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PALLIATIVE CARE FOR ADVANCED DEMENTIA

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Dementia is defined as a syndrome of acquired and persistent impairment in cognitive and intellectual functioning.[1] The acquisition of cognitive impairment after a long period of normal functioning differentiates dementias from developmental disorders and mental retardation; the persistence of the deficits differentiates dementing conditions from delirium. Multiple domains of mental activity are affected including prominent loss of memory, but also impairments in language and visuospatial skills, impairments in executive functioning, loss of emotional control, apraxia, agnosia, and personality changes as dementia progresses. This range of associated (and typically progressive) deficits helps to differentiate dementias from other neurologic conditions such as aphasias, amnestic syndromes, and neurocognitive manifestations of stroke.

Dementia is associated with a wide variety of underlying conditions that affect the integrity of the central nervous system (CNS), including primary neurodegenerative disorders, vascular injuries, infections, hydrocephalic conditions, drug-induced or metabolic conditions, and trauma.[14] By far the most common cause of dementia in the United States is related to Alzheimer's disease (AD), which accounts for approximately 50% of all cases of dementia.[14] Multiinfarct dementia or vascular dementia (VaD) accounts for most of the remaining cases of dementia in the United States, either alone or as a comorbid condition with AD. Together, AD and VaD

account for 70% to 90% of cases of dementia in this country.[10,14,36] There are approximately 4 million Americans with severe dementia, and another 1.5 million with mild to moderate dementia.[14] AD affects 2% to 4% of the population over the age of 65 years and more than 45% of those over age 85 years.[10,14]

END-STAGE DEMENTIA

Progressive dementia, particularly dementia related to AD, is an incurable and invariably fatal illness. Therefore, palliative treatments are most appropriate. Dementias vary greatly in their course and rate of progression. The usual time from diagnosis of AD to death is approximately 10 years,[1,14,28] with the end stage of the illness lasting as long as 2 or 3 years. The course of VaD is somewhat more rapid in most cases. Death does not result from neurodegeneration itself but occurs as a consequence of one of the many secondary impairments associated with dementia. Advanced dementias are associated with progressive immobility and reduced capacity for self-care; poor nutrition resulting from diminishing intake of fluids and liquids; infections related to immobility, skin breakdown, and catheterization; and general debilitation. Most elderly patients who develop dementia also have other illnesses (e.g., diabetes, heart disease), which can contribute to overall decline and eventual death.

In monitoring the progression of dementia, it is important to recognize that there is a wide variation in the course of illness among individual patients. Generally speaking, as dementing illnesses progress, memory and other cognitive deficits worsen and become severe. Independent mobility is lost, as is capacity for self-care. Speech becomes progressively impaired and eventually lost. Appetite and ability to eat independently almost invariably decline with advancing illness, as does the capacity to swallow. Bowel and bladder incontinence develop in response to immobility and loss of neuromotor control of elimination. The loss of various capacities and the development of end-stage symptoms do not progress in a uniform or even predictable way. However, a consistent grouping of signs and symptoms heralds the final stages of dementia:

Neurocognitive
  Progressive worsening of memory and other cognitive deficits
  Confusion, disorientation become profound
  Behavioral changes: combativeness, resistance giving way to apathy, coma
  Progressive worsening of speech, ability to communicate; patient eventually becomes incoherent, mute, unresponsive
Functional
  Independent mobility progressively lost; patient becomes bedbound
  Capacity for self-care (performance of independent activities of daily living) progressively lost; patient becomes totally dependent

Nutritional
  Progressive loss of appetite
  Progressive loss of capacity to swallow; ability to eat independently almost invariably declines
  Aspiration becomes increasing risk
Complications
  Bowel and bladder incontinence
  Fevers and infections (pneumonia, urinary tract infections, sepsis)
  Decubitus ulcers

Successful management of terminal dementia requires a willingness to palliate symptoms in a patient who is not fully able to report on the experience of his or her illness and suffering and can only participate in his or her care in a limited way. Although it is impossible to understand the experiential world of a patient with advanced dementia, this does not necessarily mean that demented patients do not suffer or that they suffer in more limited ways than other patients. In fact, there is ample evidence that the suffering that commonly accompanies advanced stages of dementia is substantial and multifaceted.[25] Assessment of suffering in the severely demented patient relies on observation and, in some instances, clinical assumptions, but the threshold for palliative intervention in an apparently uncomfortable demented patient should be low.

