Challenges in Dementia Care

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The Alzheimer's Study Group released its report, "A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group," in March, stating that new cases of the disease, which strikes almost half of those over age 85, are projected to increase by more than 50% in 20 years and double again to as many as 16 million cases by 2050.

These alarming statistics point to the need for better care, adherence to treatment guidelines, recognition of quality indicators and measures to guide management of patients with dementia, and strategies and tools to improve compliance and medication adherence among dementia patients.

The following article is based on a presentation given by Eric G. Tangalos, MD, FACP, AGSF, CMD, at the Advancing Senior Healthcare Conference (ASH), held in Philadelphia, PA, in the fall of 2008. Dr. Tangalos also served as the American Geriatrics Society official member to the Alzheimer's Study Group.

Definitions of Dementia

Webster's Third New International Dictionary defines dementia as "A condition of deteriorated mentality that is characterized by marked decline from the individual's former intellectual level and often by emotional apathy."[1] However, that definition does not go far enough to define the disease in diagnostic terms.

The fourth edition of *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) criteria provide health care practitioners with parameters to accurately diagnose dementia. First, there must be documented evidence of[2]:

- Previously normal intellectual and social function
- Progressive decline in intellectual, cognitive, or social function that is not reversible with medical or psychiatric treatment
- Memory impairment
- Decline sufficiently important to impair age-, education-, or occupation-appropriate lifestyle adjustment

In addition, at least 2 of following signs must be present:

- Disorientation
- Personality/behavioral problems
- Dyscalculia
- Aphasia or apraxia or agnosia
- Impairment of judgment or abstract thinking

In all definitions of disease, Dr. Tangalos stressed that memory and problem solving are not only the hallmarks of disease recognition, but that in combination they create the greatest challenges to both patient and caregiver alike.

Stages of Alzheimer's Disease

Alzheimer's disease (AD), a type of dementia, is staged according to deficiencies in three domains: cognition, function, and behavior, and the typical presentation of the disease is along this continuum (Table 1).[3] Treatment guidelines and use of pharmacologic agents differ according to the stage of dementia. The evidence for drug intervention is strongest in the domain of cognition (early disease), while the evidence is still emerging in behavioral intervention (generally late-stage disease). Nondrug or environmental interventions can be started early and continued throughout the course of disease progression.

Guidelines for the Treatment of Dementia

Guidelines for the treatment of patients with dementia have been created by a variety of organizations, including:

- Agency for Healthcare Policy and Research (AHCPR)
- American Medical Directors Association (AMDA)
- American Psychiatric Association (APA)
- American Academy of Neurology (AAN)
- American Geriatrics Society (AGS)
- American Academy of Family

Physicians (AAFP)
- The Expert Consensus Guideline Series
- Alzheimer's Association Campaign for Quality

The objectives of the AMDA guidelines are to[4]:
- Improve quality of care delivered to patients in long-term care (LTC) facilities
- Provide LTC facilities with a systematic approach for assessing and managing patients with dementia, including problems directly and indirectly related to impaired behavior and cognition

These guidelines are applicable not just to LTC facilities, but to all practitioners who care for patients with dementia.

In Step 10 of its treatment guidelines for patients with dementia, AMDA[4] recommends optimizing the function and quality of life of patients with dementia and capitalizing on their remaining strengths. Suggested treatments include:
- Consider using complementary and alternative therapies to improve quality of life.
- Prevent excess disability by looking for unrecognized or inadequately treated medical conditions; adverse medication effects; or emotional, psychological, and environmental factors that may be causing more functional disability than could be attributed to the disease itself.
- Consider medical interventions, if appropriate, to prevent worsening of multi-infarct dementia and to reduce the rate of decline (cholinesterase inhibitors). Memantine is used to treat moderate to severe Alzheimer's dementia and can be combined with cholinesterase inhibitors. Behavioral symptoms related to an acute condition may benefit from other appropriate medications.
- Before initiating drugs, ensure that the patient is appropriately assessed.
- Discuss the goals of therapy with the patient and responsible party.
- Set realistic expectations.
- Monitor closely for adverse drug reactions (ADRs).
- Observe for symptom progression.
- Periodically assess the patient's response to treatment.

