
Caring for Patients with Terminal Alzheimer's Disease

Patients with terminal Alzheimer's disease (AD) are characterized by their inability to communicate verbally and ambulate even with assistance, and by their complete dependence in activities of daily living. Due to a mean survival of one year, interventions that only have a long-term effect and the use of invasive procedures leading to the patient's discomfort may not be appropriate. The goal of care may be overall comfort instead of survival at all costs and maintenance of function. The risks and benefits of any procedure should be considered with this goal of care in mind.

By Ladislav Volicer, MD, PhD, FAAN, FGSA

The progression of Alzheimer's disease (AD) can be divided into several stages, most commonly described as mild, moderate and severe. Two more stages (profound and terminal)² were added as the severe stage did not have a generally accepted definition, and according to the Clinical Dementia Rating (CDR) scale,¹ patients retained certain functions at this stage.

Patients are defined as having terminal AD when they have no comprehension or recognition, must be fed or require tube feeding, are totally incontinent and bedridden (*i.e.*, not able to ambulate, even with assistance), and are not able to communicate verbally. The median survival of patients in this stage is one

year.³ Other progressive dementias (*e.g.*, vascular dementia, dementia with Lewy bodies and frontotemporal dementia) may have different symptoms and course than AD. However, once the patient's dementia progresses to the severe stage, the symptoms and clinical problems presented are the same regardless of the initial diagnosis.

It should also be noted that autopsy examinations have revealed more than one pathological process that may cause dementia, including AD and vascular changes, and AD with multiple cortical Lewy bodies. Thus, management of terminal dementia is similar in all progressive dementias. Also, the medical issues of patients with dementia may be divided into three broad categories: chronic conditions, comfort and end-of-life issues, listed in Table 1.

Chronic Conditions

Many patients with terminal demen-

tia suffer from comorbid conditions, such as congestive heart failure, chronic obstructive pulmonary disease (COPD) and diabetes. The prevalence of these conditions is higher in patients with dementia than in cognitively intact elderly patients.⁴ Thus, management of these conditions should be modified in terminal dementia. Most important, since these patients are unable to report symptoms of their disease or side effects of treatment, comorbid conditions should be treated conservatively to avoid consequences of overtreatment, such as hypoglycemia.

Due to the fact that individuals with terminal dementia have short life expectancy, interventions that have only a long-term effect, including treatment with cholesterol-lowering agents or restrictive diets, are not appropriate. Any medical intervention causing discomfort, even a routine examination,

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Table 1

Medical Issues in Terminal Dementia

Chronic Conditions	Comfort Issues	End-of-life Issues
<ul style="list-style-type: none"> • Diabetes • Arthritis • Hypertension • Congestive heart failure • COPD • Malignancy 	<ul style="list-style-type: none"> • Pain • Behavioral symptoms • Environmental factors • Constipation • Pressure ulcers • Shortness of breath 	<ul style="list-style-type: none"> • Cardiopulmonary resuscitation • Transfer to an acute care setting • Treatment of generalized infections • Eating difficulties (tube feeding)

such as measuring blood pressure, may cause behavioral problems in persons who do not understand the need for this intervention. Before any treatment is initiated or continued, the risks and benefits should be considered and physicians should ask, “Are the intended results of this treatment promoting the goal of care for this patient?”

Comfort Issues

Since patients diagnosed with terminal dementia are patients with a terminal disease, comfort may be the most appropriate goal of care. Two alternative goals, survival at all costs and maintenance of function,⁵ may no longer apply.

In an effort to ensure the patient’s comfort, it should be taken into consideration that even individuals with terminal dementia most often do not progress to a vegetative state where they would not feel discomfort or pain.⁶ Physical and psychological comfort should therefore be monitored and maintained until death. These comfort issues include pain, behavioral symptoms, environmental factors, constipation, pressure ulcers and symptoms which mani-

fest during the dying process, such as shortness of breath.

