

The Role of Hospice Philosophy of Care in Nonhospice Settings

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Many advances in public health and medical technology have contributed to the improved well-being and overall longevity of Americans. Such benefits, however, have been offset by a change in the nature and prolongation of the dying process. Daniel Callahan offers a challenge to caregivers in his observation of “violent death by technological attenuation,”¹ and he sets an agenda to identify a more appropriate approach to the needs of the dying.

Over the past quarter century, hospice has increasingly been used as a resource for care at the end of life. However, according to 1995 estimates by the National Hospice Organization (NHO), hospice care presently accounts for only about 15 percent of the care of terminally ill patients in the United States.² We will review issues of access and use of hospice services and examine the various institutional, professional, societal, and cultural barriers to hospice principles of care, and consider various options to promote optimal care at the end of life. We think the underlying principles of an interdisciplinary hospice model of care provide a framework of care for the dying patient and are applicable in various settings.

Terms

Several terms require definition. *Hospice services* provide support and care for persons in the last phases of incurable disease so that the dying may live as fully and comfortably as possible. Hospice recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life; it neither hastens nor postpones death. An underlying tenet of hospice is that with appropriate care

and a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.³ The *hospice team* is an interdisciplinary group of professionals, with expertise in palliative pain and symptom control, who attend to the psychosocial needs of both the patient and the family.

According to the World Health Organization (WHO), *palliative care* is the active total care of patients whose disease may not respond to curative treatment.⁴ The goal of palliative care is to achieve the best possible quality of life for patients and their families. It affirms life and regards the dying process as normal. It emphasizes relief from pain and other distressing symptoms, integrates the physical, psychological, and spiritual aspects of patient care, offers a support system to help the patient live as actively as possible until death, and helps family members cope during the patient’s illness and in their own bereavement.⁵

The terms *hospice* and *palliative care* are used interchangeably in the literature, and represent the shared goals of meticulous attention to optimal pain and symptom management. Hospice care is distinguished from palliative care in that hospice care is rendered at the end of the palliative care spectrum. From its roots as a social movement, hospice has nurtured the evolution and maturation of palliative care.⁶

Hospice and palliative care

Points of entry to hospice and palliative care differ. Admission criteria for Medicare- and Medicaid-funded hospice programs require that a physician’s prognosis be six months or less, that care be delivered mostly in the home, and that the patient no longer be pursuing curative interventions. In contrast, palliative care can be initiated earlier in the

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disease process, while the patient may be receiving aggressive curative treatments, with the opportunity to benefit from skilled symptom management and supportive services. Hospice remains the appropriate option when the burden of treatment outweighs the benefit to the patient and the patient's prognosis is less than six months.

Although growing in public and professional awareness, palliative care is not commonplace in academic medicine, due to lack of knowledge about the needs and care of the dying and to inadequate funding for palliative care research and education.⁷ As a result, the provision of hospital-based palliative care services for those with advanced disease has been a relatively novel concept until recently.⁸

Access and use

NHO estimates that 390,000 patients and their families were cared for in the United States by hospice programs in 1995.⁹ This represents only a small percentage (15 percent) of the approximately 2.4 million Americans who die each year. Dr. Christine Cassel and Bruce Vladeck cite several reasons why only a relatively small percentage of dying patients are served by hospices:¹⁰ beyond the obvious problem of limited availability, many physicians are reluctant to articulate the realities of terminal illness because they feel it robs patients of hope. More relevant, perhaps, are the declining lengths of stay: one recent study reported a median stay for 6,450 hospice patients in five states as being only thirty-six days.¹¹ Our societal aversion to death also contributes to our inability to integrate hospice and palliative care into our health care system on a large scale. Other recent studies demonstrate that hospice services are underutilized, that referrals to hospice service are made very late, and that patients are uninformed about the availability of appropriate terminal care.¹²

According to recent studies, the predominant racial group among hospice patients is Caucasian, totaling 85 percent, followed by African-American at 9 percent, and Hispanic at 3 percent. The remaining 3 percent are not identified.¹³ These percentages, which are consistent with other data,¹⁴ reflect a significant issue of minority access to hospice services. Hospice programs face a formidable challenge to represent their diverse communities, in board and staff makeup, and in patient populations served.¹⁵

Challenges

The Robert Wood Johnson Foundation funded the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), a research project including over 9,000 patients at five major teaching hospitals. Significant deficiencies were identified in the care given to the dying in those hospitals. Close to 60 percent of the population still dies in hospitals.¹⁶

Although the SUPPORT project encouraged the use of advance directives and nurse advocacy to guide and communicate treatment decisions, patients' preferences were either unknown to their physicians or ignored. Comprehensive attempts to change the practice of professionals caring for the dying were profoundly ineffective. In the last three days of life, more than 50 percent of the patients in the study were in moderate to severe pain more than half of the time, and 38 percent of the study population spent at least ten days in an intensive care unit (ICU) on life-support systems.¹⁷

A central tenet of American health care is the patient's right to refuse treatment. The health care professional's ethical responsibility is to relieve pain and to prevent unnecessary suffering. The goals of care are to address the patient's physical comfort and peace of mind, and to provide the opportunity for a peaceful death, including those patients "who have serious and eventually fatal conditions, regardless of their likely survival time."¹⁸

But despite the goals of medicine, a disparity exists between patient preferences and actual practice, and it is reflected in the poor outcomes for the majority of dying patients studied in a variety of settings. Mildred Solomon and her researchers found that the majority of nurses and physicians they surveyed agreed with the patient's right to forgo treatment, yet the same study also revealed that the majority of dying patients were overtreated with technology but their pain was undertreated.¹⁹ The results of Solomon et al. and SUPPORT present both a challenge to and an opportunity for hospice professionals to assist in developing a new paradigm for optimal terminal and palliative care programs in hospital, long-term, and home care settings.

