Late-State Dementia Care

Christine R. Kovach
Marquette University College of Nursing

Follow this and additional works at: http://scholarship.law.marquette.edu/elders
Part of the Elder Law Commons

Repository Citation
Available at: http://scholarship.law.marquette.edu/elders/vol2/iss3/7

This Featured Article is brought to you for free and open access by the Journals at Marquette Law Scholarly Commons. It has been accepted for inclusion in Marquette Elder's Advisor by an authorized administrator of Marquette Law Scholarly Commons. For more information, please contact megan.obrien@marquette.edu.
Late-Stage Dementia Care

Too little is known about the late stages of Alzheimer’s and other dementia illnesses. However, as more research findings become available, new programs of care are being implemented. Understanding the natural progression of these types of diseases is essential to choosing appropriate care.

By Christine R. Kovach

Introduction
The National Institute on Aging projects that fourteen million people in the United States will be afflicted with dementia by the year 2050. Prevalence of severe dementia is estimated at less than 1 percent of those aged sixty-five, but at more than 15 percent in adults who are older than eighty-five years. Since there is no cure for Alzheimer’s disease as well as other illnesses that cause irreversible cognitive impairment, most persons with dementia progress through several stages of decline prior to death. Patients with dementia have a decreased life expectancy, with an average duration of illness of ten to twelve years for those with Alzheimer’s disease. Mortality tabulations are, however, unreliable estimates because the death of people with dementia is often attributed to coexisting medical conditions.

For the purpose of this article, dementia symptoms will be divided into early, mid, and late stages. Care needs differ significantly during these stages. A variety of care settings and therapeutic care options are available for people with early- and mid-stage dementia. Less is known or written about late-stage dementia, and care options are more constrained. This article will describe stages of dementia symptoms, needs of persons with late-stage dementia, and care giving options.

Stages of Dementia
The term “dementia” refers to broad impairments in intellectual function that are usually progressive and that interfere with normal activities of daily living. Alzheimer’s disease accounts for fifty to sixty percent of dementia cases. The rate of progression of Alzheimer’s disease is highly variable between people. Alzheimer’s disease has an insidious onset of symptoms, though people who notice symptoms at earlier ages (i.e., forties to fifties) tend to have a faster decline and shorter survival time. During the early stage, short-term memory loss, personality change, time and spatial disorientation,
and poor judgment are evident. Language disturbance starts with poor word-list generation and difficulty naming common objects such as a fork, or hairbrush. Family members may notice that the person becomes lost, has difficulty with numbers involved in money handling or phone calling, or becomes more suspicious of and negative about other persons. At this stage, the person will have a normal physical and neurological examination.

It is rare for the symptomatic person to seek medical help. It is unclear if denial, nonrecognition of symptoms, or fear is responsible. Medical care is initially sought for the vast majority of symptomatic patients by a concerned family member, friend, or neighbor. People with beginning symptoms of dementia need a thorough evaluation to rule out common causes of reversible confusion. Common reversible causes of confusion include medication intoxication, depression, grief, infections, low blood sugar, thyroid abnormality, vitamin B12 deficiency, and sleep deprivation. A thorough evaluation should be completed by health care professionals with expertise in diagnosing Alzheimer's disease and related dementias. While most people with irreversible dementia symptoms have Alzheimer's disease, other causes of dementia include multi-infarct dementia and other vascular problems in the brain, Parkinson's disease, Huntington's disease, chronic alcohol abuse, HIV encephalopathy, and traumatic brain injury.

By the time the person reaches mid-stage dementia, memory loss is severe enough that judgment becomes impaired and safety is often a concern. For example, the person may leave the stove on or leave the house on a cold winter day without warm clothing. Personal grooming is often neglected. Behavioral symptoms commonly associated with dementia become most severe during mid-stage dementia. These behaviors include agitation, wandering, aggression, rummaging, sleep-wake pattern disturbances, socially inappropriate behavior, perseveration (repetitive verbalizations or movements), suspiciousness, delusions, hallucinations, and difficulty with language progresses. The person may use illogical words or have difficulty "finding" the right word. The person may speak many words, but there is often little discernible content in the message. Visuospatial problems include changes in depth perception and continued way-finding problems. There may be an increase in muscle tone that contributes to changes in gait and balance. These changes make the person more susceptible to falls. The person may be hyperoral, eating frequently and putting objects in their mouth. At this stage, the person often can no longer live in the community without assistance.

