Mrs. H is an 87-year-old woman with New York Heart Association Class IV heart failure, hypertension, and dyslipidemia. She can transfer from bed to chair, but reports being dyspneic at rest. Mrs. H is being treated with maximally-dosed captopril, carvedilol, diuretics, and vasodilators. Her daughter asks you how long her mother has left to live and if hospice care would be appropriate.

During the twentieth century, people in the United States and Western Europe have enjoyed the spoils of healthcare’s advancement, namely a marked decrease in mortality from infectious diseases and death from accidents and trauma. With the accompanying increase in life-expectancy, cancer, dementia, and chronic obstructive pulmonary disease are joining heart disease on the list of causes of death. Since many people are now dying with and from chronic diseases, often with a roughly predictable decline over the course of months and years, we have the unparalleled opportunity and responsibility to improve care as patients near the end of life. Palliative care and hospice have emerged in the last few decades as wonderfully valuable partners in this care.

The concept of hospice care, which etymologically comes from the same Latin root as hospitality, was conceived of by Dame Cicely Saunders in the 1960s, and was truly born with the opening of Saint Christopher’s Hospice in London in 1967. The hospice movement was nurtured in the United States in the late 1960s at Yale University, and America’s first hospice, The Connecticut Hospice, opened in New Haven in 1974. In 1979, the Health Care Financing Administration endorsed demonstration programs throughout the country to determine the role for and scope of hospice care, and in 1982 the Medicare Hospice Benefit was created. This benefit, which has had many changes since then, paid for 84% of hospice patients in 2006.

The number of patients served by hospice care has increased by 162% in the last 10 years, standing at 1.3 million patients in 2006, the most recent year for which there are complete data. Hospice organizations were involved in caring for 36% of those who died nationwide. A major goal of the hospice movement is to provide care and allow a comfortable, dignified death in whatever setting a patient calls home, be that a private residence, assisted living, or nursing home. To that end, 74% of people who died with hospice care did so in their homes (including those who died in nursing homes or assisted living facilities), with 17% dying at an inpatient hospice center and 9% in an acute care hospital.

A patient is eligible for the Medicare Hospice Benefit if she “is eligible for Medicare Part A, is certified as having a terminal disease with a prognosis of six months or less if the illness runs its normal course, receives care from a Medicare-approved hospice, and the individual signs a statement indicating that she elects the hospice benefit and waives all rights to Medicare payments for services for the terminal illness and related conditions. Medicare will continue to pay for covered benefits that are not related to the terminal illness.” Medicare will pay for care related to the terminal condition, including physician services; nursing care; medical equipment and supplies; drugs for symptom control or pain relief; home health aide and home-maker services; physical, occupational, and speech therapies; social worker services; dietary, spiritual, and grief counseling; short-term and respite care and any covered medically necessary services identified by the interdisciplinary team. Medicare will not pay for curative therapies, care from a provider not set up by the hospice, and care from another provider that is the same care that the individual must receive from her hospice.

A major component of eligibility, and one of the more nebulous parts of moving a patient toward hospice care, involves predicting the patient’s life expectancy. Historically, physicians do a poor job predicting time of death, especially in non-cancer cases. Generally, predictions are overly optimistic about prognosis. In a study of 343 physicians referring 468 patients for hospice care, physicians predicted the time of death of their patient within 33% of actual survival only 20% of the time. Sixty-three percent of predictions were too optimistic; 17% were too pessimistic. The average overestimation was by a factor of five. When paired with hospice length-of-service data showing an average enrollment of 59.8 days and a median enrollment of just 20.6 days, it seems likely that we are underutilizing hospice care by referring patients too late.

The Medicare Hospice Benefit can be accessed by a patient with a “terminal disease with a prognosis of six months or less if the illness runs its normal course.” Though hospice care is often considered for cancer patients, seven of the top ten diagnostic codes for hospice care in 2005 were for non-malignancies, and more than half of hospice patients were non-cancer patients. Lung cancer leads the list for the eighth consecutive year, but congestive heart failure, chronic obstructive pulmonary disease, Alzheimer’s disease, stroke, and adult failure to thrive rank above the only other two cancers, prostate and breast, in the top ten diagnoses referred for hospice care.

The National Hospice Organization’s guidelines aid clinicians in determining when patients with chronic diseases are likely to have a life expectancy of fewer then six months, though these have been shown to be less valuable in acutely ill, hospitalized patients.
Either the medical director of the hospice or the physician member of the hospice interdisciplinary team and the individual’s primary attending physician may certify a patient for hospice care. Initial certification lasts for 90 days and may be renewed for an additional 90 days. If the patient lives beyond the initial six months, she may be recertified for an unlimited number of 60-day periods, as long as she still meets the six-month prognosis. Of the 1.3 million patients cared for by hospice programs in 2006, 220,000 were discharged alive.

An important caveat in electing the Medicare Hospice Benefit is its flexibility and reversibility. A patient or representative can revoke the election of hospice at any time, completely resuming all previously waved Medicare services. Often this is done to seek curative treatment not permitted while on the hospice benefit. The choice of hospice agency may also be changed once during each election period.

Election of the Medicare Hospice Benefit does not eliminate the role for the patient’s primary physician. In fact, most hospice organizations will not accept patients without the full participation of the patient’s primary care physician (PCP). All recommendations of the hospice team are implemented only with PCP approval. The hospice team acts as a “one-stop-shopping” organization, fielding the patients’ and families’ phone calls, dispatching hospice nurses around the clock for evaluation and treatment, and offering support during and after the dying process. As an additional benefit, when the PCP requires assistance with management, the medical director of the hospice, usually board-certified in Palliative Medicine, is available for consultation.

Hospice care is an important tool at the end of life. The Medicare Hospice Benefit has made quality end-of-life care available to many patients with chronic diseases, and the number of patients being cared for by hospice programs has been climbing. Remembering that physicians err toward overestimating a patient’s remaining time, it would be beneficial for clinicians to lower their personal thresholds for referral to hospice care, and to recall that patients with chronic diseases may benefit from hospice care. Electing hospice care will not eliminate the PCP’s role, but will add expert help in symptom management to improve care at the end of life.

Christopher A. Jones, MD, is a second year Internal medicine resident at Rhode Island Hospital/Brown University.

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