

Management of the Hospice Patient with Dementia

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Dementia is a fatal illness that afflicts 10% of people over the age of 65. Over 60% of individuals in nursing homes and over half of assisted living facilities residents suffer from dementia. The number of demented persons will grow over the next 20 years as the number of elderly Americans increases.

The average life expectancy of a person with dementia is 8-10 years depending on the physical health and type of dementia. Survival duration depends on age, other health problems, quality of care, and rate of cognitive decline, i.e., intellectual loss. Hospice provides valuable services to persons dying with dementia at home, in the nursing home, or within an assisted living facility. Some demented patients may die from unrelated medical problems early in their disease, e.g., a mildly demented patient with cancer. The hospice recipient may also be a caregiver who is dying from age-related medical problems. In all cases, the hospice professional is well-equipped to provide comprehensive care when they understand the symptoms of dementia and the problems associated with caregivers. Demented patients at the end of life need the same assistance as a cognitively intact person, e.g., reassurance, pain management, optimal nutrition, etc., as well as unique assistance, e.g., behavioral management adjustment of cholinesterase inhibitors, etc.

Hospice services for persons with dementia have suffered from many obstacles placed by funding agencies, healthcare professionals, long-term care providers, and public misperception. Funding agencies seek assurances that patients will die within six months from an illness that can span an entire decade. Some healthcare professionals are hesitant to refer patients to hospice because they believe patients with advanced dementia cannot benefit from the services. Long-term care providers are confused about how nursing home or assisted living facility care differs from hospice care. Caregivers can resist a hospice referral because of problems with denial and caregiver guilt.

Failure to use hospice services may increase patient suffering, burden the family, as well as expend financial resources on futile therapeutic interventions. Most resistance to hospice

services develops because the resistive individual is not knowledgeable about the care provided at end-of-life.

Understanding the Natural History of Dementia

Hospice care helps persons dying with all types of dementia. Most dementias are progressive and terminal producing massive neurological damage or other health problems. Some demented patients may deteriorate to a certain level of disability and then stabilize; however, the vast majority of individuals continue to progress overtime. For example, patients with post-concussive dementia or alcohol-induced dementia with subsequent sobriety may remain stable over prolonged periods of time. Very old persons with Alzheimer's disease, i.e., over age 85, may progress slower than younger individuals with the same diagnosis.

The typical Alzheimer's disease patient will lose about 2 points per year from their mini-mental status exam (MMSE) score in the early stages and 2-3 points per year in the later stages. Severe dementia exists when the mini-mental is below 10. Most patients with mild dementia are capable of giving informed consent and these persons can provide guidance on advanced directives or end-of-life care. Patients with MMSE score below 15 are rarely capable of giving such consent. Caregivers are encouraged to discuss end-of-life issues with demented patients while that individual is still able to express their desires. Families are often hesitant to discuss these issues for fear of upsetting the demented individual. Patients who are approached in the proper manner rarely develop distress or anger. This discussion allows the Alzheimer patient to control their own destiny and exercise self-determination. These issues can be discussed in terms of self-determination, future plans, and autonomy. Most older individuals recognize the finiteness of life and the elders are not disturbed over discussion of dying and end-of-life care. Families need basic information about the futility of resuscitation and feeding tubes for patients with end-stage dementia.

Common causes of death in persons with dementia include aspiration pneumonia, urosepsis, and infected decubiti. Hospice guidelines indicate that a demented patient has less than 6-months of expected life when the individual has severe expressive aphasia and repeated bouts of aspiration or fevers of undetected origin. Expressive language skills are a crude measure of swallowing

competency in demented patients. Neurons in the inferior frontal cortex, i.e., Brocas area, that control language also coordinate swallowing mechanisms. Repeated bouts of fever or infection suggest unrecognized silent aspiration. Individuals who choke or cough following the rapid consumption of 3 oz. of water are at risk for aspiration.

End of Life Care for Persons with Dementia

Advanced stage Alzheimer patients with repeated bouts of aspiration do not benefit from PEG tube insertion. Multiple publications in highly respected journals discourage the use of nasogastric or PEG tubes in demented patients with advanced disease. Studies demonstrate that PEG tubes fail to improve nutrition, quality of life, longevity, or patient autonomy. Families are often under-informed about alternatives to PEG tubes, e.g., spoon feeding. The caregiver may believe that prolonged malnutrition produces severe suffering and distress (See handout, entitled “A Physician’s Guide to the Use of Peg Tubes in Managing Terminal Alzheimer’s Patients” and “The Caregiver’s Guide to Peg Tubes for Patients with Dementia”).

Many demented persons who develop life-threatening medical complications lack advanced directives. Distressed, exhausted caregivers often avoid the larger emotional burden of discussing the dying process with other family members. Most last minute decisions tend to use all available means to sustain life.

