
Hospice in the Nursing Home — A Valuable Collaboration

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Long-term care facilities have one of the most difficult tasks in health care: to maximize the health of frail elderly people. However, our society's resistance to the natural process of dying commands the assistance of hospice services in helping patients and their families cope with illness and death. The presence of such hospice services in long-term care facilities is relatively recent, and the two teams are still negotiating an optimal collaboration.

George W., an eighty-eight-year-old male who has lived in a nursing facility for three years, has a history of strokes, dementia, hip fractures, congestive heart failure, and anxiety. He moved into the nursing home when his wife of fifty-seven years was no longer able to care for him. In the past few months, he has been admitted to the hospital three times for pneumonia and urinary tract infections. He is bed-bound, with contractures of his lower extremities. He is no longer able to speak and has a feeding tube in place. Medications have been started for pain, and he appears comfortable.

George's family is exhausted by his long illness, but unable to agree completely on whether to continue to send him to the hospital when problems arise. His wife and three of his five children want hospice involvement and comfort care. One daughter, Debbie, is not ready to lose her father. Another daughter, Sally, lives in the area but is estranged from the family and has not spoken to them for several years. The family describes George as having been controlling, with episodes of explosive anger, often embarrassing them in public settings. They also report that he has always expressed guilt over the loss of his brother, who burned to death in a truck accident. George felt that he should have persuaded his brother to quit

that job before the accident. The social worker in the nursing home recommended to the physician that a hospice referral be made to give care to the family for their various types of emotional and spiritual suffering.

History of Hospice Services

Soon after Congress authorized and defined hospice care coverage under Medicare, the question arose as to whether a Medicare beneficiary residing in a long-term care facility, but not in a skilled bed, had the right to a hospice benefit. The Health Care Financing Administration (HCFA) affirmed this right, stating that the facility would be considered the patient's place of residence and that eligibility for hospice care would continue, as long as Medicare Part A was not covering the nursing facility care. This decision opened the door for the collaboration of hospices and nursing facilities in caring for individuals with terminal illnesses. Widespread initial skepticism about the wisdom and feasibility of this arrangement gave way to appreciation of the value of the collaboration.

Changes in payments to hospitals under the Medicare Diagnosis Related Group program, changes resulting from managed care, and quests by patients and families for the most appropriate end-of-life care have resulted in fewer people dying

in hospitals and a corresponding increase in deaths in nursing homes. Currently, approximately 20 percent of Americans die in nursing facilities, and 10 to 15 percent of residents in any given facility may be in the final six months of their lives. Growing interest exists in providing care to relieve the various types of suffering that these patients and families experience as the end of life approaches.

Rationale for Hospice Services in the Nursing Home

Dying patients average more than ten symptoms at any given time. Numerous studies have documented that pain and other symptoms are inadequately controlled for dying patients in nearly all medical settings, unless the patients are under the care of a hospice or palliative care team. In addition to the management of physical symptoms, patients and their families need information, opportunities to set goals of care, and support for their emotional and spiritual suffering.

Hospice staff members have expertise in symptom management and supportive care. The hospice team includes specialized professionals who work with patients and families to address different types of suffering, such as emotional or spiritual distress. Hospice staff can also help

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patients and families review information about diagnoses and prognoses and set appropriate goals of care. Many patients and families are not ready for life to end at the time of admission to hospice services, even if they understand the

terminal prognosis. One important role of hospice is to help patients and families come to terms with their situation. Staff members keep family members informed and meet with them off-site to provide counseling and support.

Hospice services can be requested by family members, social workers, nurses, or others who are involved in a patient's care. Services begin after the patient's terminal prognosis has been confirmed by one or more physicians. When the patient chooses to be on the Medicare hospice benefit, Medicare pays the hospice a fixed amount each day. The hospice staff provides visitations, medications related to the primary diagnosis, durable medical equipment, volunteer support, and bereavement support.

The care must be in accord with a plan developed by the hospice and nursing facility. The plan must be updated with each change in the physician's orders. The patient and family must accept a palliative approach to care, with an emphasis on comfort and symptom control rather than cure of a disease. This approach minimizes the use of technologically advanced testing or treatment. The goal is to maximize one's quality of life and opportunities for a meaningful existence as death approaches.

Hospice staff provide nursing assessment and symptom management; social services and counseling; home health aides for personal care such as additional baths; chaplains for spiritual support; volunteers to provide companionship; and bereavement support for surviving families for a year following the patient's death.

Since much of the care provided by physicians in nursing homes is done by triage over the telephone, the hospice team can provide skilled assessment and information for the attending physician. The team in turn receives consultation and oversight from the hospice medical director.

Moreover, the hospice team educates facility staff about palliative care, and supports them as they experience grief over the loss of their patients.

Ethical Considerations

The presence of hospice signals the reality of approaching death and can help the family understand and accept this prognosis. The extra medical support and solicitude provided by hospice reassures family members that their loved ones are receiving the best care possible.

