



*Photo by Senator Tom Dempster*

## Hospice Care at the End of Life (Beware the H-word)

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By Michael Robinson, MD

The word “hospice” has dissimilar meanings to different people, including physicians. To some it carries negative connotations: giving up life-prolonging options, pulling the plug, a place to die, a death sentence or added paperwork. Others look to hospice as a means of better symptom control, better quality of life, cost savings, and access to experts in end-of-life care such as physicians, social workers, nurses, volunteers and chaplaincy.

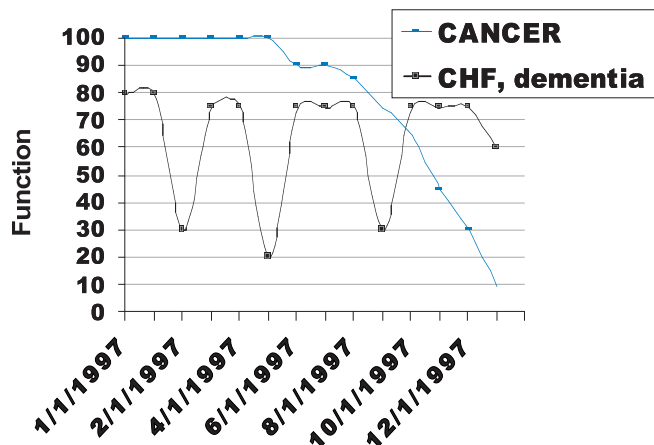
Surveys suggest that physicians see the benefit of hospice in terms of improved symptom management and quality of life. There are essentially three barriers that remain to hospice referrals: physician barriers, patient/family barriers and system barriers. This article will explore some of the barriers to hospice referral and look at potential solutions.

The National Hospice and Palliative Care Organization<sup>1</sup> (NHPCO) has information available about hospice care in the United States. The first hospice program in the country

began in the early 1970s. Medicare started to fund hospice programs in 1983 (the Medicare Hospice Benefit), and initially this benefit was developed for end-stage cancer patients. This benefit covers hospice services for those with a terminal diagnosis (likely to take the patient’s life within six months if the illness continues on trajectory). There are two 90-day benefit periods followed by unlimited 60-day extensions if the patient meets criteria (disease progression or continued decline in physical function) for continued hospice care. Eligibility for these benefits are certified by the patient’s physician and the hospice medical director.

Currently (2005), there are over 4,100 hospice programs nationwide that cared for or are caring for over 1.2 million people (83 percent over age 64). Cancer was the No. 1 diagnosis (46 percent), followed by cardiac disease, dementia and chronic obstructive lung disease (12, 10 and 7.5 percent, respectively). Of these patients, 75 percent died in a

Figure 1.



“home-like setting” (home, nursing home or residential facility). The current median length of stay (MLOS) nationwide in hospice programs in 2005 was 26 days. In the Avera McKennan Hospice program, the MLOS in 2004 was 13 days.<sup>2</sup> Yes, days. This most likely represents a nationwide lack of early referrals to effective palliative care programs, and instead, the common practice is to wait to delay referral until the patient is very ill.

If only one-third of terminally ill patients and half of end-stage cancer patients are referred, then why are there not more and earlier referrals to hospice? Physicians may be reluctant to refer to hospice programs for a number of reasons. Initially, hospice programs were designed for patients with end-stage malignancies and their prognosis was relatively easy to estimate. Once function of the end-stage cancer patient declined to less than 50 percent of time out of bed, there was a relatively predictable downhill decline and death, whereas patients with cardiac disease, dementia, chronic obstructive pulmonary disease (COPD), and general debility and decline had a gradual downhill course punctuated by periods of worsening and improvement (Figure 1).<sup>3</sup>

Since the Medicare Hospice benefit now includes over 50 percent of patients with non-cancer diagnoses, one can see the difficulty in estimating prognosis. Hence, the difficult decision as to when a patient may “be ready for hospice.” Remember, “hospice” is a philosophy of care that can take place in many settings including the home, nursing homes, hospice residences and even in the hospital for acute symptom management. Hospice admission guidelines are

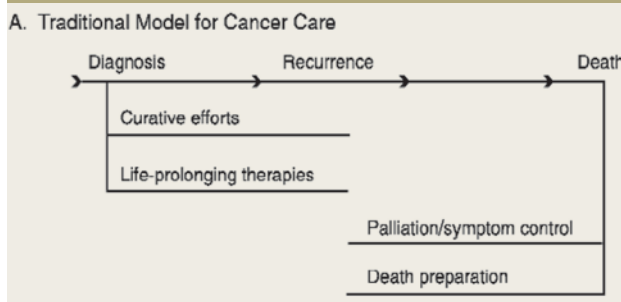
available for non-cancer diagnoses such as cardiac disease, chronic lung disease, dementia, stroke, ALS, renal and hepatic disease, as well as debility and decline.

