

Research Article

Palliative Care for Elderly with Dementia

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Abstract

Dementia is a progressive terminal illness for which there is currently no cure. The prognosis may range from 2 to more than 15 years, with the end-stage lasting as long as 2–3 years. Although the frequency of dementia in low- and middle-income countries is uncertain due to few studies and varying estimates, most people with dementia live there (60% in 2001, rising to 71% by 2040).

The care of older people with dementia is widely inadequate on the continuum from prevention to the end of life. At the end of life, this inadequacy has been summarized as: too much intervention with little benefit such as tube feeding or too little (poor pain control, dehydration and malnutrition). There are many reasons why people with dementia do not receive adequate palliative care, including health care professional's not perceiving people with dementia as having a terminal condition and difficulty in prognosis.

The number of symptoms is similar to that of people with cancer, but people with dementia experience them for longer. People with dementia have cognitive, functional and physical impairment, which gets progressively more severe, often over a prolonged period of time. The most frequent symptoms in the last year of life are cognitive impairment, urinary incontinence, pain, low mood, constipation and loss of appetite. Palliative care for people with dementia urgently needs to be improved. Approaches could include interventions for agitation, constipation and pain, which may improve the quality of life, decrease the number of unnecessary investigations and reduce costs.

Abbreviations: *Mild Cognitive Impairment (MCI); Alzheimer Disease (AD); St. Louis University Mental Status exam (SLUMS); Montreal Cognitive Assessment (MOCA); Motor Vehicle Administration (MVA)*

Introduction

Dementia is a group of symptoms related to impaired memory and thinking skills. People with dementia begin to forget things and can have problems with everyday tasks. There are different types of dementia. Dementia symptoms usually start slowly and get worse over time.

It is defined as a decline in two or more cognitive capacities, causing impairment in function but not alertness or attention. The decline in cognition distinguishes it from lifelong intellectual disability (previously called “mental retardation”) and single learning disorders, both of which are present from birth and symptomatic in childhood. That 2 or more cognitive capacities must be impaired distinguishes dementia from amnesic mild cognitive impairment (MCI), the amnesic syndrome (previously called the Korsakoff syndrome), and single focal brain lesions. Requiring impairment in functional activity also distinguishes it from MCI, although this interpretation is controversial. The requirement for intact attention and alertness distinguishes it from delirium. The *Diagnostic and Statistical Manual of Mental Disorders, version 5*, has recently proposed replacing the word “dementia” with the phrase “neurocognitive disorder” to destigmatize the syndrome. However, opponents point out that the term “neurocognitive disorder” lacks specificity because it includes other categories of cognitive impairment, such as intellectual disability, learning disabilities, and delirium [1].

Dementia is a syndrome rather than a specific illness; the most common types are Alzheimer disease (AD), vascular dementia, Lewy body dementia, and frontotemporal dementia. One or 2% of these patients presenting with dementia has a potentially reversible disorder, such as normal pressure hydrocephalus, medication-induced cognitive impairment, hypothyroidism, or major depression.

Although it can begin at any age after childhood, dementia is predominantly a syndrome of later life, with the prevalence in persons older than 65 years estimated to be 9%–13%. The annual incidence rate is 0.25% at age 65 and doubles every 5 years, reaching approximately 15% at age 95 [2].

Should clinicians screen for dementia?

Universal screening for dementia is not recommended [3], but the disorder is prevalent and often goes undetected in the primary care setting [4]. As a result, the clinician should consider dementia in the differential diagnosis of adult patients of any age with symptoms of memory difficulty interfering with daily function, unexplained functional decline, deterioration in hygiene, questionable adherence to medication regimens, or new-onset psychiatric symptoms. *In a study reviewing the primary care records of 297 patients, dementia in 65% of patients meeting the criteria was not noted on the patient's chart, including 20% of those with advanced dementia [4]. In a retrospective review of 1489 patients referred to a memory disorders program, those referred from a dementia screening program had a mean Mini-Mental Status Examination (MMSE) score of 20.8 ± 5.7 compared with those referred from their physicians (18.8 ± 6.6), from families (16.8 ± 6.6), or from other sources (15.3 ± 7.1) [4].*

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Evaluating patients with suspected dementia

Patient's History: Clinicians should use the patient's history to characterize the cognitive deficits, generate a differential diagnosis, and determine the cause of the dementia. This goal is best accomplished by identifying medical, neurologic, and psychiatric signs and symptoms that may be clues to the cause of the cognitive problems and establishing their order of appearance, severity, and associated features. In the case of cognitive difficulties, it is most important to try to obtain collateral information from a knowledgeable informant, because cognitive dysfunction can impair the patient's ability to report accurately. It is often easier to collect this information without the patient present.

