

Diagnosing Dementia in Long-Term Care Facilities

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Some might think that diagnosing dementia in residents of long-term care facilities (LTCF) is less important than in patients who are living at home. People living at home are much more likely to be working; driving; and managing their own medications, finances, cooking, and household responsibilities than are residents in LTCF. Without as many cognitive demands in day-to-day living, people with dementia in residential and nursing settings can have their dementia overlooked until it is quite advanced. We discuss why the diagnosis of dementia in the LTC setting is so important, and review the clinical diagnosis and treatment of dementia in LTCF.

WHY DIAGNOSE DEMENTIA IN LONG-TERM CARE FACILITIES?

Dementia increases risk to many iatrogenic factors. Neurodegenerative diseases increase sensitivity to central nervous system effects of medications, especially confusion, and failure to appreciate this sensitivity can lead to prescribing medications that worsen dementia. For example, anticholinergic medications are still inappropriately administered to people with dementia, even those who are diagnosed and receiving cholinesterase inhibitors.¹ Dementia is a risk factor for falls and can limit the effectiveness of training to reduce the risk of falls.^{2,3} Dementia increases risk for delirium from acute illness and medications,⁴ and the underlying dementia is sometimes recognized for the first time only when delirium develops.⁵ Although delirium itself is predictive of poor functional outcomes,⁶ delirium superimposed on dementia is associated with even poorer outcomes if the dementia is not recognized.^{7,8}

Dementia can impair a person's ability to report pain. Awareness of dementia and the atypical and nonspecific features of pain behavior in people with dementia are likely to improve pain detection and treatment.⁹ Special pain assess-

ment scales for people with dementia have been investigated and found to improve detection of pain in this population.^{10,11}

Depression is underrecognized in patients with dementia residing in LTC, particularly those with more severe dementia.¹² Nursing home residents with dementia receive less routine medical care and physician visits than nondemented residents.¹³ Although it is hard to conceive why residents with dementia could receive fewer annual physician visits, reduced physician visits related to fever and infection is plausibly related to informed end-of-life decisions in residents with advanced dementia.¹³ Cognitive status and dementia prognosis need to be accurately determined to better inform these decisions. However, because patients with dementia are less likely to report depression, pain, and other health problems, recognition of the dementia should lead to more active surveillance of health status. This could be especially important in assisted-living and residential care facilities.

Accurate diagnosis of dementia and its underlying cause will allow clinicians to provide a prognosis and expectations for families having to make difficult decisions on behalf of LTC residents with dementia. Families often feel overwhelmed by seeing a loved one succumb to a dementing disease, the need to place them in a LTCF, and the need to make plans for end-of-life care.¹⁴ Families need as much information and support from the healthcare team, and this includes accurate diagnosis and prognosis. Accurate diagnosis and documentation of dementia can also facilitate recruitment into clinical dementia trials in LTCFs.

Unrecognized dementia can subject an LTC resident to the risk of fiduciary abuse or other forms of undue influence. Residents can be called on to make decisions when they lack capacity to appropriately do so.

Resistance to physical care assistance is a common problem for caregivers of LTC residents with severe dementia. The resistance can be misinterpreted as intentionally hostile or oppositional behavior without a complete understanding of the medical (eg, pain), cognitive, and psychologic impairments motivating the behavior.

Staff-related factors can have a major impact on the LTC resident with dementia, particularly when the dementia is undiagnosed. Weight loss and eating-related behavioral disorders are common in dementia, and the staff's interpretation of resistance to feeding can contribute to inadequate caloric

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DOI: 10.1097/01.JAM.0000095362.22706.EA

Table 1. *Clues to the Presence of Dementia in Long-Term Care Residents*

Clue	Examples
Recorded diagnosis	Dementia, senile dementia, organic brain syndrome, chronic brain syndrome, chronic encephalopathy, Alzheimer's disease, Parkinson's disease, Lewy body disease, Pick's, frontal lobe dementia, multi-infarct dementia, vascular dementia, stroke, Wernike's, and so on
Memory impairment	Repetitive questions and stories, disorientation, forgets instructions
Motor programming impairment (apraxia)	Dependent in activities of daily living, "won't eat" "uncooperative with care," swallowing problems, falls
Language impairment (aphasia)	"Won't follow directions," can't follow conversation, word-finding problems, paraphasic errors/word substitutions
Perceptual problems (agnosia)	Doesn't recognize faces, gets lost easily, urinates in wastepaper baskets or other inappropriate places, wandering, frightened
Personality and behavior change	Apathetic, suspicious, irritable, labile, impulsive, new onset of sleep disorders (insomnia, daytime sleepiness, parasomnia)
Susceptible to delirium	Agitated when tired ("sundowning"), confused with mild infection, sensitivity to central nervous system-active medications, prolonged postoperative confusion

