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To cite this article: Robert E. Enck (1994) Palliative Care: Enhancing Physician Involvement, *Oncology Issues*, 9:1, 24-25, DOI: [10.1080/10463356.1994.11904450](https://doi.org/10.1080/10463356.1994.11904450)

To link to this article: <https://doi.org/10.1080/10463356.1994.11904450>



Published online: 18 Oct 2017.



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Palliative Care: Enhancing Physician Involvement

by Robert E. Enck, M.D.

Although hospice care in the United States has emerged as a significant treatment for the dying patient, physician involvement in this program has remained elusive. The lack of physician input should not be construed as apathy, but rather should be viewed as exclusion and misunderstanding. To appreciate this unfortunate fact, one has only to review the history of the hospice movement in the U.S. beginning in the late 1970s.

Initially, community-based hospices were started by advocates who believed strongly that the medical community was not adequately addressing the medical and social needs of the dying patient. As the hospice movement gained momentum, hospitals and advocates developed alliances to develop inpatient units. Hospice demonstration grants abounded, publicity for hospice soared, and every community had to have a hospice. Overnight, dying persons were not patients of their own doctors. They were, instead, participants in hospices who direct-

ed all aspects of their care. Physicians were no longer in control, although they remained legally responsible for patient care. Turf battles were common.

To further confuse these issues, in response to intense lobbying from hospice advocates, Congress debated the enactment of a hospice Medicare benefit in 1982. Organized medicine opposed this proposed legislation on the grounds that hospice care was not proven to be less costly than conventional care and that predicting a six-month survival was tenuous at best. These objections notwithstanding, Congress passed the legislation, and the Medicare hospice benefit program began in 1983. Weary from fighting an unpopular battle, medicine chose the ostrich approach, that is, sticking its head in the sand and hoping that hospice would go away.

As the 1980s progressed, hospice continued to hover outside the mainstream of medicine. There was a general lack of physician understanding and of appreciation of the benefits of hospice. The Government Accounting Office identification in the late 1980s that the six-month survival prognostication was a major impediment to patient participation in the hospice Medicare benefit led physicians to say, "I told you so." At that time administrators at some hospices realized that their real customer was the doctor and actively started to promote their programs to capture physician referrals. Unfortunately, this strategy proved to be too little, too late.

Today, most physicians still view hospice cautiously; they still lack an overall understanding and enthusi-

asm of its principles and goals. The lack of physician understanding has been compounded by the fact that hospice has moved from an inpatient emphasis to one of predominantly home care, an area where most physicians are inexperienced and uncomfortable. Furthermore, few physicians appreciate this change and still perceive hospice as akin to nursing home care. In the physicians' mind, as well as in some patients', hospice care is only for those with less than six months to live and for those with complex psychological and social problems. For their part, administrators of hospices are frustrated because patient referrals are late and deprive the patient and family of the true benefits of the program.¹

WHERE DO WE GO FROM HERE?

Certainly, the ostrich effect will not work in 1994 because of societal pressures on the medical community to manage more effectively the pain and symptoms of the dying. The ongoing controversy of Dr. Kevorkian's euthanasia and popularity of *Final Exit* attest to this need for increased physician involvement in hospice.

How then do we enhance physician involvement in hospice? Since most physicians do not understand hospice, a starting point is to redefine the concept in terms of the pathophysiology of the dying process. Chronic, incurable diseases inevitably evolve through three distinct periods: 1) stable, 2) symptomatic, and 3) final.² The stable period generally lasts from months to years, and as the name implies, is a quiescent time. As symptoms occur

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and become troublesome, the patient enters the symptomatic period, which usually lasts weeks to months. Finally, as the disease progresses, the final or twilight period occurs and encompasses only days to weeks.

Within this context, care given in the symptomatic and twilight periods is palliative in nature. The term palliation is more palatable to both physicians and patients because it does not imply giving up completely with no hope in sight as does the general perception of hospice. Also, palliative care involves a wide range of chronic, incurable diseases that are symptomatic and life-ending, such as cancer, motor neuron disease, Alzheimer's disease, end-stage pulmonary and cardiac diseases, and AIDS. For many, hospice denotes only dying cancer patients and the inevitability of death.³

A CASE IN POINT

Because of the narrow perception of hospice by physicians, Mercy's Regional Cancer Center and Mercy's Continuing Care (home care) in Davenport, Iowa, have developed a palliative care program in collaboration with the medical staff. All patients with incurable chronic diseases who are in the symptomatic and/or final stages are considered for enrollment in the Palliative Care Service (MercyCare). MercyCare is physician-ordered and offers virtually the same array of services as does hospice. Patients eligible for hospice benefits, be it Medicare or other payers, and who opt for this program are then enrolled in this portion of MercyCare.

During the six-month period from September 28, 1992, to March 31, 1993, 40 patients were admitted to the Palliative Care Service. There were 14 women and 26 men, ranging in age from 38 to 94 with a mean of 69 years. The majority (88 percent)

of patients had advanced malignant disease, with the most common tumor sites being the gastrointestinal tract (29 percent) and lung (23 percent). Twelve percent of the patients suffered from end-stage nonmalignant diseases such as dementia of the Alzheimer type, Parkinsonism, chronic congestive heart failure, and chronic obstructive pulmonary disease. The mean length of stay for all the patients was 30 days, with a wide range of 3 to 118 days. Only 15 percent of the patients opted for the hospice Medicare benefit. Today, 14 patients are alive, 9 with malignant and 5 with nonmalignant diseases.

As anticipated, there was an enlarged base of referring physician specialties (in addition to medical oncology), such as general internal medicine, pulmonary, hematology, neurology, family practice, and orthopedic surgery. Not surprising, given the demographics of the patient population, was that Medicare was the major payor (75 percent), followed by other insurances, Medicaid, and self-pay.

As part of a financial analysis, the assumption was set forth that all the

patients were enrolled in the hospice Medicare benefit. Under this scenario, the program would have lost more than \$125,000 in six months. In reality, since the program was home-care based, a modest profit was realized.

It is our experience that broadening the concept of hospice into a home-care based palliative care program for patients in the symptomatic and/or final stages of life-ending chronic diseases provides a clearer understanding and better physician participation in the management of the dying patient. Certainly as the United States ages, as effective therapies for these diseases continue to plateau, and as health care rationing becomes a reality, society's demand for palliative care will only increase. This time, physicians must be in the game, not on the sidelines. ■

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NUMBERS, PLEASE

According to the Hospice Association of America, the number of Medicare-certified hospices increased from 480 in 1988 to 1,368 in 1993.

Generally, hospices are categorized into one of four categories:

- 1) *Home health agency-based hospices* are owned and operated by freestanding proprietary and nonprofit home health agencies (197 in 1988; 474 in 1993).

- 2) *Hospital-based hospices* are operating units or departments of a hospital (122 in 1988; 357 in 1993).

- 3) *Skilled nursing facility-based hospices* are operating units or departments of a skilled nursing facility or nursing facility (11 in 1988; 10 in 1993).

- 4) *Freestanding hospices* are independent, mostly nonprofit organizations (150 in 1988; 527 in 1993).

The number of noncertified hospices is estimated at 477.

For more information, write the Hospice Association of America, 519 C St., N.E., Washington, D.C. 20002-5809. Or call 202-546-4759.