Table 1. Stage of Alzheimer's Disease

	Mild	Moderate	Severe
Activities of Daily Living (ADLs)	Problems with complex tasks	Needs help with more basic ADLs (eg, feeding, proper dress for weather, toileting)	Progresses to total dependence on caregiver (eg, feeding, toileting)
Behavior	Decreased time with hobbies, social withdrawal	Changes in personality; anxiety, suspicion, pacing, insomnia, agitation, wandering	Crying, screaming, groaning
Cognition	Short-term memory loss, eg: –Misplacing objects –Forgetting names –Disorientation	Confusion, difficulty recognizing family and friends (moderate to severe)	Loss of speech Inability to recognize familiar people

In its 2001 evidence-based review of management of dementia, the AAN's Quality Standards Subcommittee[5] recommended the following steps for the management of dementia:
- Treat cognitive symptoms of AD with cholinesterase inhibitors and vitamin E in mild to moderate AD patients.
- Treat agitation, psychosis, and depression.
- Encourage caregivers to participate in caregiver educational programs and support groups.

The AAN also assessed strategies to improve functional performance and reduce problem behaviors and ranked them according to strength of evidence (Table 2).[5] Expect the AAN to reassess the data and release a new set of expectations in another 2 years.

The AGS's Clinical Practice Guideline—Management of Dementia (AGS Web site) are focused on[6]:
- *Early Detection:* Determine whether screening for mild cognitive impairment (MCI) in general and specialty practice would be beneficial in detecting dementia.
- *Diagnosis:* Update 1994 practice parameters for diagnosis of dementia.
- *Management:* Define and investigate key issues in the management of dementia.

The AAN guidelines currently recommend a treatment trial with a cholinesterase inhibitor for patients with mild to moderate dementia (Grade 2A) in appropriate individuals.[5] Donepezil has FDA approval to

be used in mild, moderate, and severe disease. The choice between donepezil, rivastigmine, and galantamine can be based on cost, individual patient tolerance, and physician experience. The efficacy appears to be similar although all three drugs in the highest doses recommended produce the best benefit if tolerated. Cholinesterase inhibitors in patients with dementia produce, on average, small improvements in measures of cognition and activities of daily living (ADLs). Not all patients respond to these symptomatic therapies, and families need to be advised about this so their expectations are not unrealistic. The impact of these medications on long-term outcomes, disabilities, and institutionalization has produced mixed results.[5]

Nihilism in the diagnosis, treatment, and management of AD and related dementias is unwarranted, impairs quality of care, and is ultimately not cost effective.

Although most studies of cholinesterase inhibitors have been in patients with AD, there is some evidence of benefit for patients with vascular dementia, mixed dementia, dementia with Lewy bodies, and dementia in Parkinson's disease. Because of overlap syndrome, it is generally suggested that a treatment trial of a cholinesterase inhibitors in these patients should be initiated.[5] One cholinesterase inhibitor, rivastigmine, even has FDA approval for use in the dementia of Parkinson's disease. Table 3 lists medications approved for use in AD.

Patients with dementia may also benefit from memantine, alone or preferably in combination with a cholinesterase inhibitor, for moderate and severe disease. In patients with severe dementia, cholinesterase inhibitors can be discontinued, but they should be restarted if the patient worsens without the medication (AAN Grade 2C).[5]

Revised treatment guidelines should address newer medications and more recent outcomes considerations, as well as provide guidance on how long to continue and when to discontinue pharmacotherapy for AD.[7]

The recommendations of the expert panel represent a clear consensus that nihilism in the diagnosis, treatment, and management of AD and related dementias is unwarranted, impairs quality of care, and is ultimately not cost effective.[8]

Table 2. Strategies to Improve Functional Performance

Strategies to Improve Functional Performance	Strength of Evidence
Behavior modification, scheduled toileting, prompting voiding to reduce urinary incontinence	Strong
Graded assistance, practice, and positive reinforcement to increase functional independence	Good
Low lighting levels, music, and simulated nature sounds to improve eating behaviors	Weak
Intensive multi-modality group training may improve activities of daily living	Weak
Strategies to Reduce Problem Behaviors	**Strength of Evidence**
Music, particularly during meals and bathing	Good
Walking or other forms of light exercise	Good
Simulated presence therapy, such as use of videotapes of family	Weak
Massage	Weak
Comprehensive psychosocial care programs	Weak
Pet therapy	Weak
Utilizing commands issued at the patient's comprehension level	Weak
Bright light, white noise	Weak

Practice Points From Dementia Guidelines

Guideline-based dementia care leads to improvements in care. Tips to help improve your ability to care for patients with dementia include[8,9]:

Table 3. FDA-Approved Medications for Alzheimer's Disease

	Donepezil	Rivastigmine	Galantamine	Memantine
Characteristic Approved for	Mild to severe	Mild to moderate	Moderate	Moderate to severe
Dosage available	5 mg, 10 mg	1.5 mg, 3 mg, 4.5 mg, 6 mg; 2-mg/mL oral solution; patch 4.6 mg, 9.5mg	4 mg, 8 mg, 12 mg; 4-mg/mL oral solution	5 mg, 10 mg; 2-mg/mL oral solution
Doses per day	1	2	1 (ER) 2 (RR)	2
Initial dose (mg/d)	5	3	8	5
Dose escalation	4-6 wk	2 wk	4 wk	1 wk
Clinically effective dose (mg/d)	5-10	6-12	16-24	20

Physicians' Desk Reference. 59th ed. Montvale, NJ: Thomson PDR; 2005. Drugs@FDA. Available at: www.accessdata.fda.gov/scripts/cder/drugsatfda. Accessed July 11, 2007.

- Accumulate information during multiple visits.
- Early detection is critical for optimal outcomes:
  - Daily function (eg, basic ADLs, ability to manage finances and medications)
  - Cognitive status (using reliable and valid instruments)
  - Other medical conditions
  - Behavioral problems, psychotic symptoms, depression
  - Reassess every 6 months
- Identify the primary caregiver and the family support system.
- Assess culture, values, primary language, and decision-making process of the patient and family.
- Prescribe treatment according to the stage at the time of diagnosis:
  - Mild (cholinesterase inhibitors)
  - Moderate (combination of cholinesterase inhibitors and memantine)
  - Severe (donepezil, memantine, or combination)
- Develop and implement an ongoing treatment plan:
  - Referral for structured activities
  - Treatment of comorbid medical conditions
- Patient and caregiver education and support:
  - Realistic expectations: stabilization, slower decline
  - Referral to available resources
- Safety: switching medications, psychotropic use

Patient-centered Care

Numerous guidelines and recommendations focus on quality of life and preservation of function. Most notable is the Alzheimer's Association Campaign for Quality, which emphasizes the importance of environment in providing quality care.

Basics of Creating a Good Life for Persons with Dementia

Underlying Elements[10]

- Persons with dementia are able to experience joy, comfort, meaning, and growth in their lives.
- For persons with dementia in assisted living and nursing homes, quality of life depends on the quality of the relationships they have with the direct care staff.
- Optimal care occurs within a social environment that supports the development of healthy relationships between staff, family, and residents.
- Good dementia care involves assessment of residents' abilities; care plans and provision; strategies for addressing behavioral and communication changes; appropriate staffing patterns; and an assisted living or nursing home environment that fosters community.
- Each person with dementia is unique, having a different constellation of abilities and need for support, which changes over time as the disease progresses.
- Determining how best to serve each resident involves knowing as much as possible about each resident's life story, preferences, and abilities.
- Good dementia care involves using information about a resident to develop "person-centered" strategies, which are designed to ensure that services are tailored to each individual's circumstances.

Process Indicators for Dementia

The Minimum Data Set (MDS) gives us opportunity to evaluate our dementia patients.

- Is there evidence of evaluation among the domains of cognitive, functional, and behavioral, as appropriate? Can we identify:
  - Evidence of an interdisciplinary care plan to optimize function and quality of life of residents?
  - Evidence that a care plan has been implemented?
  - Evidence that the care plan has been updated and reevaluated?
- This can further be reported as:
  - Subtotal per case
  - Mean percent for all 4 indicators per facility

Outcome Indicators for Dementia

One can also use the nursing home survey data to evaluate dementia care. Within the MDS are items that show up in most clinical practice guidelines:

- Unpleasant mood
- Insomnia
- Change in mood
- Resistance to care
- Change in behavioral symptoms
- Function

Centers for Medicare and Medicaid Services "F-Tags"

There is detailed scoring that can be applied generally or specifically to the dementia care a resident is receiving in a skilled care facility. Any one or more of these F-tags may apply:

- *F154:* Fully informed about care and treatment that may affect resident.
- *F157:* Notification of changes: Did the facility document the resident's change in mental capacity when the medications were discontinued? Did they notify the family?
- *F222:* The resident has the right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms.
- *F 241:* Dignity: The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition.
- *F 250:* The facility must provide medically related social services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.
- *F272:* The facility must conduct initially and periodically a comprehensive, accurate, standardized, and reproducible assessment of each resident's functional capacity.
- *F274:* Within 14 days after the facility determines, or should have determined, that there has been a significant change in the resident's physical or mental condition , an assessment is performed.
- *F 278:* The assessment must accurately reflect the resident's status.
- *F279:* The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident's medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment.
- *F 280:* Unless adjudged incompetent or otherwise found to be incapacitated under the laws of the State, participate in planning care and treatments or changes in care and treatment.
- *F282:* Be provided by qualified persons in accordance with each resident's written plan of care.
- *F309:* Each resident must receive and the facility must provide the necessary care and service to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.
- *F310:* A resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrates that diminution was unavoidable.
- *F311:* A resident is given the appropriate treatment and services to maintain or improve his or her abilities.
- *F319:* A resident who displays mental or psychosocial adjustment difficulty, receives appropriate treatment and services to correct the assessed problem.
- *F323:* The resident environment remains as free of accident hazards as is possible.
- *F324:* Each resident receives adequate supervision and assistance devices to prevent accidents.
- *F329:* Each resident's drug regimen must be free from unnecessary drugs.
- *F331:* Residents who use antipsychotic drugs receive gradual dose reductions and behavioral inter-