AGITATION AND DELIRIUM

One of the most troublesome complications of advanced dementia is the agitation that often develops as cognition declines.[32] Restlessness or agitation in the setting of advanced dementia may be caused by delirium, a very frequent complication of dementia. The cognitive impairment of dementia renders the patient susceptible to delirium as a consequence of even minor infections, modest electrolyte imbalances, or otherwise well-tolerated medications. It is unclear how much suffering patients with advanced dementia undergo as a consequence of agitation or delirium. On the other hand, agitation and restlessness are clearly quite disturbing to family members and other caregivers. The suffering and distress family members experience from witnessing a loved one so apparently uncomfortable are not to be trivialized.

Causes of agitation other than frank delirium, however, should be investigated in the setting of dementia. Patients who are in pain are very likely to manifest restlessness, especially nonverbal patients. The general discomfort of immobility and bed confinement can be substantial. Constipation and urinary retention are also very common and treatable causes of restlessness at the end of life. Acute dyspnea, with or without hypoxia, which can lead to delirium, can produce agitation. The absence of reassuring friends or relatives can produce agitation. Alternatively, the presence of certain others (including family members) occasionally can lead to agitated behavior, even if the patient had an amiable relationship with

that person before becoming ill. A person experiencing such perceived rejection by a demented friend or relative may require support and education from professional staff.

Delirium is defined formally as a disturbance in consciousness and cognition that develops over a short period of time.[1] Lipowski[19] defines delirium as "a transient organic mental syndrome of acute onset, characterized by global impairment of cognitive functions, a reduced level of consciousness, attentional abnormalities, increased or decreased psychomotor activity, and a disordered sleep-wake cycle." Delirium is a consequence of metabolic disturbance of CNS function, typically as a consequence of physical illness or toxicity. Resolution of delirium depends on resolution of the underlying cause, an unusual circumstance in the setting of terminal dementia.

Estimated prevalence rates of delirium and acute agitation at the end of life range from about 25% to about 85%.[4,7,8,11,18,24,26,32] The highest rates of delirium are seen in the days and hours just prior to death. As death approaches, reductions in CNS perfusion, renal filtration, drug clearance, fluid and electrolyte balance, and oxygenation can lead to increased delirium.

Medication side effects are common causes of delirium at the end of life. Anticholinergic drugs, even at very low doses, can produce delirium in the demented patient, especially in the setting of AD (a disorder characterized by primary loss of cholinergic neurons). Opiates, or more specifically the metabolic products of opiates, can accumulate and produce delirium in the terminally ill patient, especially in the presence of renal insufficiency. In this situation, rotation to an equianalgesic dose of another opiate may help reduce delirium and maintain pain control.[6,23] Levels of potentially neurotoxic drugs (e.g., digitalis preparations, theophylline, anticonvulsants) should be measured, if possible.

Other remediable causes of delirium in the setting of terminal dementia include dehydration and infections (most commonly urinary-tract infections caused by indwelling catheters). Intervention in either of these two situations depends on decisions made by the patient or the surrogate about the desired and proper role of hydration and antibiotics. Assuming such interventions are clinically appropriate and consistent with the wishes of the patient or surrogate, cautious rehydration by mouth, intravenous infusion, or hypodermoclysis can help reduce agitation resulting from dehydration. In the palliative care setting, symptomatic dehydration is one of the few indications for parenteral hydration.

