Providing palliative care to a patient like the one in the following case scenario is a complex task.

You are an hour behind in your afternoon clinic when you are paged to call the nursing home regarding Anna Jones. Anna has moderate Alzheimer’s dementia, coronary artery disease, and congestive heart failure for which she has had five hospital admissions in the past 3 months. Her most recent echocardiogram showed an ejection fraction of 15%. “Dr Smith, Mrs Jones isn’t doing well...she’s moaning that she hurts, she’s dyspneic, and won’t get out of bed. Her lungs are congested. Anna doesn’t want to go to the hospital anymore. What should we do?”

Physicians have a critical role in improving communication between the family and the healthcare team, making the transition from rehabilitative to palliative care. Hospice can be a valuable partner to deliver excellent pain and symptom management in end-of-life care. This article reviews that partnership.

Dying With Pain and Disability
People are living longer but are dying with more disabilities, often in nursing homes. Identification of those who are dying needs to be quicker to allow discussion of goals of care and to meet their individual needs at a higher level. Pain is pervasive and undertreated in general, but institutionalized individuals are even at greater risk of receiving inadequate analgesia. Competing goals of providing good-quality palliative care while meeting federal and state expectations of improving or maintaining function can create dilemmas for those caring for terminally ill patients in nursing homes. Physicians play a critical role in improving communication between the family and the healthcare team during the transition from rehabilitative to palliative care. Hospice can be a valuable partner in the delivery of excellent pain and symptom management in end-of-life care.
assessment and management involve an interdisciplinary approach to treat patients for physical, psychological, social, and spiritual symptoms. Pain, a pervasive symptom throughout end-of-life care regardless of diagnosis, is under-treated in general; institutionalized patients are at even greater risk of inadequate treatment for pain.

Teno et al11 found that 25% of newly admitted nursing home residents were in daily pain and 67% of these residents were still in pain 2 to 6 months later. Bernabei et al8 reported that up to 40% of elderly nursing home patients with cancer had daily pain and more than 25% of these patients received no analgesics. They also found that the elderly were less likely to receive opiates than younger patients. Buchanan et al8 showed that among recently admitted hospice patients, more than 70% had pain, with almost half having it daily. To improve their ability to treat pain, physicians not only must rely on patient self-report, but they also must have good assessment tools, especially for those patients who are unable to communicate their needs.

**Overview of Palliative Care and Hospice**

According to the World Health Organization,9 palliative care is the active total care of patients who are dealing with a life-threatening illness. Such care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It provides relief from pain and other distressing symptoms and offers a support system to help families cope with the illness of their loved ones. The goal of this care is to achieve the best possible quality of life for patients and their families. Palliative care is consistent with osteopathic principles of providing holistic healthcare, captured succinctly by the American Osteopathic Association’s motto, “D.O.S.: Physicians treating people, not just symptoms.”

Dr Cicely Saunders started the modern hospice movement. She was a nurse who became a social worker and then a physician. She taught physicians, nurses, counselors, chaplains, and therapists how to work together to provide comprehensive care at the end of life. In 1967, with her colleagues, she developed St Christopher’s Hospice in the south of London, England.

Hospice is a program that provides palliative care by attending to the emotional and spiritual needs of terminally ill patients through an interdisciplinary team approach. Payment for hospice services in the United States is dependent on the fiscal intermediary; however, most other benefit plans are based on the hospice Medicare benefit (See http://www.cms.hhs.gov).

**Determining Hospice Eligibility**

For patients to qualify for hospice, attending physicians must certify that if the disease process runs its normal course, life expectancy is less than 6 months. Unfortunately, referrals to hospice have a mean length of stay of 22 days, with 32% dying in 1 week or less.2 Reynolds et al10 noted that families and staff expected 51% of the deaths occurring in nursing homes, having anticipated death as imminent a week or more before it occurred. One week is not enough time to ensure good palliative care.

Clearly, prognosticating death is difficult for most physicians. Abicht-Swensen and Debner11 identified predictors of short-term mortality in nursing home residents independent of age, gender, and diagnosis. Predictors include:

- Decreased cognitive functioning,
- Decrease in ability to communicate,
- Decrease in physical functioning (ADL),
- Decrease in nutrition (weight loss), and
- Incontinence.

These common factors are clinically useful to help identify those who might be hospice eligible in a more timely manner.

Deaths due to cancer may be easier to predict because of the typically slow steady decline in function. It is more difficult to predict the death of patients with chronic progressive diseases such as congestive heart disease, chronic obstructive pulmonary disease, and other end-stage diseases because of the waxing and waning of acute symptoms. The possibility exists that any acute episode could be fatal. Patients like Anna who have a poor ejection fraction and symptoms at rest while optimally treated with medicine qualify for hospice care.