Adapted from Clinical Practice Guideline on Dementia, 1998, published by American Medical Directors' Association, Eric Tangelos, MD, CMD, Steering Committee Chair. Available at www.amda.org or by calling 1-800-876-2632.

intake.¹⁵ Staff can intervene to improve fluid intake in residents known to have dementia.¹⁶ Recognition of dementia can allow interventions that prevent elopement¹⁷ and that otherwise facilitate the safety of the resident. In general, failure to teach staff to recognize dementia, to provide them with the skills they need, and to support their efforts to provide appropriate care is a recipe for disaster in LTCFs.

DIAGNOSIS OF DEMENTIA IN LONG-TERM CARE FACILITIES

Deterioration in memory and cognitive function is the core clinical feature of dementia. For dementia to be diagnosed, the change in cognition must be severe enough to impair the patient's ability to function independently and must not represent a recent mental status change (ie, delirium) from an acute, reversible illness, or intoxication or withdrawal from medications, drugs, or alcohol.¹⁸ Although many diseases can cause dementia, Alzheimer's disease (AD) is the etiology in more the two thirds of cases of dementia in older adults. Patients will sometimes report the memory or cognitive impairment and prompt evaluation, but family or caregivers are often the source of the presenting complaint. In the LTC setting, nursing and caregiver staff typically will alert the physician or practitioner to the problem, although it can be missed until severe because of the decreased cognitive demands of life in LTCF. In one study, only 46.4% of nursing home residents with Mini-Mental State Examination (MMSE) scores below 15 (moderate to severe dementia) were recognized as having dementia by nursing staff.¹⁹ The problem of underdiagnosis can be even worse in residential care. In a study of 299 residents of Oregon assisted-living facilities, more than 60% had at least mild dementia but only 15% had a documented diagnosis.²⁰ Because of the importance of early recognition, clinicians need to be alert to the nonspecific signals of dementia in LTC residents. Table 1 provides examples of clues to dementia in these settings.

Most diseases that produce dementia are slow, gradual, and

insidious in onset, and questions directed toward the caregivers and family are necessary to understand the course of illness. A recent move to LTC, change in caregivers or roommates, or any disruption of routine can transiently affect cognitive function, and one needs to keep this in mind when gathering history. For patients with recent or mild impairment, a more detailed assessment of cognitive function will likely be necessary. However, there will be patients (particularly in a skilled nursing facility) in whom brief examination and history reveals that further assessment is unnecessary. In these patients, the dementia is advanced, has been progressing for several years, has already been adequately evaluated, or when, in the opinion of the clinician, further assessment or treatment will not change the comfort, management, or treatment plan of the resident.

Residents with obvious impairment can be easily assessed at the bedside or in the office with brief assessment of orientation, recall, and language function. A quick review of functional status for activities of daily living (ADLs) will assess praxis and executive function. When the dementia is less severe, one should use a validated cognitive testing instrument to both screen for and rate the severity of the dementia. Standardized assessment tools have dramatically improved the detection of dementia, particularly by nonspecialists. Table 2 provides brief descriptions of commonly used instruments. The most widely used of these instruments, the MMSE,²¹ has demonstrated sensitivity in detecting dementia in nursing home residents, although it could show false-positives, especially in residents with depression, low education levels, or in the oldest old.²² The MMSE also lacks sensitivity to certain nonmemory impairments that are typical in mild dementia or frontal lobe diseases such as problems with verbal fluency, problem solving, and judgment.²³ However, for most dementias in LTC residents, it is an adequate instrument for screening and rating severity of dementia.