In most cases of delirium complicating terminal dementia, pharmacologic treatment aimed at symptom reduction is indicated. The antipsychotic medications, most commonly haloperidol, are the mainstay of treatment (Table 1).[3,9,31,32,35] Other agents also commonly are used, but haloperidol has the multiple advantages of long record of reliable efficacy, low cost, and multiple routes of administration (by mouth, intramuscular injection, or intravenous or subcutaneous infusion). Some of the newer antipsychotic agents, such as olanzapine and risperidone, appear to be effective and well tolerated for delirium complicating dementia.[2,13,34] Start-

Table 1. ANTIPSYCHOTIC MEDICATIONS FOR DELIRIUM COMPLICATING ADVANCED DEMENTIA

	Starting Dose, mg	Routes
Haloperidol	0.5–2.0 mg, BID–TID	PO, IM, IV, SQ
Chlorpromazine	12.5–50 mg, BID–TID	PO, IM
Olanzapine	5.0 mg, QD	PO
Quetiapine	25–50 mg, BID	PO
Risperidone	0.5–1.0 mg, BID–TID	PO

BID = twice daily; TID = three times daily; PO = by mouth; IM = intramuscularly; IV = intravenously; SQ = subcutaneously; QD = once daily.

ing doses are at the low end of the therapeutic range of a given agent, but frequent monitoring of therapeutic and side effects allows rapid dose titration. The most common side effects are sedation and extrapyramidal effects, especially akathisia. Akathisia can mimic or exacerbate agitation if severe, but this therapeutic dilemma usually can be avoided by low initial dosing and careful dose titration.

In the only published double-blind, controlled study comparing pharmacologic treatments for delirium, Breitbart and coworkers[5] compared haloperidol, chlorpromazine, and lorazepam for delirium in hospitalized patients with AIDS. Both antipsychotic drugs were effective in improving the symptoms of delirium at relatively low doses, but lorazepam treatment was not associated with improvement. In the setting of terminal illness, however, some cases of severe agitated delirium may be refractory to standard interventions and only manageable by sedation with benzodiazepines or opiates. Early intervention is more likely to be effective in managing terminal delirium, but detecting the relatively subtle signs of early delirium in the setting of advanced dementia is a difficult challenge.

Nonpharmacologic interventions are important adjuncts to the management of delirium and agitation in the setting of terminal dementia. A soothing, physically comfortable environment including familiar people and objects, familiar music, old photographs, and other personal items can provide calm and comfort. Demented patients benefit from frequent reassurance and gentle redirection and orientation. The correct balance of sensory stimulation should be sought. Overstimulation tends to make the delirious or confused patient agitated; understimulation can cause the patent to be afraid.

DELUSIONS AND HALLUCINATIONS

Patients with advancing dementia often are troubled with delusions and hallucinations. These range from benign (even pleasant or reassuring) perceptions of visits from relatives or other people to distressing, frightening, or bizarre experiences. Additionally, the misplacing of items because of progressive memory loss often is interpreted delusionally by the

patient as proof that others are stealing from him or her. If present as consequences of dementia, these symptoms seldom resolve with treatment with antipsychotic medication and are managed best by reassurance and support directed to the patient and caregivers. Family and caregiver support becomes extremely important if the content of delusions and hallucinations leads to paranoid ideation or hostile accusations.

PAIN

It is unreasonable to assume that demented patients do not suffer pain simply because they do not complain about pain.[12] Even cognitively intact patients underreport pain. Demented patients, particularly those with prominent degeneration of the frontal lobes, might be hindered in their ability to report pain by disease-related reductions in verbal capacity, motivation, and complex thinking. Such deficits blunt pain behavior without necessarily altering pain perception. Memory deficits can block the ability to remember being in pain in preceding moments and hours without blocking the miserable experience of pain in the moment. Additionally, it is unclear how CNS degeneration might alter the perception of pain.[12] Some patients might experience relative analgesia as a consequence of their dementia; others might have pain perception and consequent suffering enhanced by a dementing process. In AD, the somatosensory cortex is relatively spared, but inputs and processing of nociception might be distorted. Particularly in patients with VaD, CNS lesions (e.g., thalamic infarctions) could produce especially distressing central pain syndromes.