**Challenges to Palliative Care in Nursing Homes**

The Federal Nursing Home Reform Act or the Omnibus Budget Reconciliation Act of 1987 (OBRA’87) created a set of national minimum standards of care for people living in certified nursing facilities to emphasize quality of life as well as quality of care.12 Nursing home policies and regulations such as OBRA’87 emphasize rehabilitation and restorative care with the goal of improving or maintaining function. Patients with progressive life-limiting disease often have a functional decline that does not necessarily indicate poor quality of care, though state surveyors hold nursing homes accountable for such decline. Buchanan et al8 indicated that 93% of hospice residents did not believe they were capable of increased functional independence at the time of their admission to the nursing home; staff concurred with this belief. Competing goals of providing good quality palliative care while meeting federal and state expectations of improving or maintaining function can create dilemmas for those caring for terminally ill patients in nursing homes.

Other challenges in providing high-quality long-term care include high staff turnover, staffing shortages, and lack of available hospice teams. Parker-Oliver13 found that the high turnover rate in nursing home staff created communication and coordination problems with the hospice plans of care. Miller et al14 reported that inadequate staff and staff turnover adversely affects the continuity of care and, in turn, the quality of end-of-life care. These effects are more prevalent in nursing homes than in other care settings.

Although the vast majority of nursing homes have access to rehabilitation services, not all have hospice contracts. Parker-Oliver and Bickel15 noted that almost 20% of facilities that they surveyed did not have a hospice contract. At least one nursing home administrator did not contract with hospice for fear that the facility would encounter difficulty at survey time.
Domains of Palliative Care

- **Structure and Processes of Care**
  - Comprehensive interdisciplinary assessment of patients and their families
  - Development of plan based on patient’s and family’s values, goals, and needs
  - Interdisciplinary team’s provision of services to the patients and their families consistent with care plan
  - Inclusion of appropriately trained and supervised volunteers on interdisciplinary team
  - Availability of support for education and training to interdisciplinary team
  - Commitment of palliative care team to improving quality in clinical and management practice
  - Program’s recognition of emotional impact on members of palliative care team
  - Relationship of program with one or more hospices and other community resources to ensure continuity of highest-quality care
  - Physical environment in setting meeting as much as possible preferences, needs, and circumstances of patients and their families

- **Physical Aspects of Care**
  - Skilled and systematic application of best available evidence on management of pain, symptoms, and side effects

- **Psychological and Psychiatric Aspects of Care**
  - Skilled and systematic application of best available evidence on assessment and management of psychological and psychiatric issues
  - Availability of grief and bereavement program to patients and families

- **Social Aspects of Care**
  - Interdisciplinary assessment to identify patients’ and their families’ social needs
  - Development of care plan to meet social needs as effectively as possible

- **Spiritual, Religious, and Existential Aspects of Care**
  - Skilled and systematic application of best available evidence to assessment and response to spiritual and existential concerns of patients and their families

- **Cultural Aspects of Care**
  - Assessment and attempts to meet patients’ and families’ culture-specific needs

- **Care of Patients Whose Death Is Imminent**
  - Recognition of signs and symptoms of impending death
  - Provision of appropriate care to patients and their families

- **Ethical and Legal Aspects of Care**
  - Respect for carrying out patients’ goals, preferences, and choices within limits of applicable state and federal law
  - Awareness of and addressing of ethical issues and concerns
  - Knowledge about legal and regulatory aspects of palliative care

Despite the positive impact hospice has on quality of care through improved pain management and lower hospitalization rates, considerable variation in utilization exists between facilities as well as between states. In 2004, the National Consensus Project for Quality Palliative Care developed clinical guidelines based on the collective scientific evidence to promote consistency, comprehensiveness, and quality across many domains of health care. These clinical practice guidelines are briefly summarized in Figure 1.

Nursing homes indicated an overall positive experience with hospice, though rural nursing homes rated hospice as slightly less beneficial than urban nursing homes. According to Miller and Mor, hospital and hospice collaborated less in states in which larger populations of older adults resided in rural areas. The Medicare Payment Advisory Commission also found that hospice use for rural Medicare beneficiaries was only 75% of the urban rate of use.

**Opportunity for Collaboration—Role of Hospice in Long-term Care**

Effective interdisciplinary teams require a shared philosophy and goals of care, skilled communication, shared decision making, and institutional support. Merging two separate interdisciplinary teams with differing philosophies and governing institutions is challenging. Despite potential conflicts, interfacing the long-term-care and hospice teams provides opportunity for collaboration. Such collaboration results in better pain management leading to improved quality of life, improved resource utilization, and improved communication with patients and families regarding goals of care.