Physician-related difficulties in referring to hospice include concern that the patient may lose hope, a feeling that the patient or family may not accept the prognosis, inability to place the patient in a disease category, and that it may deny potential life-prolonging treatment. Other potential concerns of the physician include a fear of fraud, too much paperwork and worry about financial pressures of the practice (the patient may not come to the office as often). Physicians may also lack communication skills or time to discuss these difficult issues.

Patients and families may construct barriers to effective and timely hospice referral. They may feel abandonment as they transition to a new care team (who is their support now?) or that they are abandoning their physician. They may not understand hospice care can be given in their homes or a home-like setting (residential facility or nursing home), and they may have a concern that they would have to “give up or forgo certain treatments.” The decision to offer more costly (potentially life-prolonging) treatments – radiation therapy, transfusions, antibiotics, hyper-alimentation and even “palliative” chemotherapy – is decided by the local hospice program. Ideally, there should be a transition to comfort-based care rather than an abrupt change in goals of care. Discussions regarding goals of care, advanced directives and options for managing the disease at different stages of illness should be discussed as a continuum rather than only during a crisis. This is where palliative care fits into the hospice continuum of care (Figures 2 and 3).<sup>4</sup>

The traditional model shows disconnect between curative

Figure 2. Traditional model for palliative or hospice care. Modified from the American Medical Association Institute for Medical Ethics (1999). EPEC: education for physicians on end-of-life care. Chicago, IL, The Robert Wood Johnson Foundation.



and life-prolonging treatment and planning for palliative or hospice care (Figure 2). The mixed management model incorporates an ongoing dialogue and plan of care throughout the illness that eventually incorporates hospice as a source of symptom management (Figure 3).

In addition to physician and patient/family barriers there are system barriers that can delay hospice referrals. Medicaid payments are often unreliable, private insurance plans often have poor and inconsistent hospice benefits, and it may be difficult to effectively work with nursing home (e.g., skilled nursing facility/SNF) payment systems. For example, patients on a skilled benefit in a nursing home may not receive hospice care until they're "off" their skilled Medicare benefit. SNFs may feel they can provide adequate symptom management and do not need hospice services. The magnitude of this potential problem will increase in the future, as it is estimated that 160 million of us will be residing in SNFs by 2040. Another system barrier in South Dakota is related to geography. Most of the large cities in the state have hospice programs, but they only cover a certain radius around that city. Because South Dakota is a rural state, there are many areas with no hospice coverage. These uncovered areas may have visiting nurses or county nurses, but this is not the same as an organized hospice program.

How do we achieve earlier referral and increased utilization of hospice services? For the physician we can improve his/her end-of-life skills (particularly with communication), support with palliative care teams, marketing at tumor conferences or discharge planning meetings, point out consequences of inaction, and support other non-physician links such as nursing and social workers.

For patients and their families we can educate the public as

well as market palliative care at church groups, nursing homes and health fairs. During visits with their physicians, patients can be encouraged to ask about hospice and how it relates to their health and prognosis.

For the system, consider changing the six-month rule to perhaps a one-year rule for hospice coverage, allow palliative care teams to more aggressively identify hospice candidates, use telemedicine for geographically underserved areas, change how reimbursement is given to SNFs and promote earlier utilization of hospice services.

Hospice is an important piece of the end-of-life pie. The benefit of hospice include better control of symptoms, the Medicare system saves money compared to traditional care, physicians are "kept in the loop" and, above all, the patient and family benefits.

REFERENCES

1. NHCPO Web site ([www.nhpc.org/templates/1/homepage.cfm](http://www.nhpc.org/templates/1/homepage.cfm))
2. Data from Avera Mckennan Hospice Program (unpublished data)
3. Data from the Center to Advance Palliative Care ([www.capc.org](http://www.capc.org))
4. American Medical Association Institute for Medical Ethics (1999). EPEC: education for physicians on end-of-life care. Chicago, IL, The Robert Wood Johnson Foundation.

Figure 3. Mixed model for Fatal Illnesses. A continuum of care from early disease modifying therapies to end-of-life care. Modified from the American Medical Association Institute for Medical Ethics (1999). EPEC: education for physicians on end-of-life care. Chicago, IL, The Robert Wood Johnson Foundation.