There is evidence that dementia is associated with undertreatment of pain. Numerous studies and surveys point to a tendency to undermedicate pain in patients with dementing illnesses.[12,37] Undertreated pain should be considered in any patient with advanced dementia who does not appear to be fully calm and comfortable. Pain in advanced dementia may present as agitation, social withdrawal, or other changes in behavior. Tachypnea, vocalizations, facial grimacing, posturing, or splinting may be manifestations of pain in the severely demented patient, and if present also are the most reliable markers of treatment adequacy.

The same principles of pain treatment apply as in nondemented patients. A stepwise approach starting with nonopiate medications as tolerated and effective and advancing to the use of opiates as indicated is helpful.[38] Monitoring and documentation of improvement in physical and behavioral manifestations of pain as well as potential side effects (e.g., sedation, constipation) is necessary.

DEPRESSION

Depression is a common and problematic complication of dementia, especially in the early and middle stages. Unfortunately, by the time most demented patients come to receive palliative care, they can neither generate a complaint of depressed mood nor report any of the target symp-

toms needed to guide therapy. For these reasons, it is unusual to initiate antidepressant therapy in the terminal stages of dementia. Considering the burden of depressive illness, however, it would seem reasonable and prudent to continue therapy in those patients who benefited from antidepressants earlier in the course of their illness, barring some complication rendering this therapy unsafe. Additionally, a time-limited trial of a standard antidepressant (approximately 8 weeks at a therapeutic dose) or a psychostimulant (1 or 2 weeks at a therapeutic dose) is a reasonable intervention if depression is suspected, even in advanced dementia.

POOR SLEEP

Insomnia and sleep-cycle disturbance are common in advanced dementia. Bedbound and debilitated patients may be hypersomnolent overall but sleep in frequent short naps, causing sleep fragmentation and nighttime wakefulness. A sudden change in sleep pattern, however, should be taken as a prompt to assess for delirium, which disrupts the sleep–wake cycle. Pain, dyspnea, and nausea can disrupt sleep, as well. Sedating medication may be useful in helping relieve nighttime restlessness, but anticholinergic medications should be avoided for reasons cited previously. Additionally, benzodiazepines and other sedative–hypnotics, used at doses intended to produce transient sleep (and not heavy sedation as with a constant infusion), may induce paradoxic agitation or residual daytime drowsiness in the demented patient. Better alternatives in this setting might be a low dose of trazodone (between 25 and 100 mg) or an antipsychotic medication (e.g., haloperidol).

FEVER

As mentioned previously, infectious complications are a very common cause of death in patients with advanced dementia. Depending on clinical appropriateness and the wishes of the patient or surrogate, diagnostic evaluation of fever or treatment with antibiotics may or may not be appropriate. In one study,[17] aggressive treatment of fevers in inpatients with advanced AD did not provide more satisfactory outcomes, including progression of AD symptoms and survival. In fact, aggressive treatment of fevers seemed to accelerate AD progression in this study. On the other hand, palliation of fever itself with antipyretic measures is appropriate as a comfort-enhancing measure.

OTHER COMPLICATIONS OF END-STAGE DEMENTIA

Patients with terminal dementia predictably need intervention for other complications of their disease. Bowel and bladder incontinence usually are managed by Foley catheter placement and careful attention to

hygiene. Meticulous skin care and frequent turning are necessary to prevent the development of decubitus ulcers. Frequent attention to mouth care is required, especially in those patients who develop frequent mouth breathing.

DEMENTIA AND HOSPICE CARE

As a cluster of diseases that for the most part have no known cure and an invariably fatal outcome, dementias would seem to be a natural fit for hospice and palliative care. Unfortunately, the invariable outcome follows a quite variable course of illness. Access to hospice care in the United States is based on a medical prediction of death within 6 months or less. This core eligibility criterion does not lend itself as well to the care of the dementia patient as to the patient with cancer. In 1995, Hanrahan and Luchins[15] reported that less than 1% of all hospice patients had a primary diagnosis of dementia, and only 21% of American hospices surveyed were admitting these patients. The difficulty in predicting survival with terminal dementia in order to meet hospice criteria was cited as the main barrier to access by 80% of the surveyed hospice care providers.

