a doctor can make is silence, providing a reassuring touch, and offering facial tissues. The most frequent mistake is to talk too much or to provide premature reassurance.

**Establish a plan.** Clarify the plan. For example, you could say: "I'll ask someone from the hospice to come by to talk with you, and then you and I can talk again."

### Common Questions and Dilemmas

- **My patient wants cardiopulmonary resuscitation (CPR). Can I still refer him to hospice?** Yes. A DNR order is not required for patients to be eligible for hospice care. Because CPR is unlikely to be successful, however, discuss your patient’s goals for such treatment. If he still wants CPR, revisit the plan after hospice care has been established. For many patients, the decision for a DNR order is a decision to die. In one single institution series of 100 patients enrolled in hospice home care with "full code" status, only 1 was resuscitated—this means most people make the right choices at the right time.

  - **My patient has a prognosis of 4 to 6 months, but the symptoms are controlled. When should I make the referral to hospice?** Now. Your patient and her family can get to know the hospice team, begin to establish trust, and be monitored for new or worsening symptoms before a crisis occurs. There is time for establishment of legacies, wrapping up important unfinished business, and the building of memories. They will also receive emotional and spiritual support, coordination of care and resources, and preparation for what to expect with disease progression.

  - **The hospice does not cover the pain medication that my patient is taking. What do I do?** Call the hospice medical director and discuss the treatment plan, explaining that other medications were ineffective prior to hospice care. Ask why the hospice prefers to use certain medications as first-line therapy, and request a consultation about how to manage the patient's pain.

  - **If I refer my patient to hospice, will I still be the doctor or will the hospice doctors take over the care?** The patient chooses the doctor to manage his care. If you are willing to do so, your patient can choose to have you as the attending doctor. Some doctors prefer to have the hospice doctor manage or co-manage their patients. Let the hospice know if you prefer that model so that your patient can make an informed choice.

  - **My patient has a prognosis of about 6 months but may need chemotherapy or radiation therapy to help manage symptoms. Will the hospice cover the treatments?** The decision to "cover" a particular treatment rests with the hospice; it is not part of the federal rules for hospice care. Many hospices will cover treatments that are expected to significantly reduce symptoms. Some hospice programs will cover all treatments as long as they are unlikely to increase the patient's life expectancy past 6 months. Most will help assess whether the benefits outweigh the burdens relative to the patient's life expectancy. Larger programs with more resources may be able to cover treatments that smaller programs cannot. If radiation therapy or chemotherapy is indicated, call the hospice medical director to discuss the treatment plan and how the treatment will benefit the patient. The patient's ability to tolerate the treatment is not evidence of effectiveness.

  - **I want to prescribe a treatment for my patient, but the hospice does not cover it and it is recommended that the MHB be revoked. What does that mean?** Your patient can revoke the MHB and use regular Medicare benefits to cover care. This is not a decision to be taken lightly, as the patient forfeits all hospice services when he revokes the MHB, unless he re-elects to use it in the future. It is important to recognize that it is illegal for the hospice to request that the patient revoke just for the treatments and then re-elect the MHB. Medicare considers it to be a fraudulent practice if a hospice were to suggest that a patient revoke and then re-enter hospice care to avoid the costs of care such as chemotherapy and radiotherapy. If it is thought that the treatment should be included in the hospice coverage, goals of care and reasons that they are not covered should be discussed with the hospice director.

  - **The hospice says that my patient has an extended prognosis and no longer qualifies for hospice services. What happens now?** If a patient no longer has a life expectancy of 6 months or less given the natural course of the disease process, the patient cannot be certified as eligible for the MHB. The hospice is expected to establish a discharge plan with the patient to ensure that care needs can be met in other ways. This is rarely the case for patients with documented cancer. More likely, the patient is living longer than normal, but can still be expected to die. The prognosis certification requires the doctor to use the averages of all cases to judge, more likely than not, when the patient...
will die.

• My patient has improved since the referral to hospice. Why doesn't the hospice discharge the patient? Some patients appear to "improve" after admission to hospice care because symptom management is improved, increased support is provided, and care needs are better met. These improvements do not change the patient's eligibility for hospice care. Other patients have illnesses marked by fluctuations and exacerbations. If the patient's death appeared imminent, but she rallied, the longer-term prognosis may still be poor and consistent with eligibility.

• My patient lives in a nursing home. Would hospice care also be needed? Nursing home care is designed for the care of patients with stable medical conditions. Hospice care augments the care to residents living the end of their lives in nursing homes. Hospice provides expertise in pain and symptom management, coverage of medications and other treatments, additional care for complex needs, and increased support for patients, family members, and other caregivers. The nurses, aides, counselors, and volunteers from hospice also work with the staff of the nursing home to provide comprehensive end-of-life care, increased presence to comfort patients and families, and support and recognition of the efforts of nursing home staff as they face the death of a resident to whom they may have become attached.

• My patient only has days to live. Isn't it too late for hospice care? Although patients eligible for hospice care are those with a life expectancy of 6 months or less, referral at any time has been shown to benefit patients and families.[19] In addition to helping the patient during an often-difficult time, bereavement support also will be offered to your patient's family.

• My patient is likely to die during this hospital admission. Can hospice still help her? Many hospices provide end-of-life care in hospitals as general inpatient care. Although you may be managing your patient's physical symptoms quite well, the additional presence of hospice staff may be especially helpful to patients and families coping with death and dying in the hospital setting.

Summary

Referral for hospice care represents the completion of comprehensive cancer care. An oncologist will want to refer patients for hospice care because of the demonstrated efficacy of hospice care over standard care: expertise and expanded support for the significant and expected aspects of end-of-life care; the ability to provide care in the home; education and skill-building for the family or other informal caregivers; payment for medications, therapies, equipment, and supplies; and bereavement support for the family after the death of the patient.

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