Pain. The most common physical symptom that causes discomfort is unrecognized or undertreated pain.⁸ It is difficult to identify and measure pain, as well as distinguish somatic pain and general discomfort in an aphasic individual. When any behavioral changes are observed in a patient with terminal dementia, an evaluation for possible pain should be initiated. These behavior changes may include oral vocalization, increased resistiveness to care, restless body movements, crying, changes in appetite, withdrawal, rubbing/holding a body area, facial grimacing, increased confusion or a change in sleep patterns. The listed changes could be due to unmet physical needs (*i.e.*, being hungry, thirsty or cold), unmet affective needs (*i.e.*, environmental stress and/or lack of meaningful human interaction) or somatic pain.

Several observational scales for measuring pain in individuals with advanced dementia have been developed and evaluated,⁷ and may help in pain assessment and communication between different care

providers, including nursing assistants, nurses and physicians.

Treating pain in persons with terminal dementia should include non-pharmacologic strategies, such as application of heat or cold compresses, massage, positioning, sensory stimulation and mild exercise.

Pharmacologic management should start with the administration of acetaminophen. If the treatment is not effective, it is best to proceed to oral morphine and to avoid use of non-steroidal anti-inflammatory agents. These agents often cause gastrointestinal side effects that the individual with advanced dementia cannot report. A concentrated solution of morphine can be used even in individuals who have difficulty swallowing as it is absorbed in the oral mucosa. Another option in an individual with chronic pain is the administration of fentanyl skin patches. However, pain management should strive for pain prevention rather than initiation of treatment after pain has already presented. Thus, chronic pain should be treated with regular doses of analgesics with an option of additional doses if needed.

Behavioral changes. The management of psychiatric symptoms in patients with dementia is as important for quality of life (QoL) as management of pain in individuals with terminal cancer. Some behaviors are caused by environmental or physical factors, by interaction between patients with dementia and their caregivers, or by the dementing process itself. It is important to first eliminate the possibility that behaviors are due to environmental or physical causes including cold or hot temperatures, noise, and hunger or thirst.

Resistiveness to care. The two most common and important behavioral syndromes are resistiveness to care and agitation/apathy. It must be noted that behavioral problems that occur during interactions between an individual with severe dementia and a caregiver are often erroneously labeled as aggression. These outbursts are actually caused by a lack of effective communication between the patient with dementia and their caregiver. The patient does not understand the need for the caregiver's actions and may resist in certain situations, including undressing, bathing, dressing and being put to bed. The behavior presented is in fact resistiveness to care⁹ and can escalate into combative behavior.

Furthermore, the patient with dementia may defend him/herself by striking out because they believe the caregiver to be an aggressor. It is therefore important to prevent escalation of resistiveness to care into combative behavior that may result in injury of the caregiver or patient.

The appropriate non-pharmacologic intervention for such a behavior is improvement in communication, delaying the caregiving activity or modifying the caregiving strategy. Another approach is distraction during care, provided by informal discussion or by a planned reminiscence that utilizes remaining long-term memories. The most effective strategy for management of resistiveness to care is modification of the caregiver approaches. This may include changes in an environment, such as making bathrooms more homelike and comfort-

affect the patients behavior.¹⁰ However, it is difficult to diagnose in the terminal dementia stage as the diagnosis must rely on vegetative symptoms.

Agitation and apathy. When a patient with dementia is solitary, they often exhibit agitation and apathy. Agitation is a term that is sometimes used to label all behavioral symptoms in dementia, but is better reserved to define behaviors that communicate to others that the patient is experiencing unpleasant state of excitement which remains after interventions to reduce inter-

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able, or changes in caregiving strategies. The substitution of a bed (or towel) bath for shower or tub bath greatly decreases resistiveness to bathing without adverse hygienic consequences.