These findings exist in stark contrast to the apparent treatment preferences of Americans regarding terminal dementia. Though dementia renders obtaining detailed and accurate information from patients impossible, surveys of family and professional caregivers reveal that the great majority would opt for a palliative approach to end-of-life care for dementia. Luchins and Hanrahan[20] surveyed physicians, nonphysician professional caregivers, and family members of patients with dementia and determined that the great majority of respondents would choose to have limitations placed on the care offered to them, including withholding cardiopulmonary resuscitation, ventilator support, medications such as antibiotics for acute illness, and placement of feeding tubes. In fact, less than 5% of those surveyed would elect to have all these therapies offered to them if they became demented. The majority of all three groups, and a full 70.6% of the family members, would select none of these treatment options (i.e., comfort care only). In another study, Patrick and colleagues[29] surveyed healthy older adults living independently and a comparison group of nursing home residents and found that 45% of the healthy sample and 60% of the nursing home sample felt that a state of dementia would be worse than death.

A diagnosis of dementia causes suffering in a number of domains. Patients with progressive dementia suffer a gradual loss of autonomy and control. They may experience fears of illness, functional decline, and abandonment. They may fear loss of dignity or personhood. Many fear the dying process, often more than death itself. The numerous neuropsychiatric complications of dementia (e.g., depression, delirium, delusional states) carry a substantial burden of suffering. A progressive neurologic and functional decline causes a great deal of stress on families and caregivers.[22] The process of grief for the loss of functional capacities, life roles,

and eventually a life itself is complicated by the prolonged course of illness in most dementias. Finally, ambivalence about end-of-life care decisions can contribute to suffering caused by a dementing illness. A quick survey of this partial list of domains of suffering from dementia shows that these problems are very consistent with the hospice model of care:

Gradual loss of autonomy and control
Fears
  Illness
  Functional decline
  Abandonment
  Loss of dignity or personhood
  The dying process
Neuropsychiatric complications of dementia
  Depression
  Delirium
  Delusional states
Physical complications of dementia
  Pain
  Fever/infection
  Skin breakdown
  Constipation/urinary retention
Stress on families and caregivers
Grief
  Loss of functional capacities
  Changes in life roles
  Approaching death
Prolonged course of illness
Ambivalence about end-of-life care decisions

Hospice offers care and comfort in the form of nonabandonment, aggressive symptom control, assistance with specific life goals, integration of the end-of-life experience, and help with bereavement, grief, and loss.[33] Its goals include:

Nonabandonment
Aggressive symptom control
  Pain
  Agitation/delirium
  Fever
  Constipation/urinary retention
  Depression
  Dyspnea
Assistance with specific life goals (patient and family; requires intervention with the patient early in the course of illness)
Integration of the end-of-life experience (requires intervention with the patient early in the course of illness)
Help with bereavement, grief, and loss

If most would choose palliative care for themselves if they became demented and the palliative care model provided by hospice programs ad-

dresses the common sources of suffering related to a progressive dementia, why is hospice not widely utilized for end-of-life care of dementia?

The most obvious barrier is the poor fit between the time course of terminal dementia and the requirement for patients in American hospices to have an expected survival of 6 months or less. The National Hospice Organization (NHO) has prepared a set of model hospice admission guidelines for noncancer diagnoses, including dementia.[28] These guidelines reflect the some of the usual signs of advanced, end-stage dementia but are focused on those signs predictive of death within 6 months, to help hospices determine eligibility for care. The guidelines for dementia are based on the Functional Assessment Staging (FAST) scale.[30] To be eligible for hospice care under these criteria, a patient must be at or beyond stage 7 (the most advanced stage) on the FAST scale. Specifically, patients must exhibit loss of ability to walk, dress, or bathe independently, must be incontinent of both bowel and bladder, and must have lost the capacity for meaningful communication. The presence of medical complications, such as aspiration pneumonia, pyelonephritis, septicemia, multiple decubitus ulcers, recurrent fevers, weight loss, hypoalbuminemia, or loss of capacity to eat, can be used to strengthen the case for justifying hospice treatment for dementia. Other factors, including tube feedings, meticulous nursing care, and aggressive management of medical complications, can prolong survival in end-stage dementia considerably. Ironically, such interventions are often consistent with excellent medical care and may be consistent with explicitly stated wishes of the patient or the family but can serve as barriers to hospice admission or continuation of hospice care under the current hospice benefit structure.[16,21]