The use of cardio-pulmonary resuscitation for end-stage dementia patients is widespread and unproductive. Outcome studies demonstrate that end-stage dementia patients do very poorly by all outcome measures following CPR. The classic DNR order is often omitted because family caregivers lack the knowledge about resuscitation and the information about long-term outcomes. Excessive, aggressive life-prolonging medical interventions are usually employed because the family caregiver was inadequately educated and alternative options were inadequately depicted. Education about the natural history of dementia and the poor outcomes produced by aggressive medical interventions is essential for all members of the family who participate in patient care or decision-making. The family cannot make an informed decision unless they understand the nature of the brain damage produced by dementia (**See End of Life Issues Handout**).

Pastoral counseling often assists families with these difficult decisions. However, many pastors lack basic understanding of dementia and these well-meaning individuals may provide inaccurate advice based on misunderstanding. Hospital chaplains and local pastors can receive education (See Pastoral Care videotapes Vol. I&II on Alzheimer's Disease and Pastoral Care handout) to assist with this educational process.

End-of-life care for advanced stage Alzheimer patients requires that the hospice team understands common behavioral problems encountered in the demented patient. Aggressiveness, wandering, resistiveness, weight loss, and other common behavioral consequences are seen in patients during the dying process. The clinical course of patients dying with Alzheimer's disease, vascular dementia, and diffuse Lewy body disease are similar and these patients benefit from similar management strategies. Antipsychotic medications should be avoided in dying patients -- especially those with diffuse Lewy body disease -- unless the clinician identifies specific psychotic symptoms that can be improved with the medication. Individuals with diffuse Lewy body dementia often become stiff with medications that block the dopamine receptor, e.g., Haldol, Risperdal.

Pain Management at End of Life

Pain management for the dying Alzheimer patient is complicated by the individual's inability to express or explain discomfort. Pain may be manifested through agitation or some other abnormal behavior (**See Management of Pain in Persons with Dementia Handout**). Alzheimer patients may require the same level of narcotics or other analgesics as other individuals with brain injury. Although some brain damaged individuals are more sensitive to narcotic analgesics, each patient must be titrated according to their individual need. Although benzodiazepines are not helpful in early disease, these medications may help the dying patient. Delirium is less problematic in the profoundly impaired patient.

The pharmacological management of pain and anxiety in patients with Alzheimer's disease is important to proper care. Dying patients with dementia experience pain like intact elders and the standard pain treatment paradigm for intact patients should be used in Alzheimer patients.

Dosages may be reduced and clinicians must carefully monitor for agitation or resistiveness produced by narcotic-induced delirium. Demented patients may not be able to ask for narcotic analgesics and medications must be prescribed on a regular scheduled basis. Anxiety and stress are difficult to manage in dying, demented patients because benzodiazepines may produce delirium. Dying Alzheimer patients may be administered modest doses of short-acting benzodiazepines, such as Ativan, in the event that anxiety is present. Benzodiazepines should be avoided for agitation or restlessness since these manifestations may actually be the symptoms of under-treated pain. Clinicians should avoid medications with low analgesic quality such as Darvon, as these may cause delirium in persons with dementia. Narcotics may produce constipation that goes unrecognized producing impaction, diminished oral intake, and agitation. Rectal impaction should be considered in the dying Alzheimer patient with symptomatic disimpaction.

Pain management is important in the majority i.e., 70% of demented dying patients, are under-treated for this disorder. The step-method progressing from non-narcotic analgesics through short-acting narcotics to long-acting narcotics is appropriate for demented patients as well as other individuals. Mild pain can be treated with acetaminophen or non-steroidal inflammatories with appropriate attention to GI distress. Moderate pain can be treated with codeine, oxycodone, or Tramadol, while severe pain should be treated with appropriate analgesics including morphine, Fentanyl patch, and oxycodone. Neuropathic pain can be treated with appropriate doses of anticonvulsants such as tegretol or neurontin (See handout, entitled “Management of Pain in Persons with Dementia”).

Caregivers need support through the dying process that accommodates the unique burden associated with Alzheimer care. Many caregivers are exhausted and disheartened by the dying process that often last 8 to 10 years. The slow cognitive disintegration of Alzheimer patients produces a piece-meal death that saddens, frustrates, and angers many caregivers. The caregiver may view the impending death of a patient with a mixture of sadness and relief that provokes guilt and self-recrimination. Caregivers need constant reassurance that their decisions are appropriate and accurate. Professional staff should validate the suffering sacrifice and devotion

of the caregiver to focus their attention on positive features rather than guilt over relief of patient demise.

End of Life Care for the Mildly Demented Patient

The mildly demented patient may develop other terminal diseases that require hospice services. The end of life progression for mildly demented patients will be similar to that of persons with intact intellect. The major difference between normal individuals and demented persons who are dying from medical problems is the vulnerability to delirium and other side effects produced by medical problems, medical interventions, and pain medications. Abrupt changes of behavior or sensorium should be assessed like delirium (**See Assessment and Management of Delirium Handout**). Demented patients may need constant reminders about therapeutic interventions to assist with medical problems or discomfort. Hospitalized dying patients with mild dementia may experience more disorientation and confusion than intact patients and this problem is best managed by sitters and reassurance rather than psychotropic medications. Alzheimer medications, i.e., cholinesterase inhibitors, should be continued during the course of hospice care for Alzheimer patients until the patient's cognitive status or level of alertness is severely impaired. Abrupt discontinuation of cholinesterase therapy may precipitate abrupt loss of function and increase of behavioral problems. Patients should continue antidepressant therapy when depression was previously diagnosed.

