The Role of the Family Physician in the Referral and Management of Hospice Patients

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Hospice is available for any patient who is terminally ill and chooses a palliative care approach. Because of the close relationship that primary care physicians often have with their patients, they are in a unique position to provide end-of-life care, which includes recognizing the need for and recommending hospice care when appropriate. The hospice benefit covers all expenses related to the terminal illness, including medication, nursing care, and equipment. Hospice should be considered when a patient has New York Heart Association class IV heart failure, severe dementia, activity-limiting lung disease, or metastatic cancer. Timely referrals are beneficial to both patient and hospice because of the cost related to initiating services and the time required to form a therapeutic relationship. Once the decision to refer to hospice is made, the family physician typically continues to be the patient's primary attending physician. The attending physician is expected to remain in charge of the patient's care, write orders, see the patient for office visits, and complete and sign the death certificate. Hospice, in turn, is a valuable physician resource when it comes to medication dosages, symptom management, and communication with patients and their families. (*Am Fam Physician*. 2008;77(6):807-812, 817-818. Copyright © 2008 American Academy of Family Physicians.)

▶ **Patient information:** A handout on hospice, written by the author of this article, is provided on page 817.

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▶ An article on this topic appears in the March 2008 issue of *Family Practice Management*, pages 18-22.

The role of the family physician is no different at the end of a patient's life than at any other time. The expectation is to provide excellent coordinated care and to inform the patient of appropriate options, including hospice. Family physicians often provide care to patients with chronic medical illnesses who are stable for long periods of time. It can be difficult to determine whether a hospice referral would be helpful, but guidelines from the National Hospice and Palliative Care Organization (http://nhpco.org) are available to assist in this decision. The majority of caregivers and families of patients who have received hospice care report that they would have welcomed more information about hospice from their primary care physician at the time the diagnosis was labeled terminal.[1,2] Research has shown that hospice can be a way to offer more support and improved care to patients during their terminal phase of illness, and patient care is enhanced when the primary care physician maintains control of the patient's care until his or her death.[3] Family physicians can play an invaluable role in caring for patients at the end of life. Continuity of care and multigenerational relationships allow a family physician to guide a patient and family through the hospice referral process with a unique knowledge of the patient's values, family issues, and communication style.

Hospice Philosophy

Hospice is built around the key concept that the dying patient has physical, psychological, social, and spiritual aspects of suffering. Hospice is a philosophy, not a specific place, and can be provided in any setting, including patients' homes, nursing homes, and hospitals.[4] The core structure of hospice includes an interdisciplinary team that consists of multiple members (*online Table A*). The interdisciplinary team provides access to a wide range of services to support the primary caregiver, who is responsible for the majority of the patient care. To be eligible for hospice, a patient must have a terminal illness and an estimated prognosis of less than six months.[5] As of 2005, there were more than 4,100 hospice agencies in the United States; 67.6 percent of those were nonprofit. During 2006, about 1.3 million patients received service from a hospice agency and one third of all deaths occurred under hospice care.[6]

Patients with a non-cancer diagnosis may also benefit greatly from hospice care; non-cancer diagnoses (e.g., congestive heart failure, chronic obstructive pulmonary disease,

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SORT: KEY RECOMMENDATIONS FOR PRACTICE

Clinical recommendation	Evidence rating	References	Comments
Patients with cancer and non-cancer diagnoses benefit from hospice services and should be referred when their prognosis is still longer than two months.	B	7, 8, 30, 31, 34-36	The most effective length of stay with hospice is debated, but most estimates say at least two to three months; very short stays have been associated with increased caregiver morbidity and depression
Discussions with patients and families about hospice should take place as early as possible and should be approached in the context of the larger goals of care.	C	37-39	Eleven to 18 percent of families feel they were referred too late; late referrals are associated with decreased family satisfaction with services and increased caregiver morbidity
When a patient has NYHA class IV heart failure and is symptomatic despite optimal medication management, a hospice referral is appropriate.	C	24, 40, 41	—
When a patient who has dementia is dependent in all activities of daily living and cannot communicate, a hospice referral is appropriate.	C	24, 42	—

NYHA = New York Heart Association.