Resistiveness to care should also be considered as one of the important indicators of possible presence of depression in the patient with dementia. If other non-pharmacologic interventions are not effective in preventing the escalation to abusive behavior, antidepressants are the first medication class physicians should prescribe. It should be noted that depression is very common in patient's with dementia and is a factor that may

nal or external stimuli have been carried out.¹¹ Apathy is a condition different from depression resulting from a different pattern of blood flow in the brain. These symptoms often occur in the same individual and are difficult to treat pharmacologically because sedatives used to decrease agitation often increase apathy, whereas stimulants used to decrease apathy often increase agitation. The best treatment approach for agitation and apathy is a provision of meaningful activities.

Environmental factors. Patients with terminal dementia may not be able to participate in regular activities because of their cognitive impairment, but they still require

stimulation and should not be isolated in their rooms or sitting in a hallway. These patients benefit from a comfortable environment and presence of others.

One strategy for maintaining QoL, even in the terminal-dementia stage, is the development of Namaste Care.¹² Namaste Care is an enhanced nursing program based in the United States and Sydney, Australia, which provides a room within the care facility where residents with terminal dementia are gathered with the continuous pres-

these patients, they are offered a beverage (*i.e.*, juice, water, smoothies and other high-caloric beverages). The Namaste caregiver also soaks the residents' feet and washes their legs. Range-of-motion exercises are accompanied by music.

In the afternoon, the patients are often visited by their families. The Namaste caregiver will sometimes offer suggestions and may encourage family members to massage residents' hands and arms, or feed them ice cream if choking is not a concern. Family members may also enjoy

includes a high-fiber diet and osmotic laxatives. Stimulating laxatives should be used only occasionally and stool softeners should be avoided because they often are not effective.¹⁴ Enemas are uncomfortable and require more staff time than administration of an oral medication. As the primary goal of care is comfort and preserving dignity, enemas should be avoided.

Finally, the use of oral laxatives, primarily sorbitol, combined with the close monitoring of bowel movements and subsequent changes in dose or frequency as necessary, minimizes the need for rectally administered laxatives, which is especially difficult in patients with dementia who become resistive during care.

Pressure ulcers, which are associated with sepsis, are most commonly located on the sacrum, trochanters and heels. A higher prevalence of pressure ulcers was associated with being chairbound or bedridden, underweight and fecal incontinence. Pressure-ulcer associated death is more common in AD patients than in matched control subjects.¹⁸

A recent study of New York nursing homes found that pressure ulcers were present in 14.7% of nursing home residents with terminal dementia before they died.¹⁵ The study also noted that, on admission from a hospital to a nursing home, 10% of residents already had one or more pressure ulcers, while only 4.7% of residents admitted from home presented with pressure ulcers.¹⁶ It should be noted that several pressure-ulcer-prevention guidelines have been

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ence of a caregiver. The room provides a home-like, pleasant atmosphere with plants, pictures and curtains, low lights and relaxing music.

The patients are placed in lounge chairs rather than a wheelchair to address the comfort issues often present in patients with terminal dementia. If they are not at risk for choking, residents are offered a small lollipop, which helps to keep their mouths moist.

The Namaste caregiver also washes each person's face and brushes their hair while the residents are spoken to about their lives or about the day, as if it were a normal conversation. To help maintain hydration, often a difficult task in

conversing with the Namaste caregiver as many spouses are very isolated when their loved ones are in a nursing facility. Of note, the Namaste caregiver is a nursing assistant who would otherwise take care of the residents in the unit. By gathering the patients with dementia in the same location, the Namaste caregiver is able to offer better individualized care and constant attention.

Constipation is very common in patients with terminal dementia, and fecal impaction may even cause death. Constipation may be due to a combination of decreased enteric neurons,¹³ medication side effects, and decreased ambulation. The usual treatment for constipation

developed, and adherence to these guidelines results in decreased incidence of pressure ulcers in hospitalized and/or critically ill patients.¹⁷ However, in nursing homes the adherence to these guidelines is relatively low and is characterized by large variations.

Shortness of breath may be the most disturbing symptom during the dying process, not only for the patient, but also for family and caregivers. The best way to manage shortness of breath is by administering morphine that will decrease the respiratory drive. Low doses of morphine administered orally are very useful during the dying process because they will not only decrease dyspnea, but also prevent most pain.