**Better Pain and Symptom Control**

Based on numerous studies, it is believed that increased availability of hospice care in nursing homes can lead to improved end-of-life care, including better pain assessment and management, for dying nursing home residents. Without adequate assessment, pain cannot be managed. Miller et al provide evidence that hospice enrollment for dying nursing home patients results in superior pain assessment and management. Patients enrolled for more than 8 days had a higher chance of pain being assessed, and they were five times more likely to receive an opioid during their last 2 days of life. Furthermore, compared with findings of a previous study by Miller et al, a higher proportion of both hospice and nonhospice nursing home residents had more pain assess-
ments completed, suggesting a beneficial collaborative effort. Wu et al confirm that hospice positively affects and improves the assessment of symptoms on both an individual and facility basis.

In the nursing home setting, however, barriers such as the prevalence of dementia, the multiplicity of pain problems, and greater sensitivity to drug adverse events pose greater difficulty in assessing and managing pain. Teno et al note that in the general nursing home population, 56% of residents are either moderately or severely cognitively impaired. Nursing staff’s astuteness and reliance on changes in patterns of residents’ behavior enable detection of pain or other changes in residents’ condition. Mitchell et al found patients with advanced dementia who were admitted to nursing homes had greater functional disability, more behavior problems, and more often had total parenteral nutrition at the end of life than patients who were cared for at home. Healthcare providers did not recognize that patients were dying and infrequent referrals were made to hospice. Dying patients were frequently hospitalized, underwent burdensome treatments, and had distressing symptoms that were potentially treatable when death was imminent.

Baer and Hanson reviewed family perceptions of hospice. Respondents rated quality of care for pain and other physical symptoms as good or excellent for 64% of patients before hospice services; after initiation of hospice, this rating increased to 93% of patients. For emotional and spiritual needs, the quality of care was excellent or good for 64% of patients before and 90% of patients after hospice was initiated. Families did not perceive nursing home and hospice staff as duplicative. The median estimated added daily monetary value of nursing home hospice was $75, with 45% of family respondents estimating this value at $100 or more per day.

**Improved Resource Utilization**

Patients are often hospitalized by default if a care plan does not incorporate good end-of-life care. Miller et al found that hospice care delivered in nursing homes is associated with a 20% lower rate of hospitalization compared with nonhospice care in the last 30 days of life. When avoiding hospitalization is consistent with the patient’s and family’s wishes, this care positively influences quality of life as well as saving healthcare expenditures. In the review of Baer and Hanson, surviving family members believed that hospice improves the palliation of symptoms and enhances quality of care for those who are dying. Fifty-three percent of family respondents believed that hospice services permitted their loved ones to avoid hospitalization in a study by Baer and Hanson.

Pyenson et al confirmed that Medicare costs were lower for patients enrolled in hospice care and that hospice patients lived longer than their nonhospice cohort. For example, caring for a Medicare patient with congestive heart failure costs approximately $9000 less with hospice care; median time until death was lengthened from 65 days to 136 days with hospice care. Further research is needed to explore this finding as this study was designed to look at cost, not length of life.

**Suggestions for Improving End-of-Life Care**

Communication between physicians, nursing home staff, patients, and family members is crucial to providing good palliative care. Surviving family members noted that educational gaps in staff training and communication problems led to their perception of less-than-ideal care for their loved ones at the end of life. Discussions regarding goals of care need to be initiated early so that potential crises and undesired modes of therapy can be avoided.

Education on pain management and regulatory guidelines that govern healthcare is essential. Physicians can become involved to help shape future healthcare policy. Taking on the role of patient advocate helps ensure open communication with patients and families, nursing home staff, as well as referring physicians. Communication with the receiving physician across different healthcare settings is crucial to foster a smooth transition to ensure that a patient’s goals of care are followed. Figure 2 outlines the physician’s role in end-of-life care decision making regarding hospice care.

**Comment**

As our population of geriatric patients continues to rapidly expand, it is time to critically assess and remove the barriers to providing good palliative care to patients (like Mrs Jones) who are dying. According to Bernabei et al, failing to prevent or effectively treat pain is indicative of poor-quality medical care.

An accurate prognosis is essential to good palliative care in the long-term care setting. Depending on that prog-
nosis, nursing home patients require one of the following: □ rehabilitation to restore function, □ treatment to maintain function, or □ palliative care to manage the process of dying.

Just as therapists are available in nursing homes to provide rehabilitation, hospice is available for palliation.15 Baer and Hanson20 summarized that initiation of hospice in a “relatively resource-poor” nursing home helps to meet the needs of its dying residents without incurring the additional expense of hospitalizations and other costly interventions. Primary care physicians must recognize the dying process in their frail nursing home patients and ensure that they receive the specialized care needed to assure good pain and symptom management. Hospice can provide such care. Osteopathic physicians are well trained in the holistic approach to medicine. The optimal place to apply this training and approach is in dealing with dying patients and their families.

References