Moreover, a questionnaire, given to 864 physicians participating in the Eastern Cooperative Oncology Group, revealed that 50 percent of the physicians sampled rated the pain management in their own practice settings to be fair to very poor.²⁰ This 1993 study, surveying attitudes and practices in cancer pain management, observed that the major barriers to optimal pain management included inadequate pain assessment, and a combination of physician reluctance to prescribe opioids and patient reluctance to report pain and take opioids, in the context of a common phenomenon: nurses and physicians not always believing their patients when they report pain.²¹

According to Dr. Charles Cleeland et al., four factors predict health caregivers' underassessment and undermedication for pain: (1) opposite gender, (2) age greater than seventy years, (3) minority status, and (4) an appearance of well-being, that is, not appearing distressed.²²

Dr. Kathleen Foley and her colleagues have provided a thoughtful framework for those caregivers attending terminally ill patients, which is applicable to care settings outside the tertiary care center.²³ Their Taxonomy of Suf-

fering addresses seven "Common Shortcomings" in terminal care, all of which have been well documented in the literature:

- (1) inadequate physical symptom control;
- (2) undiagnosed depression or anxiety (major depression occurs in up to 25 percent of terminally ill patients);
- (3) unaddressed existential distress;
- (4) untreated psychological distress in family members;
- (5) untreated family fatigue (which is particularly critical because the greatest fear of the dying is being an intolerable burden on caregivers);²⁴
- (6) lack of skill in effective communication, particularly where cultural differences exist; and
- (7) unrecognized professional health care provider fatigue and/or moral distress.²⁵

The interdisciplinary model

The hospice interdisciplinary model has been implemented in various settings: home, nursing home, and hospice residence. The challenge is to provide such a model of comprehensive services for the terminally ill in acute and long-term care settings, where patients enter for diagnosis, treatment of disease, and palliation.

The Cleveland Clinic Palliative Care Program (PCP) was the first program in the United States to provide comprehensive and coordinated care for those with advanced disease in outpatient, inpatient, home health, and hospice care settings. Implemented in 1987, PCP began as an inpatient consultation service. In 1988, an outpatient clinic, research program, and community board of advisors were added, and thereafter a hospice home care service, a cancer home care service, and a dedicated inpatient unit.²⁶ The mission of PCP is to provide excellent care for patients with advanced cancer and their families throughout illness and grieving. A business plan to monitor costs and reimbursements and a marketing approach to improve referrals and education have been developed.²⁷

Another model program, the Palliative Care Consultation Service of the Medical College of Wisconsin, began clinical activities in 1993. Its goals are to provide symptom control, to assist with end-of-life decision making, and to serve as a resource for appropriate discharge planning for all dying patients. Pain and end-of-life decision making are the most frequent reasons for consultation. The service's clinical and educational roles have received widespread acceptance by the medical, nursing, and support staffs.²⁸

JoAnn Dalton and colleagues have demonstrated in North Carolina how palliative principles of care can be successfully implemented in a rural setting.²⁹ And for those communities where the hospital remains the focus of care for the terminally ill, Betty Ferrell et al. propose creation

of the position of pain resource nurse to direct the interdisciplinary palliative care team and to provide a hospital-wide network of support.³⁰

A two-year quality improvement project on dying in various settings has recently been initiated at three hospitals in Vermont and New Hampshire. A principal investigator, Dr. Sarah Goodlin, is identifying patient and family values and other aspects of the dying experience to help define appropriate and desirable goals of care. Critical pathways are being developed with a focus on coordinating care in hospital, nursing home, home health, and hospice settings. Dr. Goodlin recommends collaboration of ethics committees with professionals in their agencies to improve care of the dying.³¹

Conclusion

Optimal care at the end of life can be offered in a variety of settings, including the home, the skilled nursing facility, the subacute unit, and the residential and assisted living setting. For those who die in the hospital, step-down units and palliative care centers can offer more appropriate levels of care where the focus changes from curative to palliative symptom control. With such care integrated into community and tertiary health care systems, major barriers to timely referrals may be overcome. In addition, the hospice palliative care model offers enormous potential for enhancing the educational opportunities for nurses, physicians, social workers, chaplains, therapists, and allied caregivers.

The burdens of technology and institutional standards that prolong pain and suffering make dying a more complex, protracted, and fearful process. Dying well requires changing unrealistic goals of cure and life prolongation to the reasonable goal of a peaceful death.³²

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