Palliative Care For the Nursing Home Resident With Dementia

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The prevalence of memory impairment, including dementia, increases exponentially with age. Of people with late-onset dementia, about half have Alzheimer's, 16% have vascular dementia, and 30% have other forms of dementia.[1] Alzheimer's disease, the most frequent cause of dementia in Western societies, affects an estimated 5 million people in the United States and 17 million worldwide.[2] The onset is insidious with manifestations evolving over a period of years from mildly impaired memory to severe cognitive loss. The course is progressive and terminates with mental and functional incapacity and subsequent death.[3] As many as 90% of Americans with dementia will be institutionalized before death.[4-5] Nursing homes are, therefore, important providers of end-of-life care. Several researchers have highlighted the need to improve the quality of palliative care in the nursing home setting.[6-8]

Understanding the Stages and Trajectory of Dementia

Dementia is defined as a syndrome characterized by multiple impairments in cognitive function without associated deficits in consciousness. The domains affected include general intelligence, learning, memory, language, problem solving, orientation, perception, visuospatial skills, attention, concentration, judgment, executive functioning, personality, and social abilities.[9] The acquisition of cognitive impairment after years of normal functioning differentiates dementias from developmental disorders; the persistence of the deficits differentiates dementia from delirium. The wide spectrum of involved domains helps to distinguish dementias from other neurologic conditions such as aphasia, amnestic syndromes, and neurocognitive manifestations of stroke.[10] Dementia is associated with a wide variety of underlying conditions that affect the integrity of the central nervous system including primary neurodegenerative disorders, vascular injuries, infections, hydrocephalic conditions, drug-induced or metabolic conditions, and trauma.[11]

Advanced dementia refers to progressive immobility and reduced capacity for self-care, poor nutrition resulting from reduced intake, infections, skin breakdown, and general debility.[12] Many patients who develop dementia have other illnesses that contribute to overall decline in health. In particular, Alzheimer's disease is an incurable and invariably fatal illness that has an average life expectancy of 4 to 7 years after diagnosis.[13-14] Most dementias follow a disease course typical of other chronic illnesses, with gradual deterioration, punctuated by substantial cognitive and functional decline, usually as a result of an acute illness.[15-16] Upon recovery from the acute illness, patients with dementia usually establish a new lower level of cognitive and physical functioning.[17-18] In the advanced stages of dementia, any acute stressor such as hip fracture, urinary tract infection, or pneumonia could become a terminal event.[19] A study by Morrison showed that demented patients admitted to the hospital for pneumonia or hip fracture had a six month mortality of 50%, substantially higher than that of cognitively intact controls.[20]

The cognitive and functional decline of Alzheimer's patients usually follow a predictable pattern.[21] Patients with mild dementia exhibit reduced memory of personal history, decreased capacity to perform complex tasks, and mild personality changes. As the disease advances to the moderate stage, patients become increasingly confused and disoriented, need assistance with most **activities of daily living (ADLs)**, and have more noticeable declines in short-term memory. The severe stage is characterized by significant personality changes and behavioral symptoms, bladder and bowel incontinence, altered sleep habits, and dependence on all ADLs.[22] Shuster describes the symptoms of this stage:[10]

Neurocognitive – progressive worsening of memory and other cognitive deficits; profound confusion and disorientation; behavioral changes including combativeness or resistance giving way to apathy, then coma; progressive worsening of speech, inability to communicate; patient becomes incoherent, mute, then unresponsive.

Functional – independent mobility progressively lost; patient becomes bedbound; capacity for self-care progressively lost; and patient becomes totally dependent.

Nutritional – progressive loss of appetite and ability to swallow or eat independently; aspiration becomes an increasing risk

Associated Complications – fevers, infection, decubitus ulcers, aspiration pneumonia, urinary tract infections

Patients in the final stages of dementia are eligible to receive hospice services. The **National Hospice and Palliative Care Organization** (**NHPCO**) uses the Reisberg **Functional Assessment Staging** (**FAST**). Patients who meet FAST 7C exemplified by the inability to ambulate, dress, and bathe without assistance; intermittent or constant bladder or bowel incontinence; and the absence of meaningful verbal communication and/or use of fewer than six intelligible words.[23] A FAST 7A demented patient with an ability to speak at least six words without necessarily having the other deficits of 7C may be eligible for hospice if the life expectancy is deemed to be less than six months and supported by one or more dementia-specific co-morbidities such as aspiration pneumonia, decubitus ulcers, persistent fever, greater than 10% weight loss, sepsis, and upper urinary tract infections.

Palliative Care for Nursing Home Residents with Dementia

More than 90% of the nearly five million Americans affected by dementia die in the nursing home.[24] Luchins reported that both relatives and health care providers believe that palliative care is an effective answer to terminal stage dementia symptom control.[25] Thus, the provision of high-quality palliative care in the nursing home setting is essential.[26-28] In the past, people with dementia received suboptimal end-of-life care.[29] In 1996, only 1.5% of patients with dementia could access Medicare hospice programs while a great number were admitted to hospitals and invasively treated despite a short life expectancy.[20,30] Many dementia patients died with feeding tubes in place, up to 44% of nursing home residents with dementia in some states, despite research suggesting little to no benefit from this treatment.[31-33]