In taking the history, the physician must be knowledgeable about the differential diagnosis and natural history of the most common types of dementia. Table 1 illustrates diagnostic criteria for different kinds of AD [5]. For example, in classic AD, early symptoms are dominated by difficulties with short-term memory, subtle language and visuospatial perceptual problems, and changes in executive function. Significant reductions in efficiency and organizational abilities that the patient may or may not recognize could also occur. Symptoms begin insidiously and are slowly progressive. The overall level of alertness remains unimpaired. Patients or families may not label these difficulties as memory problems but may instead report conversations when the patient has no recollection of previous discussions, increased forgetfulness that causes the patient to lose objects or become confused while shopping, or simply increased disorganization and decreased efficiency. Symptoms are often first noticed or reported at the time of a life change, such as the death of a spouse, a move into a new residence, or being in an unfamiliar place on vacation.

Clinicians evaluating a patient with a change in cognition or overall function must consider delirium. Delirium is characterized by cognitive impairment and an impaired level of alertness/attention/consciousness. In contrast to dementia, the onset of delirium is usually abrupt, and fluctuations over minutes or hours are prominent. Although some patients may be agitated and manifest psychotic symptoms, others are slow and drowsy and appear mildly depressed or withdrawn. Prompt diagnosis of delirium is critical because it usually reflects an underlying systemic condition, such as infection, metabolic derangement, medication effect, or cancer. Use of an instrument, such as the Confusion Assessment Method, increases identification of delirium in high-risk settings, such as the intensive care unit [6]. It is important to remember that many elderly patients report minor cognitive problems, such as mild forgetfulness, difficulty remembering names, and reduced concentration. These problems are typically sporadic, do not worsen significantly over time, are easily compensated for, do not affect function, and are often judged to be worse by the patient than by others. In contrast, early dementia insidiously becomes a pattern; worsens over time; is difficult to offset; eventually interferes with routine activities, such as bill paying and meal preparation; and is often judged to be worse by others than by the patient. Patients with memory problems should be screened for dementia, but a complete evaluation should be reserved for those with measurable impairment in memory or other aspects of cognition.

Physical, mental, and cognitive status of patients with suspected dementia: During the physical examination, the clinician should look for conditions that can cause or worsen cognitive symptoms, with an emphasis on vascular and neurologic disease. The examination should include a mental status evaluation that begins with an assessment of the patient's level of alertness, general appearance, and cooperation, which can provide clues to delirium, depression, or nutritional deficiencies. Speech should be evaluated for its content (grammatical or semantic errors) and form (rate, fluency, and volume); the patient's

Table 1: Diagnostic Criteria for Different Kinds of Alzheimer Disease (Adapted from [5]).

<p><i>Probable Alzheimer disease is defined by:</i> Dementia established by clinical examination and documented by an instrument, such as the MoCA, SLUMS or Mini-Mental Status Examination Deficits in 2 or more areas of cognition, one of which is usually memory Progressive decline No disturbance of consciousness Onset between age 40–90 years Absence of other disorders that could account for the deficits</p> <p><i>Possible Alzheimer disease is defined by:</i> Dementia established by clinical examination and documented by an instrument, such as the Mini-Mental Status Examination Absence of other conditions that would cause dementia Variations in the clinical course from the typical course of Alzheimer disease; when another condition is present that could cause dementia but is not felt to be the primary cause; or when there is a single, severe, progressive cognitive deficit without an identifiable cause</p> <p><i>Definite Alzheimer disease is defined by:</i> The presence of clinical criteria for probable Alzheimer disease combined with biopsy- or autopsy-confirmed histopathology</p> <p><i>The diagnosis of probable Alzheimer disease is supported by the presence of:</i> Specific cognitive deficits, such as executive dysfunction, aphasia, agnosia, and apraxia Impaired activities of daily living Positive family history Supportive laboratory tests, such as normal lumbar puncture, normal electroencephalography, and cerebral atrophy on neuroimaging</p> <p><i>The diagnosis of Alzheimer disease is unlikely when:</i> The onset is acute Focal neurologic findings are present Seizure or gait disturbance is present early in the disease course</p>