The essential, ethical rationale for using hospice in the nursing home is this: dying people — and their families — deserve the best medical and emotional support possible, whether they live in private dwellings or in long-term care facilities. Since our society does not educate its members effectively about end-of-life issues, hospice team members provide a needed service for any person or family member facing the end of life. To deny this service based on the fact that a dying person happens to live in a nursing home would be unconscionable.

Differing Competencies of Nursing Home Personnel

Care of the dying is a unique discipline, with a different orientation from care of the elderly. Palliative care instruction is only now being introduced into medical and nursing school curricula. Consequently, the rapidly increasing knowledge and skills of palliative care are not widely available to patients in nursing homes not enrolled in hospice services, despite the fact that one-fifth of Americans die in these facilities. An estimated 90 percent of personal care in long-term care facilities is provided by certified nursing assistants who have minimal clinical education, limited time to give emotional support to patients and families, limited skills in assessing patient needs, and a high turnover rate.

The typical registered nurse in a long-term care facility has an average of forty-two residents under his or her care, which makes it difficult to devote extra time and attention to dying residents and their families. In addition, most skilled registered nurses in a facility are likely to be expert in care of the elderly, rather than in care of the dying.

Inadequate Management of Pain

Bernabei et al. (1998) found that daily pain was prevalent among nursing home residents with cancer, and that 26 percent of elderly cancer patients did not receive any treatment for their daily pain. Staff in nursing facilities have been shown to

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lack knowledge and skills in symptom management and communication about end-of-life issues (Ersek, Kraybill, and Hansberry 1999). Long-term care physicians, trained and oriented to maintain their charges in a functional and alert condition and lacking adequate education in pain management, are sometimes reluctant to prescribe morphine for severe pain. In recognition of the deficiencies in pain management for older persons, the American Geriatric Society has developed guidelines for managing both cancer and chronic pain in older persons (AGS Clinical Practice Committee 1997; AGS Panel on Chronic Pain in Older Persons 1998).

Uncertainty of Prognosis

The Medicare hospice benefit requires that a patient have a life expectancy of six months or less for eligibility. Prognosis is most clearly predictable for patients with incurable cancer, but most nursing facility residents die of causes other than cancer. On admission to nursing homes, patients are listed as terminal if their life expectancies are less than six months; however, one study showed that 70.7 percent of patients listed as terminal were still alive at six months (Finne-Soveri and Tilvis 1998).

Attempts are being made to create assessment tools for nursing home residents that will more accurately predict prognosis, and the National Hospice Organization has published prognosis guidelines for patients with noncancer diagnoses.

Late Enrollment

Referrals for hospice services are often made very late in the course of illness, with a median survival of twenty-seven days in one facility, despite a strong recommendation for earlier enrollment in palliative services and hospice care for patients with terminal illness (Ackermann and Kemle 1999).

Barriers to Collaboration between Long-Term Care Facilities and Hospices

As in many new alliances, miscommunication and conflicts arise concerning which services should be provided by hospice staff and which by nursing facility staff. Nursing facility staff have sometimes resented hospice staff who seemed to imply that they knew the best way to handle patient problems, or seemed to interfere in the relationship that facility staff had previously developed with a patient and his or her family. Some nursing home administrators or medical directors have not been supportive of the hospice approach to care. Hospice staff may have inadequate knowledge of nursing home policies and regulations, and may not appreciate the perspective of nursing home staff.

Divergence in Focus

Nursing facilities have developed as health care institutions that focus on providing medical services, rehabilitation, and safety. Treatment is provided according to a formalized care plan, as dictated by law, which emphasizes medical care over individuality or privacy. Although many facilities attempt to provide inviting surroundings and activities, attending to a resident's immediate physical needs sometimes takes precedence over the fullness of living or comfort and support for the dying. Since hospice focuses on helping the patient live as fully as possible in the late stages of life, and maintaining control over goals of care and daily routine, the divergence in focus leads to potential conflict between the two types of organizations.

For instance, the nursing home staff may insist that a patient go to the dining room for meals to encourage socialization and activity, while the hospice staff supports the patient's wish to simply remain in bed because of severe weakness. In other cases, the nursing home staff may worry about a diabetic patient who is not eating and not adhering to a diabetic diet, while the hospice staff may be encouraging the patient to eat more by enjoying her favorite foods, even if she craves candy bars and soda.

Conflict in Regulatory Guidelines

The regulations for long-term care facilities may also create conflict with hospice approaches. Nursing facility surveyors have traditionally focused on determining whether a patient's decline is avoidable or unavoidable. They are often not trained in standards of palliative care. Consequently, they employ the assumption that, if a facility has not aggressively attempted and exhausted all reasonable options for care, the decline is likely avoidable and should have been prevented (Lawhorne 1999). Although patients and families are allowed to refuse aggressive treatments, there is often an ongoing effort to counsel them and offer alternative therapies.

Even when patients are admitted to hospice care, there may be ongoing pressure to enhance nutritional status by placing feeding tubes, or to perform other interventions that are unlikely to enhance patients' comfort and dignity as death approaches. A recent analysis of data available on the practice of tube feedings in patients with advanced dementia showed that providing supplemental nutrition by tube feedings has not been shown to achieve any of the desired goals of preventing aspiration pneumonia, prolonging survival, reducing the risk of infection, or providing comfort (Finucane, Christman, and Travis 1999). Yet feeding tubes continue to be commonly recommended in patients who refuse to eat a sufficient amount.

