Working With Hospice Teams to Improve Pain Management in Nursing Homes

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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.

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In refreshing this article, a different case scenario is substituted for the one appearing in the 2005 pain management series1 to again illustrate the complexity of providing excellent, compassionate care and symptom management at end of life.

Case Presentation

Mrs White, an 86-year-old woman, has been admitted to Dr Jones' service for rehabilitation at the local nursing home following a recent hospital stay for a hip fracture. She had a radical mastectomy 2 years ago for breast cancer and now is complaining of hip pain. She has not had any falls and was doing well until she tried to get up from her recliner and collapsed because of the pain in her hip. Surgical fixation was accomplished, but she will only be allowed toe-touch weight bearing because of the osteolytic destruction of the bony cortex due to metastatic disease. Oncologic consultation was sought to evaluate treatment options.

After a lengthy family conference, Mrs White decided not to pursue any further chemotherapy or radiation. She wants to focus on symptom management to maximize her quality of life. She realizes that she can no longer live independently, thus nursing home placement is selected. Mrs White attempts physical and occupational therapy at the nursing home, but the severe pain in her hip is limiting her involvement. Pain medications ordered by her orthopedic surgeon are inadequate. She is unable to sleep, has a poor appetite, and is complaining of excruciating pain radiating down her left leg. The nurse pages Dr Jones to address Mrs White's pain and symptoms and asks, "Why are we pushing her to do therapy? Is rehab really appropriate? Can't we do something to make her more comfortable?" Clearly, these issues are not going to be handled easily over the phone.

Providing palliative care to a patient like Mrs White is a complex task. 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.

Dying With Pain and Disability

People are living longer but are dying with more disabilities. The fastest growing segment of the population is that comprising those older than 85 years. Frailty and disability increase with age. Many patients will require assistance with activities of daily living (ADL), which may necessitate institutionalization if adequate resources are not available. Teno and colleagues[2,3] found that 67% died in either a hospital or nursing home while only 23% died at home; furthermore, they estimated that by 2020, 40% of older persons who die of nontraumatic causes will reside in a nursing home at the time of death. Discussion with patients and families in a physician's daily practice often deals with concerns about quality of life, including attention to pain and symptom management. Physicians need to consider who among their patients might likely die in the near future to identify those who might prefer a palliative care approach to better meet their needs.

Many studies indicate that the rates of untreated severe pain are high among the general nursing home population.[3-8] Teno et al[3] report that on their initial

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assessment, 41% of nursing home residents were in pain. Inadequate assessments, as well as the high proportion of cognitively impaired patients, lead to an underestimation of the prevalence of pain. In 1995, Ferrell[6] reported that up to 80% of nursing home residents had pain that contributes materially to functional impairment and decreased quality of life. Trask et al[9] also reported high percentages of distressing pain observed in individuals transitioning from hospital to the nursing home at the end-of-life. Physicians must ensure that the rapidly increasing numbers of patients who are dying in long-term-care facilities receive good-quality care by incorporating sound palliative care practice.

Teno et al[3] found that 25% of newly admitted nursing home residents were in daily pain and 67% of them were still in pain 2 to 6 months later. Bernabei et al[5] 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. Several studies found that the elderly were less likely to receive opiates than younger patients.[5,10] Buchanan et al[7] showed that among recently admitted hospice patients, more than 70% had pain, with almost half having it daily.

Pain is poorly understood because of the lack of objective biologic markers. It is commonly defined as an individual's unpleasant sensory and emotional experience and can profoundly diminish a person's quality of life. Effective pain 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 undertreated in general; institutionalized patients are at even greater risk of inadequate treatment for pain. To improve their ability to treat pain, physicians not only must rely on a patient's self-report, but also must have good assessment tools, especially for those patients unable to communicate their needs.

Overview of Palliative Care and Hospice

According to the World Health Organization,[11] palliative care is the active total treatment of patients who are dealing with a life-threatening illness. Such attention affirms life and regards dying as a normal process. It neither hastens nor postpones death yet 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 a motto of the American Osteopathic Association, "D.O.s: Physicians treating people, not just symptoms."

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. The late 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.

A recent study by Pleschberger[12] looked at dying nursing home residents' concerns regarding dignity. Residents were most concerned by the threat of illness and by not having their care needs met, which was fostered by their perception of inadequate care in nursing homes. This investigation highlights the challenges of dying in nursing homes and demonstrates the high vulnerability of this population. Palliative care or hospice services can provide additional support in the nursing home environment.