mood and affect should be assessed for depression, anxiety or mania, and the risk for suicide; and thought content and perception should be examined for delusions or hallucinations and obsessions or compulsions.

The cognitive examination should include a standard instrument, such as the SLUMS, which takes 5 minutes to administer, or the MOCA, which can take 10 minutes. Both tests have strengths and limitations. The MOCA emphasizes executive function and is more sensitive; the SLUMS evaluate orientation, immediate recall, concentration, naming, language function, praxis, and visual-spatial perception. Patients with cognitive difficulties less than 3 years in duration should have a neuroimaging study of the head using computed tomography or magnetic resonance imaging to exclude cerebrovascular disease, hemorrhage, tumor, abscess, and hydrocephalus.

What should clinicians advise patients and caregivers about general health and hygiene?

In the early stages of dementia, patients may have difficulty comprehending the details of their medical care, organizing care, and keeping track of appointments and medications. The clinician should be alert to these limitations and prepare a care plan that compensates for them. Later in the illness, patients may be unable to identify symptoms, such as constipation, dysuria, tooth pain, or diminished visual or auditory acuity, and the clinician should proactively look for these problems. It is important to attend to general medical and preventive care as conscientiously as in patients without dementia. A stroke or heart attack due to uncontrolled hypertension is likely to impair a patient's function and quality of life as much as the dementia itself, at least in the early and middle stages of the disease. Thus, caring for patients with dementia includes careful attention to basic general health practices, including good control of hypertension, diabetes, and cholesterol; antiplatelet therapy where appropriate; and vaccinations. For patients with more advanced dementia, it becomes increasingly important to pay attention to nutrition, skin care (particularly of the perineum), toileting schedules, and dental care.

Advise about safety issues, such as driving, cooking, and other activities that may require supervision?

Patients with progressive dementia ultimately lose the ability to drive, but predicting when an individual patient should stop driving is difficult, particularly if the restriction significantly burdens the patient or family members. Nonetheless, addressing the issue is imperative, as numerous studies have shown that driving ability becomes impaired in early stages of the disease. The patient should be asked about recent motor vehicle accidents, near misses, and changes in driving ability. These inquiries should be made in a setting that facilitates an open exchange of information and may necessitate meeting with an informant without the patient present. Patients with early dementia whose driving ability has already deteriorated should be instructed to stop driving immediately. Those with early dementia

who have no history of driving problems should undergo a driving evaluation through the local motor vehicle administration (MVA) or an occupational therapy program at a local hospital. If no impairment in driving is evident and the patient continues to drive, the history should be updated regularly to determine whether the capacity to drive has deteriorated. State laws differ in regard to reporting patients with a diagnosis of dementia to local MVAs, and the clinician should be familiar with the applicable regulations. The American Academy of Neurology Evidence-Based Practice Parameter outlines an approach to assessing driving in patients with dementia [7].

In a prospective, case-control study using the Washington University Road Test, which has an off-road and on-road component, only 3% of controls failed the test, 19% of patients with very mild AD failed, and 41% with mild AD failed (P < 0.001). Previous driving experience did not protect against failure [8].