The cognitive function items on the Minimum Data Set

Table 2. Commonly Used Cognitive Assessment Instruments

Instrument	Cognitive Domains	Scoring
MMSE ²¹	Orientation, word recall, attention, concentration, language, constructional praxis	30-point scale with scores <24 suggesting dementia and scores <12 indicating severe dementia
Information-Memory-Concentration Test ³⁶	Orientation, attention, concentration, recent and remote memory	33-point scale with lower scores indicating better performance
Dementia Rating Scale ²⁶	Attention, initiation and perseveration, memory, constructional praxis, conceptualization	144-point scale with higher scores indicating better performance, separate scores for each of the 5 subscales
Clock Drawing Test ^{37,38}	Brief assessment of visuospatial skills, constructional praxis, conceptualization, planning skills	Various scoring methods based on number of correct features of clock face, usually with higher scores indicating better performance
Alzheimer's disease assessment scale:cognitive ³⁹	Orientation, word recall and recognition, naming, follow commands, constructional praxis	70-point scale with lower scores indicating better performance

Adapted from Salmon DP, Lange KL. Cognitive screening and neuropsychological assessment in early Alzheimer's disease. In: Galasko D, ed. Clinics in Geriatric Medicine: Alzheimer's Disease and Dementia. 2001;17:229–254.

Plus Resident Assessment battery mandated by the 1987 Omnibus Budget Reconciliation Act (OBRA) for all nursing home residents in the United States at the time of admission (plus quarterly and with change in functional status) shows fair correlation with the MMSE).²⁴ Powell et al.²⁵ found that the MDS cognitive items also had fairly good internal consistency and validity, as well as correlation with the Mattis Dementia Rating Scale (MDS)²⁶ and Reisberg Global Deterioration Scale.²⁷ Cognitive assessment tools that are modified versions of the MDS evaluation cognitive items have been developed for clinical use and show somewhat better correlation with MMSE than standard MDS cognitive items.^{28–30}

Although the MDS is a reliable screening instrument, its validity relies on the skills of the nurse completing the scale. Nursing home staff can identify dementia based on a few impressions of behavior and speech that are nonspecific, and therefore can assume dementia in cognitively intact residents and miss dementia in those who are impaired.³¹ At this point in time, no standardized assessments are required in residential care facilities (RCF) and assisted living facilities (ALF) in most areas of the United States, although some individual facilities have assessment protocols in place that are overseen by nurse consultants and medical directors. However, physicians and nurse practitioners in LTC settings should conduct cognitive assessment themselves as routine parts of their assessments of new residents and at least every 6 months in long-term residents. We think it is reasonable to rely on the MMSE as a minimum screen for cognitive impairment in most LTC residents. Some patients, especially those with very subtle impairment or patients whose difficulties in non-memory domains of function such as language or executive function, should receive further evaluation by a dementia specialist (geriatrician, neurologist, geropsychiatrist, or neuropsychologist). See Table 2 for a summary of the commonly used cognitive-rating instruments.

Executive function is not well assessed by most cognitive

screening instruments.³² Executive functions are complex cognitive abilities that are served by the frontal lobes and are the basis of abstract thinking, decision-making, initiative, and impulse control. Assessment of executive function can be necessary to diagnosis early dementia without severe memory loss.^{32,33} Referral to neuropsychologists could be necessary to detect and characterize frontal lobe dysfunction, although bedside tests are emerging that can be administered by physicians, nurse practitioners, and others. For example, an evaluation of executive function using the Executive Interview (EXIT) can be done by most clinicians and can be a more effective way to identify the nonmemory-based cognitive impairments in LTCF residents than the MMSE.³⁴ Executive dysfunction early in the course of dementia will be apparent to some family members and caregivers through observations of impaired reasoning and decision-making. Interviews with family and caregivers, especially those with close contact, will also add significantly to the detection of mild dementia.³⁵

Once dementia is diagnosed, the clinician should attempt to determine the underlying cause. AD is present in at least two thirds of older patients with dementia. Standardized diagnostic criteria for AD (either NINCDS-ADRDA⁴⁰ or DSM-IVR criteria¹⁸) provide good sensitivity (average across 23 studies of 81%, range 49–100%) and specificity (average 70%, range across studies 47–100%) relative to neuropathologic “gold standard” diagnosis.⁴¹

Diagnostic criteria for vascular dementia (VAD) are less reliable, probably because cerebrovascular disease alone is responsible for only a minority of dementia cases, although it can contribute to a substantial degree of the dementia associated with AD⁴¹ (see the accompanying article by Quinn in this supplement). The diagnosis of VAD remains a clinical one, based on history, examination, neuroimaging studies, and risk factors. The Hachinski Ischemic Score, based on clinical history and examination, can help with the diagnosis.⁴²

Dementia with Lewy bodies (DLB) is characterized by

dementia, Parkinsonism, prominent visual hallucinations and delusions, sensitivity to typical antipsychotics and dopamine antagonists, and rapidly fluctuating alertness. However, when diagnostic criteria are applied in clinical studies, diagnostic sensitivity is low, although specificity tends to be high.⁴¹ That is, patients with other types of dementia can easily be misdiagnosed with DLB, because some of the features, such as parkinsonism and psychosis, occur in AD and VAD also, although with lower frequency.