During late-stage dementia, the person becomes more chair-bound or bed-bound. Muscles become quite rigid, and primitive reflexes such as hand grasping, sucking reflexes, and paratonia may be present. Paratonia is the involuntary resistance of an arm or leg to movement of the limb by another person. This may be misinterpreted as aggressive behavior on the part of the person with dementia but is actually a reflexive process. The person may have active hands and repetitive movements or vocalizations. The number of words in the person's vocabulary, as well as the amount of speaking, is typically very limited. Appetite decreases, and there are impairments in swallowing that can lead to food or fluid being aspirated into the lungs. Aspiration pneumonia is one cause of death in people with dementia. The person may no longer recognize family members. Bowel and bladder incontinence is present, and caregivers need to complete most or all activities of daily living for the person. The sleep-wake cycle is greatly altered, and the person may spend increasing periods of time dozing, socially withdrawn, and less aware of the surrounding environment or activities. Immune system function is depressed, and infections are the most frequent cause of death for patients in the terminal stage of dementia.

Needs and Interventions
The late-stage of dementia presents new challenges that may require a redirection of goals. Most experts believe that, at this stage, the focus should be on comfort, prevention of comorbid conditions, and human dignity. Palliative care is directed toward relieving a person's distress rather than curing an illness. Principles of palliative care include the following:

- Affirm life
- Regard dying as a normal process
- Never hasten or postpone death
- Provide relief from pain and other distressing symptoms
- Prevent injury
- Integrate the psychological and spiritual aspects of care
Health care personnel must work closely with the family to be certain the level of medical care provided is consistent with evidence of the patient's choices, or the choices of the designated surrogate decision-makers.

**Common Medical Conditions**

In addition to the medical conditions commonly prevalent in this age group, people with late-stage dementia are more likely to suffer from pressure ulcers, infection, and inadequate pain control. In general, illnesses that cause late-stage irreversible dementia are considered serious enough that patients are only subjected to the difficulties of hospital admission, if comfort is severely compromised and likely to be improved through medical interventions that necessitate hospitalization. Examples may include repair of a fractured hip or relief from intestinal obstruction.

Flu and pneumovax vaccinations are needed to prevent infection. The single most important measure caregivers can employ to prevent infection is hand-washing. Common infections in late-stage dementia are urinary tract infections, respiratory tract infections including pneumonia, skin infections (cellulitis or infected decubitus ulcers), conjunctivitis, and diarreal illnesses. Feeding interventions and oral hygiene are discussed later, but are used to assist in preventing aspiration pneumonia. Conjunctivitis can often be prevented through hand washing and adequate storage and administration of eye medications.

Urinary catheters should be avoided. Cranberry juice and adequate fluid intake may assist in preventing urinary tract infection. Taking antibiotics can lead to proliferation of the bacteria clostridium difficile in the intestines. Diarrhea due to C. difficile has become an increasingly prevalent problem.

The topic of administering antibiotics to patients with late-stage dementing illness is under some debate. One study reported that patients treated for pneumonia in long-term care who had feeding dependence and a mechanically altered diet had significantly higher rates of treatment failure than patients with unimpaired eating. Fabiszewski, Volicer, and Volicer, however, found that aggressive treatment of fever episodes was successful in preventing death from infection in patients with low severity of dementia. Another study found that patients with late-stage dementia had similar levels of comfort and survival when they were treated with antibiotics or comfort measures only. The benefits of antibiotic therapy need to be weighed against the potential side effects such as rash, allergic reactions, diarrhea, secondary infections, and blood abnormalities.

Pressure ulcers and skin infections may be prevented through measures including adequate nutrition and hydration, keeping skin clean and dry, turning and repositioning the patient frequently, skin emollients, and early treatment of any skin redness or skin breakdown. Constipation may be a problem and should be treated with adequate fluids, fiber, and bowel softeners. Laxatives and enemas may be needed on occasion.

**Nutrition and Hydration**

In late-stage dementia, weight loss and problems with eating are usually due to swallowing problems. The person loses the ability to coordinate and time the complex movements associated with swallowing. A decrease in motivation to eat may also be present. Strategies that are used to manage feeding, eating, and swallowing problems include diet and medication modifications, an upright feeding position, creating a non-distracting environment, use of special utensils and table settings, verbal/physical cues and encouragement, and physical assistance with eating. Providing pleasant aromas, small frequent feedings, and food that the person has enjoyed in the past may also improve food intake.