The situation is complicated further by the fact that the nonhospice care system also is poorly suited to the care of those with advanced or terminal dementia. Because Medicare is not designed to function as a primary reimbursement system for long-term care, only care for the complications of dementia (or collateral illnesses) is relatively well reimbursed. The care of such complications is shifted toward general medical facilities and away from care settings often more suitable for patients with advanced dementia. The public "safety net" reimbursement system, Medicaid, is available only to persons who become thoroughly impoverished. Once a patient qualifies for Medicaid, care reimbursement under this system is often so limited as to present its own barrier to appropriate care. These reimbursement systems, if applied to the patient with advanced dementia, encourage fragmentation of care, limited availability of appropriate care, and extreme rationing of patient and family financial assets.

SPECIFIC CHALLENGES IN PALLIATIVE CARE OF TERMINAL DEMENTIA

Prognostic Uncertainty

Despite substantial effort to develop models to predict death within 6 months in dementia, accurate prediction remains difficult.[16,21] The 6-month prognosis criterion is clearly a poor fit for terminal dementia.

The NHO guidelines themselves acknowledge that "even severely demented patients may have a prognosis of up to two years."[28] Application of these guidelines for dementia is challenging. The stages of illness outlined in the FAST scale are not ordinal—many patients with some symptoms of advanced dementia do not exhibit all the symptoms on the scale consistent with less advanced disease. Accurate prediction of death within 6 months using these guidelines is dependent largely on a plan of care avoiding interventions such as antibiotics or feeding tubes, a plan of care many surrogates are not willing to endorse. The difficulty in qualifying for hospice care and the risk of having hospice care discontinued if terminal dementia does not follow the predicted time course are substantial barriers to hospice care for end-stage dementia. Such prognostic uncertainty, as a hindrance to hospice care access for patients with terminal dementia, is a major impediment to quality care. Despite a probable survival often far exceeding 6 months, patients with dementia and their families suffer from problems best addressed by hospice and palliative care. Once hospice admission occurs, families of demented patients often report that they have been in need of such care for years.

Treatment Decisions

Care for a patient with advancing dementia usually involves difficult decisions about treatment goals and elements of the care plan. As the illness robs the patient of more and more function, decisions must be made incrementally. As a demented person loses the abilities to keep up with meal preparation, to feed him or herself, and even to swallow, decisions must be made about nutritional support. Decisions regarding placement and removal of feeding tubes cause substantial distress in patients, family, and staff. Patients commonly lose the sensation of hunger along with the drive and capacity to eat, but families often feel that withholding artificial feeding is equivalent to starving their loved ones to death. The social and interpersonal meaning of meals and sharing food among family members is easily, albeit inappropriately, transferred to medical interventions (e.g., feeding tubes) that provide artificial nutritional support. Similarly, decisions about appropriateness of resuscitative efforts and continuing or withholding treatments (e.g., antibiotics for fever) can cause great distress.

The distress in these situations is complicated by the long course of the typical dementing illness, the patient's diminished capacity to have input into medical decisions, caregiver stress, and the frequent underestimation of the terminal nature of advanced dementia. It is important to initiate discussions about treatment preferences as early as possible, ideally while the patient is still capable of meaningful participation in the discussions. Discussion of such decisions is best conceived as a dialogue held over multiple sessions. Discussions must explore the perceived meaning of withholding treatments and estimates of the suffering caused by continuation versus discontinuation of treatment interventions. It is important to recognize and acknowledge that even routine procedures are significant causes of pain and discomfort.[27]