End-of-life Issues

There are several conditions that may be treated by aggressive or palliative medical interventions. The decision about their management should be made by a proxy before any crisis situation. However, to make an informed decision, the proxy must have information regarding the burdens and benefits of these interventions.

Cardiopulmonary resuscitation (CPR). The immediate survival of resuscitated nursing-home residents is 18.5 %; only 3.4% are discharged from the hospital alive.¹⁹ The presence of dementia decreases the probability of successful CPR by three times, as only 1% of demented residents suffering cardiac arrest can be expected to be discharged alive from the hospital.

Even this potential benefit may not be desirable in individuals with severe dementia because CPR is a stressful experience for those who survive. These patients may also experience CPR-related injuries, such as broken ribs, and often have to be on a respirator. Patients who are discharged alive from the hospital after CPR are much more impaired than they were before the cardiac arrest. Finally, the intensive care unit environment is not conducive to appropriate care for demented individuals who may

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experience worsening confusion and often develop delirium.

Transfer to acute care setting. The transfer of demented individuals to an emergency room or hospital exposes them to serious risks. Even cognitively intact hospitalized elderly individuals develop depressed psychophysiological functioning that includes confusion, falling, not eating and incontinence. These symptoms are often managed by medical interventions, such as psychotropic medications, restraints, nasogastric tubes, and urinary catheters, which expose the patient to possible complications, including thrombophlebitis, pulmonary embolus, aspiration pneumonia, urinary

tract infection and septic shock. A hospital admission may not be necessary for treatment of pneumonia and other infections because six-week mortality is lower in residents treated in nursing homes than residents treated in hospitals.²⁰ Thus, transfer to an acute care setting should be used only when it is consistent with the overall goals of care and not as a default option.

Treatment of generalized infections. Effectiveness of antibiotic therapy is limited by the recurrent nature of infections in advanced dementia.

Antibiotic therapy does not prolong survival in cognitively impaired patients who are unable to ambulate even with assistance and who are mute.²¹ Antibiotics are also not necessary for maintenance of comfort in demented individuals because their comfort can be maintained equally well with analgesics, antipyretics and oxygen, if necessary.²²

In addition, antibiotic use is not without adverse effects. Patients may develop gastrointestinal upset, diarrhea, allergic reactions, hyperkalemia, agranulocytosis, and *Clostridium difficile* infection. Diagnostic procedures, including blood drawing and sputum suctioning necessary for rational use of antibi-

otics, can cause discomfort and confusion in demented individuals who do not understand the need for the procedure. Thus, the decision to administer antibiotics to patients with advanced dementia should take into consideration the recurrent nature of infections caused by persistent swallowing difficulties, aspiration and other factors predisposing these patients to the development of infections.²³

Eating difficulties. Patients with terminal dementia are unable to feed themselves and often develop swallowing difficulties that provoke choking on food and liquids. They may also start refusing food by not opening their mouth when they are fed. Of note, choking and food

refusal are often exhibited simultaneously. Swallowing difficulties and choking may be minimized by an adjustment to the texture of the patient's diet, and by replacing thin liquids with thick ones (e.g., yogurt instead of milk). Food refusal often responds to administration of antidepressants or appetite stimulants.²⁴

There is no evidence that long-term feeding tubes are beneficial in individuals with advanced dementia. Tube feeding does not prevent aspiration pneumonia and actually might increase its incidence because it does not prevent aspiration of nasopharyngeal secretions and of regurgitated gastric contents. Tube feeding also does not prevent occurrence of other infections.

Nasogastric tubes may cause infections of sinuses and middle ear, and gastrostomy tubes may cause cellulitis, abscesses and even necrotizing fasciitis and myositis. The imbalance between burdens and benefits justifies a recommendation that tube feeding generally should not be used in individuals with advanced dementia.

Conclusions

In conclusion, the management of terminal dementia should have as its main goal the maintenance of the overall comfort of the patient. Thus, aggressive medical interventions should be limited and emphasis should be placed on palliative care interventions.

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