The courts have recognized tube feedings as a medical treatment that can be refused. Debate exists regarding whether or not dehydration and malnutrition cause the person discomfort and if providing food and fluid through artificial means meets the goals of palliative care. While no randomized clinical research has been done, tube feedings have been associated with increased aspiration in several studies. Another relevant clinical question is whether gastrostomy or jejunostomy tube feedings prolong life by preventing infection, skin breakdown, and other physical problems associated with inadequate nutrition and hydration. A recent review of the available research found no published studies supporting that tube feeding placement was associated with prolonged survival in patients with dementia who had difficulty swallowing.
Behavioral Symptomatology

It is estimated that 70 to 90 percent of patients with Alzheimer's disease will develop behavioral symptoms. Behaviors associated with dementia should be considered signs of unmet needs. Most of the literature frames behaviors as psychosocial problems that need to be managed. Viewing behaviors solely from a mental health perspective may lead to undertreatment of physical problems and pain. In addition, the psychosocial or environmental source of the behavior may never be modified if the focus is on the behaviors as the problem rather than as a symptom of the problem. Optimally, behavioral symptoms are prevented through assiduous anticipation and fulfillment of needs. Because the person with late-stage dementia is unable to verbalize unmet needs, and is often unable to introspect regarding internal states, an assessment of sources of unmet needs should be done when behavioral symptoms are manifested. This assessment may be organized to look for basic needs, physical needs, and affective needs.

Basic needs include the need to avoid feeling hungry or thirsty, too cold or too hot, having one's eyeglasses and hearing aid in place, having elimination needs met, and being kept comfortably clean and well-groomed. People should be dressed in comfortable and well-fitted clothes and shoes. Oral hygiene should be regularly provided. Range of motion exercises are needed to prevent muscle contractions and feelings of stiffness.

The affective needs of the person with late-stage dementia include the following:

- Feeling safe and secure in the environment
- Maintaining a sense of personhood
- Balancing sensory-stimulating and sensory-calming activity
- Maintaining positive social connections
- Engaging in pleasurable activity

People with dementia are able to tolerate less stress from the environment and may become frightened or overwhelmed by too much environmental stress. Examples of environmental stressors that are commonly not tolerated by this group include noise, too much activity or too many people, a new environment, rooms that are too big or too small, and glare from lighting.

Recent research suggests people with even late-stage dementia do maintain some sense of personhood. As the dementia progresses, the person needs assistance maintaining their sense of self. This may be augmented through photo albums, simulated presence tapes, and other physical and verbal cues that tie the person to their identity.

To prevent agitation there is a need for caregivers to provide a balance between sensory stimulating activity and sensory-calming activity. As the dementia progresses, the person may need more time to rest, retreat from the environment, and not be taxed by stimulation. However, the person also needs some form of regular meaningful human interaction and pleasurable activity. These activities should not tax the person's cognitive ability. Listening to music the person enjoys, sharing a beverage, receiving a brief massage, folding baby clothes fresh from the dryer, or kneading a small piece of bread dough may be pleasurable.

Many physical needs have already been addressed. Research indicates that 45 to 80 percent of nursing home residents are in pain at any one time. The most common reported causes of pain in nursing home residents with cognitive impairment are arthritis (70 percent), old fractures (13 percent), neuropathies (10 percent), and malignancies (4 percent). We recently tested the use of a protocol in six long-term care facilities in Wisconsin. Our goal was to decrease both physical pain and affective discomfort. One hundred sixty-one protocols were implemented for people with late-stage dementia who exhibited behavioral symptoms. Symptoms of possible distress/discomfort were reduced for 37 percent of the group through nonpharmacological comfort interventions. The most common nonpharmacological comfort interventions used were therapeutic communication, repositioning, cueing/redirectioning, providing a snack, ambulating with staff, toileting, massage, and providing a quiet environment/quiet time. For the ninety-one people who received a pain medication (analgesic), 83.5 percent had symptoms of possible pain reduced after taking the medication. The most commonly given medication for pain relief was acetaminophen (Tylenol), though stronger medications were used when needed. Findings from this study suggest that increased analgesic use for people with late-stage dementia may be warranted.