Frontotemporal dementia is more likely to develop in late midlife (50s and 60s) rather than very old individuals. Despite the patients' lack of frailty, the disease still frequently leads to LTC placement because of the severe emotional and behavioral symptoms it causes. It can be difficult to distinguish from AD (see the article by Merrilees and Miller in this supplement).

Knopman et al. provide a concise summary and expert consensus recommendations for the diagnostic evaluation of dementia.⁴¹ The consensus of experts remains that patients newly diagnosed with dementia ought to receive a structural neuroimaging study such as noncontrast computed tomography or magnetic resonance imaging to rule out structural lesions and hydrocephalus. Quantitative imaging and functional imaging (single-photon emission computed tomography, positron emission tomography, functional magnetic resonance imaging) can be helpful in the differential diagnosis of dementia but are not warranted for routine diagnostic assessment. It is still not known whether the recommendations of Knopman et al.⁴¹ should be applied to assessment of dementia in LTCF residents who are very elderly with severe dementia that has been progressive over time and who have previously had an adequate diagnostic assessment. Most clinicians will be very conservative in their diagnostic assessments of these patients, preferring to limit assessment to physical and cognitive examinations with only a few routine laboratory studies unless there is something atypical about the patient such as a rapid decline in alertness, gait, or balance. The routine assessment for comorbid conditions contributing to dementia, and rarely as a primary cause of cognitive impairment, should be limited to depression, B12 deficiency, and hypothyroidism.⁴¹

The symptomatic overlap of depression and dementia make the clinical diagnoses of dementia and depression very challenging. The relationship of depression and dementia is reviewed by Peskin in this supplement. In long-term care, comorbidity with medical illness can also make the diagnosis of depression more difficult. The instrument most widely used to diagnose depression in demented patients, the Cornell Scale for Depression in Dementia, retains its validity in nursing homes,⁴³ but the authors note that some items were highly correlated with the comorbid illnesses and not necessarily related to the presence of depression. Unfortunately, the MDS has not proven sensitive for detecting depression in the nursing home.⁴⁴ LTCF staff often do not recognize depression in residents, and psychiatric evaluation is justified if there is any question of comorbid depression complicating dementia.⁴⁵

TREATMENT OF DEMENTIA IN LONG-TERM CARE FACILITIES

Cholinesterase inhibitors (ChE-I) have become the standard of practice for treating mild to moderate AD,⁴⁶ and there is an increasing body of evidence to justify treating patients with certain non-AD dementias (see the article by Gustavson and Cummings in this supplement). Given the evidence that these medications can either improve or forestall functional decline and delay nursing home placement,⁴⁷ their use should be encouraged in patients at home, as well as in RCF and ALF. A study of Oregon ALF found only 4% of residents on ChE-I, although more than 60% had at least mild dementia, indicating severe undertreatment of a population that can clearly benefit from treatment.²⁰ The situation in nursing homes is less clear. A majority of residents in skilled nursing facilities have moderate to severe dementia, and there are fewer data to guide ChE-I-prescribing for these patients. As investigators begin to focus on factors that could be relevant to LTC such as ADL function, behavioral symptoms, caregiver burden, quality of life, and resource utilization, we will better appreciate the role of these medications in the care of LTC residents with more severe dementia.⁴⁸ A placebo-controlled multinational study of community-residing patients and ALF with moderate to severe dementia (MMSE range 5–12) treated with donepezil found improved ADL function and reductions in caregiver stress measures in donepezil-treated subjects as compared with those receiving placebo.⁴⁹ This study also found impressive reductions in the amount of time caregivers spent in ADL care with patients, contributing significantly to reductions in caregiver stress.