A = consistent, good quality patient-oriented evidence; B = inconsistent or limited quality patient-oriented evidence; C = consensus, disease-oriented evidence, usual practice, expert opinion, or case series. For information about the SORT evidence rating system, see page 739 or http://www.aafp.org/afpsort.xml.

failure to thrive, dementia) currently represent 56 percent of all hospice admissions.[6-8] The responsibility for hospice referral in a non-cancer diagnosis often falls to the primary care physician, facilitating continuity of care for the patient in his or her final days and months. To make an appropriate referral, physicians need to be aware of some of the common misconceptions about hospice care *(Table 1)*.[9]

Hospice Eligibility and Cost

Patients who are eligible for Medicare are also eligible for hospice benefits.[5] Medicare covers hospice care for patients who are older than 65 years or have been disabled for more than two years. In 2005, the Medicare Hospice Benefit covered 82.4 percent of all hospice patients.[6] To be eligible for the Medicare Hospice Benefit, four criteria must be met: the patient is eligible for Medicare Part A (hospital insurance); the patient is enrolled in a Medicare-approved hospice; the patient has signed a statement choosing hospice; and both the patient's physician and the hospice medical director certify that the patient has a terminal illness with an estimated life expectancy of less than six months. Most private insurance companies model their hospice benefit on the Medicare benefit. Local hospice agencies should be able to provide specific information about what local insurance carriers will cover. In addition, some hospice agencies are willing to take patients without insurance.

Hospice can be a tremendous financial benefit to patients because the hospice benefit covers all expenses related to the terminal illness, including medication, skilled nursing, nursing aides, and hospital equipment, in comparison to the standard Medicare home health care benefit.[5] Medicare allows a $5 co-pay for medication, but most hospice organizations do not require patient payment. Of all hospices, 97 percent are Medicare certified and follow Medicare guidelines that require a hospice to provide treatments related to the terminal diagnosis and that are "reasonable and necessary for palliation."[6] Currently, no Medicare regulations specify which treatments are considered palliative, and individual hospices have a wide latitude to determine which treatments they will cover.[10,11] This means that the services a hospice can offer are often based, in part, on the size and financial reserves of the hospice. Larger hospices may be able to financially support medications and procedures such as palliative radiation or chemotherapy, whereas smaller hospices may not be able to offer such expensive therapies.[12,13]

Physician Billing

As long as the attending physician is not an employee of hospice, he or she can bill

Table 1. Common Misconceptions About Hospice

Misconception	*Clarification*
Patients will be discharged from hospice if they do not die within six months	There used to be a six-month regulation that penalized hospices and patients when a patient lived too long, but it was revised and there is no longer any penalty for an incorrect prognosis if the disease runs its normal course
Patients in hospice must have a DNR order	Medicare does not require a DNR order to enroll in hospice, but it does require that patients pursue palliative, not curative, treatment; individual hospice organizations may require a DNR order before enrolling a patient
Patients in hospice must have a primary caregiver	Medicare does not require a primary caregiver, but this may be a requirement of some hospice organizations
The primary physician must transfer control of his or her patients to hospice	Most hospice organizations encourage primary physician involvement; the primary physician becomes a part of the team and contributes to the hospice plan of care
Only patients with cancer are appropriate candidates for hospice	Anyone with a life expectancy of less than six months and who chooses a palliative care approach is appropriate for hospice*
Only Medicare-eligible patients may enroll in hospice	Most commercial insurance companies have benefits that mimic the Medicare Hospice Benefit; individual hospices vary in their willingness to take uninsured patients
Patients in nursing homes are not eligible for hospice	This was once true, but Medicare now covers patients in nursing homes
Patients are not eligible for hospice again if they revoke the hospice benefits	Patients who want to return to hospice care can be readmitted as long as hospice conditions of participation are met
Only physicians can refer patients to hospice	Anyone (e.g., nurse, social worker, family member, friend) can refer a patient to hospice
Hospice care precludes patients from being able to receive chemotherapy, blood transfusions, or radiation	Medicare requires that hospice must cover all care related to the terminal illness; individual hospice agencies are allowed to determine whether a specific treatment is palliative (providing symptom relief), which will guide what treatments they are willing to cover
Patients who have elected the hospice benefit can no longer access other health insurance benefits	Each insurer has rules defining eligibility for covered services; medical problems unrelated to the terminal illness continue to be covered under regular Medicare insurance
Patients in hospice cannot be admitted to the hospital	While the patient is enrolled in hospice, most insurance companies, including Medicare, will still cover hospital admissions for unrelated illnesses, as well as for the management of symptoms related to the terminal diagnosis, and respite care
Hospice care ends when a patient dies	All hospice programs must provide families with bereavement support for up to one year following the death of the patient