In summary, the person with late-stage dementia continues to need a complex array of care. While cure is currently not possible, palliative care
does not mean little or no intervention is available to help the person with symptomatic needs. Little of what is known or believed about optimal care for this population has been subjected to rigorous clinical trials or evaluation studies, so there is a need for more research in virtually all areas of late-stage dementia care.

**Care Options**

Family members provide most care given to people with dementia. In earlier stages of dementia, adult day care, group homes, and assisted-living facilities are available in many regions to provide specific programming and/or living quarters for people with dementia. Because of limited regulation and standards, these settings vary greatly in quality as well as services offered. Nursing homes also provide services to people with dementia. During the 1990s, nursing homes began opening special care units (SCUs) for people with mid-stage dementia. Though the specific services offered vary, most SCUs provide specialized activity programming, modified physical environments, controlled on/off access, special staff training, and extra staff. Research on the efficacy of these units has been inconsistent and contradictory.

As the dementia progresses, care options are more limited. Family members may choose to care for a loved one at home until the time of death, but the burden of care is considerable. Unlike cancer, which has a more time-limited and more easily determined survival time, people with late-stage dementia may require assistance with most or all self-care activities for years prior to death. Family members are often not available or able to provide this level of caregiving. Respite care is available, but offerings vary in different geographical locations. Some nonprofit religious groups and health care organizations will provide sitters and/or short-term overnight stays. These services are designed to provide a temporary break for the caregiver and may be insufficient support to keep the person at home. Home care is available from nursing service agencies. Most home care is provided by certified nursing assistants (CNAs) who work under the supervision of registered nurses following established protocols and care plans. Providing competent end-of-life care at home has been hampered by inadequate reimbursement options for home health care services.

A consistent research finding is that family caregivers experience increased psychiatric and physical illness compared to matched non-caregivers. Social support, home nursing services, and intervention programs may ameliorate some of the stress of family caregiving. Family caregivers, however, use fewer supportive services than comparison groups of non-dementia caregiving families, delay use until late in the disease process, and use services at lower levels than expected once initiated.

Hospice services can be used in the home, nursing home, or some inpatient settings. The criteria for receiving Medicare benefits for hospice care are, however, quite stringent.

**Hospice Medicare Benefit**

A key criterion for receiving the Medicare hospice benefit is an expected survival time of six months or less. Determining prognosis in dementia is difficult. In a national survey of hospice staff, 80 percent noted that difficulties predicting survival time in patients with dementia hampered their ability to serve these patients. Severity of dementia does correlate with poor survival in studies of nursing-home and community-dwelling elderly. But people with severe dementia can live for years if they receive meticulous care and do not develop comorbid conditions. So severity of dementia is not a good prognostic indicator.

Death in people with dementia usually occurs as a result of comorbid or coexisting medical conditions. The Medicare guidelines emphasize that presence of certain medical complications within the previous year, that were of sufficient severity to warrant hospitalization, whether or not the decision was made to hospitalize, is associated with decreased survival time in dementia. These conditions are aspiration pneumonia, pyelonephritis or other upper urinary tract infection, septicemia (blood infection), multiple stage 3 to 4 decubitus ulcers (i.e., bedsores), and a recurrent fever after antibiotics have been administered.

Functional ability has also been found to be a strong prognostic indicator in people with dementia. The Medicare guidelines require administration of the Functional Assessment Staging Tool (FAST). This tool has primarily been studied with people who have Alzheimer's disease and is based on the assumption that the progression of functional decline occurs in an ordered fashion. While
the tool met the Guttman criteria for a unidimensional and ordinal scale, others have reported difficulty scoring patients on the FAST because their functional decline did not progress in the ordinal fashion explicated in the FAST.

The person must be unable to ambulate without assistance (criteria 7c of the FAST) to receive Medicare hospice benefits. Recent data indicate that patients who retain the ability to ambulate independently do not die within six months, even if all other criteria for advanced dementia are present. In one study, of forty-seven patients who met the FAST 7c criteria, the mean survival time was 3.2 months. The researchers concluded that the FAST 7c criteria allows the identification of a subgroup with very high mortality and a short time until death. Use of this 7c criteria may be decreasing access to hospice care for many dementia patients who have a short survival time.