For example, a fifty-seven-year-old patient with end-stage dementia (bed-bound and unable to respond to voices) continued to receive tube

feedings at a rate that had caused her weight to increase thirty pounds in three years. The facility had a policy against discontinuing tube feedings in any patient who could not maintain adequate nutritional status. When the patient was no longer tolerating the feedings, and liquid feedings were foaming out of the patient's nose and mouth, the hospice team was finally able to arrange for the rate of feeding to be decreased to a minimal rate, although the feedings were not stopped completely.

Physicians' notes may not explicitly state the goals of care, leaving the surveyor to interpret whether the care was acceptable or unacceptable. Most physicians who treat elderly patients are familiar with the person of advanced age who has numerous chronic illnesses and undergoes functional decline as well as decreased nutritional intake. Their decline cannot be attributed to any reversible condition or cause. These people seem to be dying of aging and a loss of the will to live. Many patients and families in this situation do not feel that aggressive diagnostic studies or interventions are appropriate, but rather that the patient should be allowed to die peacefully. Facility staff, physicians, and regulators sometimes feel that an evaluation should be done for reversible conditions before allowing the patient to die.

Such conflicts have led to the question of whether regulatory efforts to improve the quality of care in nursing homes have inadvertently impaired the quality of dying. Although some regulatory entities have supported the presence of hospice in nursing homes, developing a coordinated care plan remains challenging for both hospice and long-term facilities. Palliative care will have to link to the Minimum Data Set (MDS) developed for long-term care, and this linkage will be a difficult undertaking.

Conclusions

Long-term care facilities have become the residence for an increasing number of elderly and dying persons in America. As they focus on keeping frail elderly people in the best health possible, these facilities do some of the most difficult, arduous work in all of health care. However, our culture's

conflict between the acceptance of death as a natural event and the attitude that death is an enemy to be defeated with medical technology (McCue 1995) remains troublesome. Nursing home staff, a microcosm of the culture, often has difficulty accepting a palliative approach as patients enter their final decline.

Hospice teams provide valuable support for the dying person, family members, and nursing home staff. They help the patient, family, and nursing home staff develop goals for this final stage of life, afford assessment assistance to the physician and staff, manage the patient's pain and symptoms, offer psychological and spiritual support for the

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person and family members, and make bereavement support available to family and staff members. Hospice is the appropriate organization to provide expertise and guidance to other health care workers who must care for the dying. By philosophy and training, hospice is the best-positioned organization in our society to bring dignity and comfort to people going through the dying experience and to the people who love them.

Conclusion of Case Study

George's family received much support from the hospice team. Nurses helped them understand his prognosis and options for treatment and assessed

his symptom management. His daughter, Debbie, met with the social worker and the chaplain, who supported her grief in losing her father. Sally, the daughter who had been estranged, agreed to visit her father and meet with other family members. Family members expressed their feelings about their father's anger and controlling behavior in earlier years, and expressed their empathy for his grief and guilt over losing his brother. The family also began to support each other. A family meeting was held, and all agreed to focus on comfort measures and discontinue the feeding tube. The patient remained comfortable and peaceful. He died two weeks later with his wife and five children at his side, supported by the hospice chaplain.

References

- Ackermann, Richard J., and Kathy A. Kemle. 1999. "Death in a Nursing Home with Active Medical Management." *Annals of Long-Term Care* 7(August): 313-319.
- American Geriatric Society Clinical Practice Committee. 1997. "Management of Cancer Pain in Older Patients." *Journal of the American Geriatric Society* 45 (October): 1273-1276.
- American Geriatric Society Panel on Chronic Pain in Older Persons. 1998. "The Management of Chronic Pain in Older Persons." *Journal of the American Geriatric Society* 46 (May): 635-651.
- Bernabei, Roberto, et al. 1998. "Management of Pain in Elderly Patients with Cancer." *JAMA* 279 (June): 1877-1882.
- Ersek, Mary, Beth Miller Kraybill, and Jennifer Hansberry. 1999. "Investigating the Educational Needs of Licensed Nursing Staff and Certified Nursing Assistants in Nursing Homes Regarding End-of-Life Care." *American Journal of Hospice and Palliative Care* 16 (July/August): 573-582.
- Finne-Soveri, U. Harriet, and Reijo S. Tilvis. 1998. "How Accurate Is the Terminal Prognosis in the Minimum Data Set?" *Journal of the American Geriatric Society* 46 (August): 1023-1024.
- Finucane, Thomas E., Colleen Christmas, and Kathy Travis. 1999. "Tube Feeding in Patients with Advanced Dementia." *JAMA* 282 (October 13): 1365-1370.
- Lawhorne, Larry W. 1999. "Avoidable and Unavoidable Decline and the Naturalness of Dying: The Nursing Home Dilemma." *Annals of Long-Term Care* 7 (August): 309-312.
- McCue, Jack D. 1995. "The Naturalness of Dying." *JAMA* 273 (April 5): 1039-1043.