The dying, dementia patient has the right to be informed about their diagnosis, prognosis, and management strategy. Dying patients with dementia do not require constant reminders about this fatal illness and discussing the matter is best limited to when the individual initiates the conversation.

Caring For the Caregiver

The hospice worker may encounter a caregiver who appears to manifest symptoms of medical or psychiatric deterioration. Depression, stress, anxiety and substance abuse are frequent complications encountered by the caregivers.

Caregivers may appear exhausted and depressed. Social isolation, sleep disruption, heavy physical labor and other issues can produce physical and emotional exhaustion. Caregivers with limited support networks and minimal use of support systems, e.g., support groups, respite service, etc., are at greater risks for burnout and poor care to the patient.

Caregivers with depression should receive antidepressant therapy. The combination of depression and caregiver burdens can produce significant disability for the individual. Caregivers should avoid long-term benzodiazepine therapy or sedative hypnotic therapy. Both sleep and anxiety medications eventually lose effectiveness, produce confusion, and worsen the clinical circumstances. Supportive psychotherapy provided through support groups is the best option for dealing with stress, distress, and bereavement.

Substance abuse is a serious problem in the elderly with 8% of older individuals experiencing problem drinking. Substance abuse includes alcoholism and overuse of prescription medications such as benzodiazepines, sedative hypnotics, and narcotics. Alzheimer's patients should not drink alcohol. Caregivers should avoid drinking more than one glass, i.e., 1 oz., of alcohol per day. The consumption of two or more ounces of alcohol on a consistent daily basis suggests self medication and staff should assess for depression. Caregivers may obtain duplicate prescriptions for benzodiazepines or narcotics and overuse these medications. Heavy drinking, excessive use of pain medications or benzodiazepines may manifest as weight loss, confusion, or deterioration in function for the older caregiver. Excessive use of benzodiazepines or alcohol produces increased medical disability as well as greater risks for falls with fracture. The treatment team should address depression, anxiety, insomnia, and substance abuse in the caregiver. Caregivers with sleep disorders should be encouraged to use sleep hygiene, exercise, and other psychological interventions prior to the use of medications. Over-the-counter sedative hypnotics that include diphenhydramine, i.e., benadryl, often produce confusion in the older caregiver. Low dose Deseryl, i.e., 25-75mg, can be used to assist with sleep as well as medications like Zolpidem. Only benzodiazepines with a short half-life should be prescribed for severe sleep disruption. Long, half-life medications such as Valium and Dalmane, should be avoided as they produce daytime intoxication. Severe sleep disruption, weight loss, increased forgetfulness, or poor performance strongly suggests depression in the caregiver.

When the Caregiver is Dying

Hospice may care for intellectually intact, dying caregivers for demented patients, e.g., the caregiver wife who develops breast cancer. The dying caregiver must cope with the loss of their own life as well as the worry about the welfare and future safety of the demented patient. The hospice team should assist the dying caregiver with planning for the future care of the demented patient. The dying caregiver may need legal, financial, and social services advice as well as assistance with family issues.

The Alzheimer patient may wish to know about the circumstances or welfare of the dying caregiver. The clinician should provide initial information but future discussions should depend on the response of the demented individual. Patients who develop catastrophic reactions to information about the dying caregiver should be managed through distraction and redirection when future questions are asked; however, all patients have the right to accurate information about their loved-one.

Can Demented Patients Attend Funerals

The decision to include a demented patient in the planning or activities of a funeral depends on the patient and their response to the dying process. In general, mild or moderately demented Alzheimer patients should be allowed to participate in appropriate ceremonies or activities, e.g., wakes, visitation, etc. Patients with mild or moderate dementia may experience a grief reaction. The intensity of the bereavement may vary according to the cognitive status of the patient. Advanced-staged dementia patients rarely benefit from involvement in such activity; however, participation can be determined by discussion with the family. Following the death of a caregiver, the demented patient may continue to insist that the individual is alive and healthy. Families should not repeatedly dispute this assertion, but rather redirect the individual to discussion about other issues. Repeated reminders for an amnesic patient about the death of a loved one simply cause the patient to relive pain and suffering without resolution of the grief reaction. Mildly demented patients will sustain a grief reaction. Family and friend should provide the same spiritual and emotional support needed by persons with normal intellect. Physicians should avoid benzodiazepines and sedative hypnotics unless the risk of delirium is worth the benefit to the patient.

The Three-Step Method to High Quality End of Life Care

STEP	CLINICAL FOCUS	STAGE	TREATMENT GOAL
STEP 1	Self-determination	Early	Self-determination
STEP 2	Functional Maintenance	Middle	Disease Management
STEP 3	Quality of Life	Late	Hospice Care

End-of-Life Care