Over the next few years, there has been a steady increase in hospice admissions for dementia, from 12,829 in 1998 to 60,488 in 2008.[29] This may in part be attributed to great strides in promoting palliative care either through research initiatives or increased awareness of the specialty such as fellowship training and education. In 2006, non-Alzheimer's dementia became the most common diagnosis among Medicare hospice patients. The percentage of all Medicare hospice patients with a terminal diagnosis of cancer dropped from 52.8% in 1998 to 31.1% in 2008.[34] Munn's study showed that the rates of hospice use in nursing homes and assisted living were considerably higher than previously reported although persons with dementia may continue to be underreferred.[35]

Barriers to Palliative Care in the Nursing Home

First, both health professionals and family members may have difficulty viewing dementia as a terminal illness.[36] In a model demonstration project integrating palliative care into the ongoing care of dementia patients, 70% of families interviewed after the death of the patient believed that the patient was terminally ill and dying prior to death; more than two thirds of those family members who believed that the patient was dying believed it was from something other than dementia.[26] Dementia differs considerably from cancer in that the time from diagnosis to death is usually longer with a length of survival typically measured in years.[37-38] Given this protracted course and the gradual loss of cognition and function, physicians and families understandably struggle to view dementia as a terminal diagnosis.

Second, despite the models that attempt to predict death within 6 months,[10] it can be difficult to determine when end-of-life care should be provided in an individual who may survive for years.

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Third, the provision of palliative care to dementia patients may be limited by the cognitive, communication, functional, and behavioral problems that arise with this disease.[29] The evaluation of needs and the management of symptoms require a broad and thoughtful approach from health providers with input from staff and caregivers.

Fourth, Medicare's policies create discontinuity in care if patients with dementia also have acute illnesses. For a typical example:[29] a patient with dementia suffers an acute illness, which results in hospitalization, followed by a decline in cognition and function; home care services start, restart, or increase in intensity; the plateau of function is set at a new baseline typically below the pre-hospital baseline; Medicare discontinues reimbursement for nursing, therapy, and other services; the patient declines in function due to underlying dementia until the next acute illness restarts the cycle.

The financial incentives often work directly against the provision of palliative care, especially for long-term residents of nursing homes.[39-40] Continuity of care both in terms of location and familiar staff is important for these patients, considering the risk for delirium and distress on transfer to the hospital.[41] As staff spend more time on managing symptoms and providing comfort near death, the facility ends up bearing the increased cost without receiving additional reimbursement.

The provision of quality palliative care to dementia patients could potentially be addressed by systematic education and information dissemination among health providers, patients, families, and caregivers; more innovative programs integrating palliative and curative care including anticipatory grief and bereavement programs; modification of the payment system extending to the state and/or federal levels; support programs for caregivers and staff; and quality improvement programs at the organizational and health systems level.[29]

Ethical Issues

Dementia patients with acute illnesses are frequently transferred to the hospital for aggressive treatment without consideration of their cognitive impairment, behavioral symptoms, and chronic co-morbidities, such as pressure ulcers and other chronic illnesses.[42-43] Keene[44] reported that autopsy reports of patients with dementia identified the main causes of death to be pneumonia, cardiovascular diseases, lung embolism, cachexia, and dehydration. As dementia patients develop infections such as pneumonia and urinary tract infections, they are subsequently hospitalized and managed with antimicrobial therapy. One study found an in-hospital mortality of 20% for advanced dementia patients receiving antibiotics, with a 6 month mortality rate of more than 50%.[20] Furthermore, these patients may be subjected to painful daily blood draws and intravenous therapy, which in turn put the patient at risk of needing restraints.[45]

Patients with advanced dementia have difficult eating. Weight loss and poor oral intake are a hallmark of the later stages of dementia. Those patients have difficulty swallowing, lose oral motor coordination, and their interest in food. Staff frequently discuss the need for a feeding tube, citing: decreased mortality, prevention of aspiration, improved nutritional and functional status, and

healing of pressure ulcers.[46] A landmark review by Finucane and colleagues demonstrated that none of these indicators are reversed or improved with tube feeding.[33] No randomized trials compare hand-feeding and tube-feeding for end-stage dementia patients, but cohort and cross-sectional studies show no improvement in patient outcomes with tube feeding. Mortality is high with or without tube feeding: 30-day mortality averages 20%; 6-month mortality, 50%.[47] Additionally, feeding tubes can lead to complications (leaking, clogging, and replacement if dislodged), which can lead to more medical care, as well as the use of restraints.

In addition to worsening nutritional status as a result of dysphagia related to progressive dementia, these patients also experience functional impairment and physical debility. They eventually become bed-bound, increasing the chances for falls and hip fractures. The in-hospital mortality rate for repairing a fractured hip in persons with advanced dementia is relatively low, about 5%; however, the 6-month mortality rate remains high (greater than 50%). Sadly, 76% of these patients did not receive a standing analgesic regimen for pain.[48]

Finally, the polypharmacy related to multiple morbidities is a concern. To date, clinicians pay little attention to discontinuing inappropriate therapy in persons nearing end of life.[49] A recently published article suggests a decision-making model that takes into consideration remaining life expectancy, time until benefit is derived, goals of care, and treatment targets.[50]

Recognition of dementia as a terminal illness can assist providers in caring for these patients as the course advances. Supportive and palliative treatment goals can aid in feeding difficulties, decreased functional status, polypharmacy and pain management.

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