DNR = do not resuscitate.

**—Refer to the National Hospice and Palliative Care Organization standards for guidance.*

Adapted with permission from Hospice and Palliative Care Association of NY State. Common misperceptions about hospice. http://www.capc.org/tools-for-palliative-care-programs/hospital-hospice-tools/hospice-misconceptions.pdf. Accessed October 11, 2007.

directly through Medicare Part B. Although most insurance companies do not reimburse telephone time, it is possible to bill for non–face-to-face services and to be reimbursed by Medicare using the care oversight code. This is helpful because, as a patient nears the end of life, the amount of care provided over the telephone typically increases. To use this code, the physician must be the same physician who signed the certification for hospice; needs to see the patient at least once every six months; and must provide a cumulative service (e.g., phone time, time spent coordinating care, records review) of 30 minutes each calendar month. The physician may not be an employee or medical director of or have a significant financial arrangement with hospice. However, the physician is allowed to bill for time spent by a nonphysician practitioner, provided that the nonphysician practitioner has a collaborative relationship with the physician who referred the patient to hospice. More information on the appropriate use of the care oversight code is available.[14]

Hospice Referrals

In general, most hospice referrals come from physicians, although social workers, nurses, and patients' families can also make a hospice referral.[1] The trend in the United States has been to refer patients in their last days of life. Nationwide, the median length of stay is

Table 2. Tools for Determining Prognosis in Terminally Ill Patients

Karnofsky Performance Scale[22]
National Hospice Organization Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases[23,24]
Palliative Performance Scale[25]
Palliative Prognosis Score[26]

NOTE: *See also the* AFP *Point-of-Care Guide on Determining Prognosis for Patients with Terminal Cancer, at: http://www.aafp.org/afp/20050815/poc.html.*

Information from references 22 through 26.

Table 3. Prognosis Factors for Considering Hospice in Selected Diagnoses

Cancer
Performance status
Eastern Cooperative Oncology Group Score > 2
Karnofsky score < 50
Signs and symptoms
Carcinomatous meningitis
Distant metastases
Malignant complication such as bowel obstruction, pericardial effusion, or hypercalcemia
Multiple tumor sites (≥ 5)
Chronic obstructive pulmonary disease
Chronic hypercapnia: $Paco_2$ > 50 mm Hg (6.6 kPa)
Cor pulmonale
Dyspnea at rest, persistent resting tachycardia
Intensive care unit admission for exacerbation
New dependence in two activities of daily living
Congestive heart failure
New York Heart Association class III or IV with symptoms despite maximal medical management
Serum sodium level < 134 mEq per L (134 mmol per L), or creatinine > 2.0 mg per dL (180 μmol per L), attributable to poor cardiac output
Dementia
Acute hospitalization (especially for pneumonia or hip fractures)
Dependence in all activities of daily living, language limited to several words, inability to ambulate
General decline (failure to thrive)
Dependence in most activities of daily living
Frequent hospitalizations, office or emergency department visits
Weight loss > 10 percent over past six months

$Paco_2$ = partial pressure of carbon dioxide; kPa = kilopascal.