There is also evidence that patients with moderate to severe AD in skilled nursing facilities benefit from cholinesterase inhibitors. In the only large-scale published study to date in an LTC population, 208 nursing home residents with AD or AD mixed with VAD randomized to donepezil or placebo, donepezil was well tolerated and superior to placebo in improving cognitive function and preservation of ADL measures, although the treatment effect was modest and the clinical significance of the findings is subject to debate.^{50–52} Another study that relied on retrospective analysis of health outcomes in a large cohort of nursing home residents over a 3-year period found lower mortality rates in tacrine-treated residents as compared with an untreated cohort matched for age, comorbid illness, and dementia severity.⁵³

Cholinesterase inhibitors can provide benefit for a longer period of time than we initially thought. There are open-label extension data for up to 240 weeks in patients taking donepezil that suggest treated patients are functioning better than projections based on historic controls.⁵⁴ LTCF residents taking cholinesterase inhibitors score higher on quality-of-life measures validated in dementia patients than untreated patients.⁵⁵ The results of these studies suggest that LTC residents with advanced dementia can tolerate and benefit from ChE-I, although the risk-benefit ratio might be different than community-residing patients, and further study is required before these medications are routinely used in LTC residents with advanced dementia.

Memantine, a glutamate/NMDA-receptor antagonist, has been shown to slow decline in cognitive and ADL function in a group of outpatients⁵⁶ and nursing home residents⁵⁷ with moderate to severe AD, suggesting this medication will have use in long-term care when it becomes available in this country.

Special dementia programming could allow increased reimbursement in the private sector, but, in the case of Medicaid-funded nursing home care, dementia does not produce any increase in reimbursement. The Medicare prospective payment system does provide increased reimbursement, but of course, this applies only to residents in short-stay rehabilitation units and not to the majority of dementia patients in long-term care. Aside from the financial challenges, facilities might not be able to find enough staff with adequate training and skills to benefit residents with dementia. Although there are financial barriers to special dementia programming in LTCF, facility design, social structures, and staff approaches can either enhance dementia residents' abilities to do things for themselves or add further to their dependency.⁵⁸ That is, "excess disability" can be imposed by environments that are overly complex, require too much choice and too little direction. Many nursing homes have sections specializing in dementia care that promote additional staff training and activities for cognitively impaired residents. These sections can be called "special care units," "memory care units," or simply, "Alzheimer's units."

Clinical studies of specialized designed environments, trained caregiver staff, and activity programs in special care units have demonstrated their ability to reduce psychotropic medications, agitation levels, physical restraint, and to improve participation in activities.^{46,59} Enhanced nursing home environments featuring enriched visual, auditory, and olfactory stimuli seemed to be preferred by residents with dementia, but such environments had little effect on specific target behaviors of agitation or pacing.⁶⁰ Family members and staff did have very positive reactions to these environmental enrichments, however, believing that the residents would appreciate the enhancements. Despite special care units, families are increasingly turning away from nursing homes for dementia care, preferring the nonnursing, more home-like environments of dementia specialized ALF and RCF.

Professional caregivers can find caring for dementia patients extremely stressful,⁶¹ a factor that can lead to professional dissatisfaction and job turnover. Daytime shifts of nursing assistants caring for dementia patients are at particularly high risk of experiencing stress.⁶² Training professional caregivers of dementia patients can improve their satisfaction with their work,⁶³ although not all interventions have proven to be beneficial.⁶⁴

An accompanying article by Masterman in this supplement reviews the treatment of neuropsychiatric symptoms of dementia in LTC. The article by Mills and Chow, also in this supplement, reviews all randomized, controlled pharmaceutical trials in LTCF.

END-OF-LIFE CARE

Most dementias are progressive illnesses that worsen until death. Decisions must be made when to limit care using a palliative emphasis rather than an aggressive one. Quality end-of-life care for residents with dementia is an appropriate goal for staff of LTCF.⁶⁵ When dementia is identified in an LTCF resident, staff can help facilitate resident and family decision-making, provide emotional support and education. As dementia progresses, the ability to communicate diminishes. Staff can be trained to use nonverbal cues to detect problems. Facial expression, for example, has been demonstrated to reproducibly and reliably indicate pain.⁶⁶ Only by identifying dementia in residents of LTCF, and providing appropriate training to staff, can optimal end-of-life care be provided.

SUMMARY

Detection and accurate diagnosis of cognitive impairment and dementia in LTCF remains deficient. Failure to recognize dementia can lead to failure to protect the patient from their own poor decision-making, and produce misunderstandings between residents and caregivers who are not aware of how dementia is influencing the resident's behavior. Failure to assess and document dementia and related problems can decrease reimbursement under the skilled nursing facility prospective payment system and lead to survey citations. Failure to accurately diagnosis dementia in LTCFs deprives the resident the advantages of early treatment and can increase the risk of medication errors, falls, delirium, and other dementia-related problems. Failure to prepare staff to provide necessary physical and emotional care will lead to unnecessary suffering of LTCF residents with dementia, from entry into the facility to end-of-life.

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