Pharmacologic agents that help in treating specific types of dementia: The acetylcholinesterase inhibitor rivastigmine has been shown to be effective in improving cognitive performance in patients with mild to moderate Parkinson disease in doses similar to those used in AD, and it is believed that this benefit occurs with the other acetylcholinesterase inhibitors [9]. Several trials have also shown the benefits of acetylcholinesterase inhibitor treatment for cognition in dementia with Lewy bodies [10,11]. However, use of these drugs in patients with vascular dementia is not recommended. Vitamin E has been shown to have modest benefit on function but not cognition in 2 well-designed trials of patients with dementia, and concerns about increased mortality were not substantiated [12,13]. The nonsteroidal anti-inflammatory drugs, estrogen, and ergoid mesylates should not be prescribed for cognitive decline. Herbal supplement does not slow progression of dementia [14]. Also, Data on whether the widely used food supplements coconut oil and Axona can be recommended are inadequate. Nearly 1/3 of patients with dementia develop an episode of major depression after the onset of dementia [15], but evidence for the efficacy of antidepressant medications is mixed [16]. Clinicians therefore need to have a high index of suspicion for major depression.

Antipsychotic agent's treatment of behavioral disturbances or psychotic symptoms

Absent a significant risk for harm, psychotic symptoms, such as hallucinations, delusions, and agitated behavior, should first be treated nonpharmacologically [17] because all drugs in this class carry a risk for elevated mortality (1.6–2.0 in the subsequent 12–52 weeks) [18]. Pharmacotherapy is indicated if symptoms are causing significant distress for the patient or creating a dangerous situation. The second-generation antipsychotic agents are usually recommended instead of first-generation agents because of a lower risk for tardive dyskinesia. Overall, the efficacy of these agents is modest [19]. Although more evidence supports the use of risperidone and olanzapine, similar drugs also are used. These drugs should be prescribed at the lowest possible dose and for the shortest possible time. Ongoing use should be monitored regularly, and attempts should be made to decrease the dose and discontinue the drug within 3 months of starting. They should not be routinely used only for sleep due to toxicity (Table 2). Treatment with antipsychotic medications is associated with the metabolic syndrome, weight gain, hyperlipidemia, and diabetes mellitus. Recent evidence supports the effectiveness and relative safety of nonpharmacologic interventions for neuropsychiatric and behavioral symptoms [17], which reinforces the recommendations to use drugs sparingly for these symptoms.

Maximizing quality of life

Dementic patient issues that have the potential to significantly affect quality of life should be proactively addressed. Examples include the working order of sensory aids, such as glasses and hearing

Table 2: The Cognitive Agents for Dementia including Alzheimer Disease*

Agent	Mechanism of Action	Dosage	Benefits	Side Effects	Notes
Donepezil	Acetylcholinesterase inhibition	Begin 5 mg/d; if tolerated, increase to target dose of 10 mg/d after 1 month	Delayed symptom progression in mild, moderate, and advanced Alzheimer disease	Nausea, vomiting, diarrhea, anorexia, syncope	The higher end of the dosing range may be harder for patients to tolerate; dose higher than 10 mg not recommended
Galantamine	Acetylcholinesterase inhibition	Start 4 mg twice daily; target dose total 24 mg/d; increase by 4 mg twice daily every 1 month until in target range	Delayed symptom progression in mild, moderate, and advanced Alzheimer disease; improvement in caregiver-rated quality of life was observed	Nausea, vomiting, diarrhea, anorexia, syncope	Routine liver function testing is unnecessary; the higher end of the dosing range may be harder for patients to tolerate; begin extended-release (once daily) galantamine at 8 mg/d; increase by 8 mg/d every 1 month to the target dose of 24 mg/d; higher dose not recommended
Rivastigmine	Acetylcholinesterase inhibition	Start 1.5 mg twice daily; target range is 6–12 mg/d; increase by 1.5 mg twice daily every 1 month until in target range	Delayed symptom progression in mild, moderate, and advanced Alzheimer disease	Nausea, vomiting, diarrhea, anorexia, syncope	Higher end of the dose range may be less tolerable; also available as a transdermal patch
Memantine	NMDA-receptor antagonism	Begin 5 mg/d; increase by 5 mg/d every 1 month until target of 10 mg twice daily	Less functional decline, improved cognition, and reduced demands on caregivers in moderate-to-advanced Alzheimer disease	Dizziness, confusion, headache, constipation	Generic available; branded drug only available in sustained-release form; available in tablets or solution; avoid concomitant use with amantadine

*NMDA = N-methyl-D-aspartic acid.

aids; dental care; noise, lighting, and temperature; sufficient social and cognitive stimuli; cleanliness; pain levels; constipation; and sleep problems. Advance directives have the potential to benefit all patients. Since full incapacitation is inevitable for every person with progressive dementia who lives long enough to experience the full course of the disease, early advance directives maximize the likelihood that the person's wishes for end-of-life care will be carried out.