It is too early to determine how well hospice services that are Medicare-funded will fill the need of the growing population of people with late-stage dementia. In long-term care, there is a growing movement to create special care units for late-stage dementia. Most of these units do not rely on Medicare hospice reimbursement. Rather, the units are funded in the same manner as traditional nursing home units—through a combination of private pay, Medicaid, and long-term care insurance sources.

Special Care Units for Late-Stage Dementia
In 1993, our group opened some of the first units designed specifically for late-stage dementia. This effort was part of an experimental research study that was funded by the Helen Bader Foundation. Our efforts were spurred by a growing realization that when a resident of a mid-stage special care unit developed late-stage symptoms, the person was generally transferred to a traditional nursing home unit. These units were providing curative care for some residents, rehabilitative services to others, and primarily palliative comfort care to people with late-stage dementia. Units that have such varied goals and therapies may not be best suited to meeting the unique needs of those with late-stage dementia.

Five hospice households were opened in three nursing homes in Wisconsin for people with late-stage dementia. Comfort, quality of life, human dignity, support for family, and support for staff were the five main goals of the project. Because staff commitment to the project was integral to its success, staff worked with the research team to operationalize these goals into a set of actions and quality indicators. The person with late-stage dementia generally has an increased need for physical care and a decreased need for behavioral management interventions. Communication is altered, and there is a need for enhanced physical assessment since the person is often unable to convey pain, other symptoms, or needs. The person often needs more brief one-on-one social contacts rather than the group social activities common in mid-stage programs.

Residents who met criteria for the study were randomly assigned either to receive care in a hospice household or to continue to reside on a traditional nursing home unit. The group that received hospice care had significantly less discomfort ($t = 3.88, p < .001$). In addition, the treatment group showed improvement over two months in all behavioral symptoms measured except delusions and hallucinations. While there was not a statistically significant difference in physical complications between the two groups, the control group had fifteen infections during the two-month period and the treatment group had four acute infectious conditions.

Conclusion
The medical model of delivering care with a focus on the treatment of illness is a limited and inadequate model for providing services to people with dementia. As the disease progresses to late-stage dementia, there is consensus that palliation should be the major emphasis of care. Little of what is known or believed about quality of care for this population has been adequately researched. Also, there are differences in views of the death and dying process, appropriate care during a prolonged end-of-life stage, and of family obligation during this period. Complicating quality indices further is awareness that the inevitable outcome for patients with late-stage dementia is death. Traditional measures of quality of health care such as mortality, patient satisfaction, and return to previous functioning are inappropriate for this population. Other outcomes such as comfort, quality of life, and positive affect are difficult to assess. Public policy makers and health care administrators may also devalue these “soft” outcome measures.
Ultimately, care of this vulnerable group tests and challenges the moral fabric of society. The population of people with late-stage dementia is growing, and their care needs are substantial. They are also a group that cannot advocate for themselves. Hope for the future of health care delivered to people with dementia rests in our ability to value the essential interdependence of humans and our concerted effort to develop and implement interventions that are effective, compassionate, and make efficient use of resources.

Endnotes


7. See generally Bruce L. Miller, Clinical Advances in Degenerative Dementia, 171 BRIT. J. PSYCHIATRY 1, 1–3 (1997); Robert Berkow et al., Cognitive Failure: Delirium and Dementia, in THE MERCK MANUAL OF GERIATRICS 1139, 1139–61 (William Abrams et al. eds., 1995).

8. See generally Helen D. Davies, Delirium and Dementia, in CLINICAL GERONTOLOGICAL NURSING: A GUIDE TO ADVANCED PRACTICE 413, 413–43 (Joyce T. Stone et al. eds., 1999).


14. Id.


31. See Kovach supra note 28.

32. See generally Joel Leon, The 1990/1991 National Survey of Special Care Units in Nursing Homes, 8 Alzheimer’s Disease and Associated Disorders S72, S72–86 (Supp. 1 1994).

33. See generally Phillip D. Sloane et al., Evaluating Alzheimer’s Special Care units: Reviewing the Evidence and Identifying Potential Sources of Study Bias, 35 The Gerontologist 103, 103–111 (1995).


39. See generally Standards and Accreditation Committee Medical Guidelines Task Force, Medical Guidelines for Determining Prognosis
IN SELECTED NON-CANCER DISEASES, Item number 713008 (1996).


42. See Luchins et al., supra note 36.

43. See STANDARDS supra note 39.

44. See Luchins et al., supra note 36.