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 26 days, with 32% dying in 1 week or less.[13] Reynolds et al[14] 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 Debner[15] identified predictors of short-term mortality in nursing home residents independent of age, gender, and diagnosis which include:

- ☐ decreased cognitive functioning,
- ☐ decrease in ability to communicate,
- ☐ decrease in physical functioning (ADL),
- ☐ decrease in nutrition (eg, weight loss), and
- ☐ incontinence.

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

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 (CHF), 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. For example, patients with CHF who have a poor ejection fraction and symptoms at rest, while optimally treated with medicine, qualify for hospice care. In the case example, Mrs White is appropriate for palliative care or referral to hospice as she has chosen not to pursue additional treatment.

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.[16] 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 al[7] 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-Oliver[17] found that the high turnover rate in nursing home staff created communication and coordination problems with the hospice plans of care. Miller et al[18] 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 Bickel[19] 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.

Hanson et al[20] found that nursing home administrators' attitudes towards hospice may influence its availability for their residents. Nursing home administrators with two or fewer hospice enrollees in the preceding 3 months were three times more likely to indicate that nursing homes were able to provide good care for dying residents and their families without the use of hospice than those administrators with three or more hospice enrollees (37% vs 11%). Despite fewer enrollees, 59% of this cohort indicated that hospice improves quality of care. The study by Hanson and colleagues[20] suggests that those nursing home administrators with positive attitudes toward hospice were associated with greater use of hospice by residents in their facilities.

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.[21] In 2004, the National Consensus Project for Quality Palliative Care[22] developed clinical guidelines based on the collective scientific evidence to promote consistency, comprehensiveness, and quality across many domains of healthcare. These clinical practice guidelines are briefly summarized in *Figure 1*.

Nursing homes indicated an overall positive experience with hospice, though consistent access to hospice continues to be an issue, especially in smaller, rural facilities.[23] Some rural nursing homes rated hospice as slightly less beneficial than urban nursing homes.[19] According to Miller and Mor,[24] nursing home and hospice collaborated less in states in which larger populations of older adults resided in rural areas. The Medicare Payment Advisory Commission[25] also found that hospice use for rural Medicare beneficiaries was only 75% of the urban rate of use. Education, such as provided by following the clinical guidelines from the National Consensus Project for Quality Palliative Care,[22] will help foster and develop new relationships.

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

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

Better Pain and Symptom Control

Based on numerous studies,[4,26-29] 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 evaluation, pain cannot be properly managed. Miller et al[4] 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 evaluated, 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,[27] a higher proportion of both hospice and nonhospice nursing home residents had more pain assessments completed, suggesting a beneficial effect of having hospice in the facility.[4] Wu et al[28,30] confirm that the presence of hospice positively affects and improves the assessment of symptoms on both an individual and facility basis.

In the nursing home setting, the prevalence of dementia, multiplicity of pain problems, and greater sensitivity to drug adverse events pose greater difficulty in assessing and managing pain.[6] Miller et al[18] 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 their condition.[18] This vulnerable population is even more prone to inadequate pain and symptom management. Mitchell et al[31] found that 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 those who were cared for at home. Healthcare providers often 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.[31]

Families feel that hospice improved the quality of life for their loved ones.[32] Baer and Hanson[26] 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. Hospice initiation increased quality of care for emotional and spiritual needs likewise up to

Figure 1. *Summary of domain structure of National Consensus Project guidelines for palliative are. (Source: National Consensus Project for Quality Palliative Care.* Clinical Practice Guidelines for Quality Palliative Care. Available at: http://www.nationalconsensusproject.org/index.html. Accessed February 11, 2005.)

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
- ☐ Skillful and systematic application of best available evidence on management of pain, symptoms, and side effects

■ Psychological and Psychiatric Aspects of Care
- ☐ Skillful 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
- ☐ Skillful 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

90% from 64%. 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.[26]