Consultation to other specialties

Clinicians should consider consulting a geriatric psychiatrist, neurologist, geriatrician, or dementia specialist in patients with atypical features of dementia, such as early onset, early non-cognitive neurologic symptoms, rapid progression, early personality changes, or unusual symptom patterns. Consulting a geriatric psychiatrist or dementia specialist should also be considered for evaluation or management of difficult-to-treat neuropsychiatric symptoms, such as depression, psychosis, or behavioral disturbances. These symptoms can create dangerous situations for the patient and others and reduce quality of life. Referral to a neuropsychologist may be necessary if it is unclear whether dementia is present and when in-depth documentation of impaired and preserved capacities would benefit the patient.

Treatment of dementia requires a broad clinical approach that ideally includes preventive medicine, psycho-education, behavioral therapy, safety evaluation, and pharmacotherapy. The clinician should expect to interact with a broad range of professionals, including occupational therapists, social workers, physical therapists, and speech and language pathologists, to provide optimal care.

How can we help families decide to move a patient with dementia into a long-term care facility?

As dementia progresses, moving to an environment that can adequately address the progressive needs of the patient with dementia is often necessary, either to an assisted-living facility or to a nursing home [20]. Some patients may need to move because of inadequate support at home. Generally, a move into a nursing home is prompted by development of physical and cognitive limitations that cannot be managed at home, such as the need for full assistance with transferring, ambulation, toileting, or feeding. Other patients have to move because of unmanageable psychiatric symptoms or high caregiver burden [21].

Families with ample financial resources may be able to provide many services at home that usually are provided in a facility. Periods of respite care may help families delay placement. Families should be supported and guided through the difficult and painful decision-making process. Families may be advised to proactively investigate facilities in their region so a good decision can be made quickly—for example, because of a sudden change in functional ability after a medical illness or accident. For end-of-life care, hospice criteria

for persons with dementia are specific to dementia. Therapy for pain, neuropsychiatric symptoms, and supportive medical care are paramount. Consider discontinuation of medications that have no short-term benefit, such as cholesterol-lowering agents [22,23].

What caregiver needs should be addressed by the clinician?

Caregiving for a patient with dementia is extremely taxing, both physically and emotionally, and inquiring about caregiver well-being is a critical component of dementia care. Common caregiver symptoms include guilt, anger, grief, fatigue, loneliness, demoralization, and depression. The patient's symptoms and the demands on the caregiver change over time, so the well-being of the caregiver must be assessed at every visit. Most caregivers benefit from a range of interventions [17] that focus on education about dementia, skills training, and the caregiver's own wellbeing. Many pamphlets, books, and educational Web sites are available. Patient and caregiver safety must be evaluated at each follow-up visit, and caregivers need to be informed about local respite programs and supported in long-term planning. Caregivers should also be informed of the potential benefits of psychoeducational and other support groups, which are available in most areas. Several large, well-conducted trials have shown that groups with a focus on problem-solving, communication, management of behavioral disturbances, and emotional support were effective in delaying nursing home placement for up to 1 year, diminishing caregiver and patient depression, and reducing patient agitation and anxiety [24,25].

Conclusion

- Dementia is a group of symptoms related to impaired memory and thinking skills.
- People with dementia begin to forget things and can have problems with everyday tasks.
- There are different types of dementia.
- Dementia symptoms usually start slowly and get worse over time.
- There is no one specific test for dementia. If a doctor thinks a patient may have dementia, symptoms and medical history should be reviewed.
- There are treatments that may help to manage different symptoms of dementia. These may help people with dementia think better and slow down the worsening of symptoms. Behavior changes can be treated in ways that promote comfort for the patient.

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