Family Guilt and Ambivalence

Advanced dementia commonly leads to illness and impairment in excess of a family's capacity to provide care. Admission to a hospital or nursing home, although often the best, safest, and most reasonable solution for care of the patient, may induce a great deal of guilt and ambivalence in the patient's family. These feelings are amplified by difficult treatment decisions. Again, supportive discussion of the problems and gentle education about the options, however limited, can go a long way toward relieving this distress. As treatment options become more limited, and especially after decisions are made to withhold or withdraw treatments, it is most important to help families cope with guilt feelings. Administration of tube feedings or advocating for aggressive treatments may be ways of demonstrating love and devotion to a relative who cannot reciprocate. Families need to find other ways to show love to patients, such as touching or stroking their skin in a soothing way, providing a favorite musical recording, or praying over their relatives. Pastoral care can be very helpful to people of faith in this situation.

Presumptive Treatment

In caring for a patient with terminal dementia, not only the family but also the professional caregivers are faced with helping a person who cannot articulate problems or complaints to focus treatment. Palliative care of the demented patient is therefore, to a large degree, presumptive. Although therapy overall is appropriately conservative, treatments aimed at relief of apparent symptoms should be as aggressive as necessary.

CARING FOR THE FAMILY

Families of patients with end-stage dementia need particular kinds of attention. As early as possible, families who are receptive to such discussions should have the typical course and complications of advancing dementia explained to them. To the extent possible and appropriate, proactive discussion of likely therapeutic decisions (e.g., feeding-tube placement) can spare some difficulty when the time comes to make such decisions. The difficulty in making accurate prognostic estimates should be included in discussions about what to expect. A pledge of nonabandonment is one of the most healing interventions a clinician can offer to the family of a dementing patient.

Providing care for a loved one whose capacity to participate in relationships is steadily waning is inherently stressful. This stress is compounded if dementia produces difficult behavioral symptoms (e.g., agitation, combativeness, resistance, paranoia) in the patient. Families should be educated as to the source of these problems (i.e., that these symptoms are consequences of dementia and not necessarily markers of inadequate caregiving or rejection of the family). Additionally, caregivers should be instructed in behavioral measures to minimize such symptoms.

Clinical management of the patient with terminal dementia should emphasize early detection and prompt intervention for causes of suffering and distress to the patient. No one likes to see someone they love in a state of agitation or undertreated pain. Successful management of these symptoms is of therapeutic benefit not only to the patient, but to the family as well. Inadequate symptom control for the dying patient adds to the burden of grief for the surviving family. Conversely, good symptom control not only may allow family members to grieve the loss of their loved one with less difficulty but may allow them to face the end of their own lives with less fear and dread.

Caring for a patient with advanced dementia can be emotionally and physically exhausting.[22] Referral to local support groups, connecting with the local chapter of the Alzheimer's Association, or engaging the family's church, synagogue, or other community of faith can be very helpful in providing support for families. Obviously, the supportive and pastoral care components of interdisciplinary hospice care are also well suited to such needs. Access to these services for family members is another benefit of hospice care for terminal dementia.

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MEASURING QUALITY IN END-OF-LIFE CARE

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Over the past decade the quality of medical care delivered to patients near the end of life has come under increasing scrutiny. A national expert panel recently confirmed that major problem areas exist in the care of dying patients, including inadequate assessment of and control of symptoms, poor doctor-patient communication regarding prognosis and treatment preferences, limited access to palliative care services, and a lack of pragmatic alternatives to hospital-based care at the time of death.[20] The panel's findings were based on a growing body of evidence, most convincingly from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) trial,[50] that has begun to elucidate the quality of care delivered to patients who are near the end of life. Given the disproportionate share of dying patients who are elderly, geriatricians have an important stake in understanding what quality of care at the end of life means and how it might be measured.

The conceptualization and measurement of quality of care is a relatively new direction in health research. Through the development of research methods to assess quality of care, investigators now have the ability to systematically evaluate the care delivered to large numbers of patients across a variety of settings and disease states. Tools exist to measure quality of care in many areas within geriatrics, including the management of pressure ulcers[2] and the care delivered to patients in nursing homes.[38] Yet, experts have only begun the process of conceptualizing quality of care in dying patients, and the range of tools to measure quality in this popula-