Improved Resource Utilization

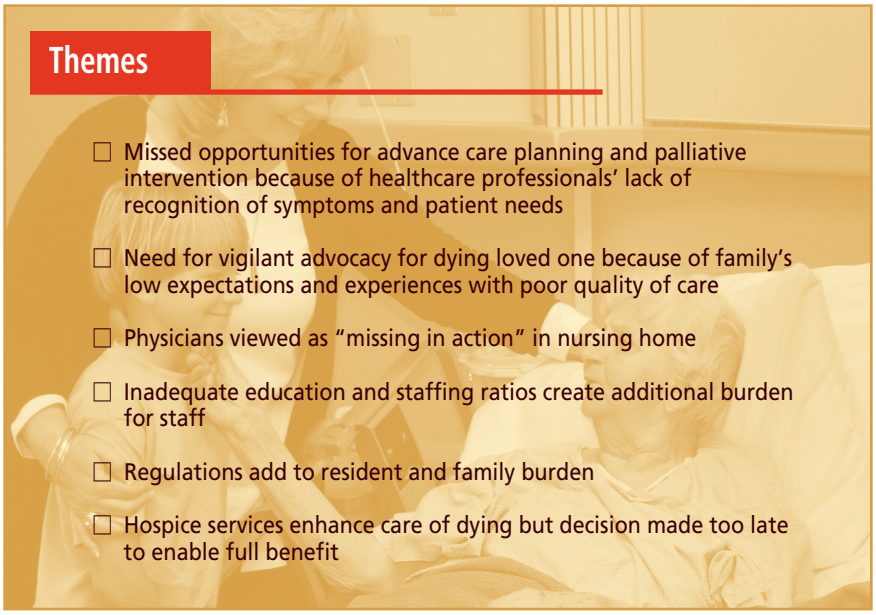
Patients are often hospitalized by default if a care plan does not incorporate good end-of-life care. Miller et al[33] found that hospice care delivered in nursing homes is associated with a 20% lower rate of hospitalization compared with nonhospice care in the last 30 days of life. When avoiding hospitalization is consistent with the patient's and family's wishes, such care positively influences quality of life as well as saving healthcare expenditures. In the review of Baer and Hanson,[26] surviving family members believed that hospice improves the palliation of symptoms and enhances quality of care for those who are dying; 53% of family respondents believed that hospice services permitted their loved ones to avoid hospitalization.

Pyenson et al[34] 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 CHF costs approximately $9,000 less with hospice care; median time until death was lengthened from 65 days to 136 days.[34] 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.[21] Complementing this perception, Wetle and colleagues[32] identified six key themes that emerged from their qualitative study (*Figure 2*). These themes certainly set the bar on improvements that can be made in caring for those with life-limiting illnesses. Discussions regarding goals of care need to be initiated early

Figure 2. *Key themes identified by Wetle and colleague. (Source: Wetle T, Shield R, Teno J, Miller SC, Welch L. Family perspectives on end-of-life care experiences in nursing homes.* Gerontologist. *2005;45:642-650.)*



so that potential crises and undesired modes of therapy can be avoided, wishes are followed, and dignity preserved.

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. Consultation 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 3* outlines the physician's role in end-of-life care decision making regarding hospice care. In addition to assuring Mrs White's symptoms are managed, it is her physician's role to facilitate a family meeting with the nursing home staff to discuss goals of care and to explore if hospice would be an appropriate option to meet her wishes.

Comment

As the population of geriatric patients continues to rapidly expand, it is time to critically assess and remove the barricades to providing good palliative care to patients (like Mrs White) who are dying. According to Bernabei et al,[5] failing to prevent pain or effectively treat patients in pain is indicative of poor-quality medical care.

An accurate prognosis is essential to good palliative care in the long-term-care setting.[21] Depending on that prognosis, 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.[21]

Just as therapists are available in nursing homes to provide rehabilitation, hospice is available for palliation.[19] Baer and Hanson[26] summarize 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. We need to be 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.

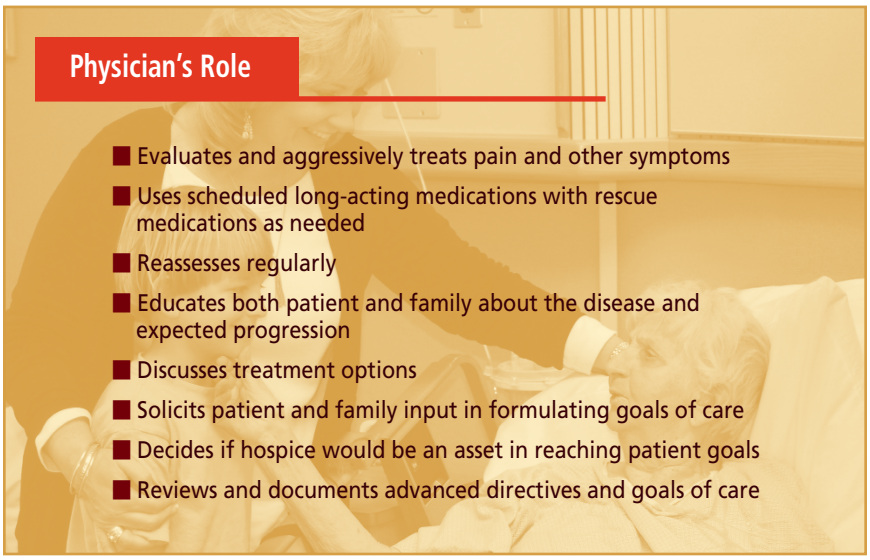


Figure 3. *The physician's role in end-of-life care decision making regarding hospice care.*

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