Adapted with permission from Casarett DJ, Quill TE. "I'm not ready for hospice": strategies for timely and effective hospice discussions. Ann Intern Med. *2007;146(6):444, with additional information from reference 27.*

26 days.[6] When given the option, 83 percent of terminal patients choose hospice.[1,15]

Numerous articles have been written about patient and physician barriers to hospice referral.[1,12] Some of the physician barriers include negative perceptions about hospice, discomfort communicating terminal diagnoses and prognosis, an inability to identify an appropriate diagnosis, a fear of losing control of the patient, and an overestimation of life expectancy.[16,17] Most of these barriers can be overcome by obtaining more information on end-of-life symptom management and communication.[18,19]

A number of scales are available to help determine whether a patient has a life expectancy of less than six months.[20,21] *Table 2*[22-26] lists tools for determining patient prognosis. Useful guidelines can be found on the National Hospice and Palliative Care Organization Web site, which provides worksheets to help determine prognoses in patients who have a non-cancer diagnosis.

Common medical triggers that should prompt consideration of a hospice referral are listed in *Table 3*.[18,27] Unfortunately, most referrals are precipitated by a crisis immediately before death. This is often a consequence of patients living with a chronic condition that they may not understand is terminal, combined with the reluctance of a physician to make a terminal diagnosis and prognosis.[17,28] Late referrals are detrimental to both the patient and hospice because of the cost related to initiating services and the limited amount of time in which to form a therapeutic relationship.[1,29] Research has shown that caregivers' satisfaction with hospice increases when patients are enrolled for more than 30 days,[30] and that patients who spend at least two months in hospice appear to benefit the most.[31,32]

Hospice Expectations of the Attending Physician

Once a patient has enrolled in hospice, the best way to obtain answers to specific questions is to talk with the specific hospice. There are some basic truisms to all hospice agencies, but day-to-day operations can vary. Most hospices expect the referring physician

Table 4. Hospice Expectations for Attending Physicians

Maintain primary responsibility for the patient
Write basic admission orders
Work in collaboration with the hospice team to manage symptoms
Provide prescriptions and medication refills as needed
Continue to certify that a patient remains eligible for hospice
Complete and sign death certificate

to remain in charge of the patient's care and to be available by telephone for consultation, although expectations for telephone availability vary by hospice. In some cases, the local hospice medical director may be willing to cover the attending physician on weekends and during vacations.

In general, the attending physician is expected to be the primary physician of record, be available by telephone or have coverage arranged, write admission orders, and handle the routine decisions for patient care *(Table 4)*. Some hospices provide attending physicians with standing orders that have broad parameters for the control of common symptoms, such as pain and dyspnea. The attending physician and the hospice medical director are expected to provide certification to Medicare that the patient continues to meet hospice eligibility criteria on a regular basis. Currently, the Medicare hospice benefit is divided into certification periods. The patient starts with two 90-day periods, followed by unlimited periods of 60 days. The attending physician is also expected to provide medication refills when needed. It is helpful that narcotics prescriptions can be faxed directly to the pharmacy for hospice patients.[33]

Potential Areas of Conflict

Because hospice is funded on a per diem basis with a fixed sum of money from which all medical care must be paid, there can be the perception, both real and imagined, that hospice is trying to reduce or prevent patient access to the acute medical care system to cut costs. This can lead to conflict between the attending physician and the hospice with regard to specific tests or evaluations necessary to care for the terminally ill patient. These obstacles can generally be overcome with good communication that focuses on the patient's goals of care. In addition, the use of specific medications can be an area of discussion between an attending physician and the hospice agency; the attending physician may be asked to consider less expensive alternatives to common medications, such as prochlorperazine (Compazine; brand no longer available in the United States) instead of ondansetron (Zofran) for nausea.

It is important to remember that, despite the potential conflicts of interest, excellent patient care is at the heart of all hospice organizations, and the hospice staff can be a valuable resource for physicians who are uncomfortable or unfamiliar with certain medications or dosages to manage end-of-life symptoms. Family physicians are in a unique position to contribute to patient care at the end of life through communication, continuity of care, and knowledge of their patients' families.

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