Good dementia care involves using information about a resident to develop "person-centered" strategies.

ventions, unless clinically contraindicated, in an effort to discontinue these drugs.

- *F353:* Sufficient staffing is available to prevent accidents.
- *F386:* The physician must review the resident's total program of care, including medications and treatments, at each visit.
- *F426:* A facility must provide pharmaceutical services (including procedures that assure the accurate acquiring, receiving, dispensing, and administering of all drugs and biological) to meet the needs of each resident.
- *F429:* The pharmacist must report any irregularities to the attending physician and director of nursing.
- *F454:* The facility must be designed, constructed, equipped, and maintained to protect the health and safety of residents, personnel, and the public.
- *F490:* A facility must be administered in a manner that enables it to use its resources effectively and efficiently to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.

Defining the External Environment

Our goal as health care providers is to create a therapeutic environment in which "a person can function with MINIMAL failure and MAXIMAL use of retained abilities." In considering the environment of care, Rader[11] in 1995 defined three domains. Interventions along these lines provide residents a better opportunity to succeed in their environment with minimal frustrations and greater opportunity to use retained abilities:

1. Physical Personalization

- Noise level
- Lighting
- Floor covering
- Furniture
- Seating and mobility devices
- Wayfinding cues
- Activity or stimulation level
- Space for privacy and socialization
- Safety and security

2. Organizational

- Philosophy
- Policies and procedures
- Staffing patterns
- Structure of the day
- Staff support and education
- Equipment and supplies

3. Psychosocial

- Communication skills
- Staff attitudes
- Types of relationships with residents
- Approaches
- Activities
- Home-like atmosphere
- Family support and education
- Counseling and consultation services

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Nonpharmacologic Interventions

Most behavioral symptoms result from cognitive and functional impairments associated with dementia[12]:

- Unmet psychosocial needs
- Sensory deprivation, boredom, loneliness
- Loss of learned behavior and consequences
- Progressively lowered stress threshold
- Loss of coping abilities, greater vulnerability to the environment

Unrecognized pain may be a stressor and underlying cause of behavioral symptoms. Nonpharmacologic interventions address the underlying deterioration of a patient's former level of intellectual function.

Nonpharmacologic interventions are effective adjuncts to psychopharmacologic therapies and may be used for most behaviors associated with dementia. As physicians, we need to help caregivers understand that behaviors are unintentional. Urge caregivers to try approaches that were helpful in the past; identify and avoid triggers; examine the antecedent, the behavior itself, and its consequences (ABCs); and repeat, reassure, and redirect (the three Rs) to modify patient behavior.[9,13]

Behavior approaches include the following[9,13]:

- Avoid confrontation.
- Use distraction and redirection of attention to divert the patient from problematic situations.
- Validation therapy: respond to the "emotion" rather than the "content."
- Simplify all tasks.

Provider Action

Impact to You

The numbers of Alzheimer's cases are projected to increase by more than 50% in 20 years and double again to as many as 16 million cases by 2050.

What You Need to Know

Good dementia care involves assessment of residents' abilities; care plans and provision; strategies for addressing behavioral and communication changes; appropriate staffing patterns; and an assisted living or nursing home environment that fosters community. Each person with dementia is unique, having a different constellation of abilities and need for support, which changes over time as the disease progresses.

What You Need to Do

Accumulate information during multiple visits. Identify the primary caregiver and the family support system. Assess culture, values, primary language, and the decision-making process of the patient and family. Prescribe treatment according to the stage at the time of diagnosis. Develop and implement an ongoing treatment plan.

- Ask closed-ended instead of open-ended questions.
- Consistency: provide the patient with a predictable routine and toileting regimen.
- Provide meaningful activities and exercise.

An environmental approach is to[9]:

- Encourage the patient's independence in ADLs.
- Reduce environmental nuisances.
- Provide a safe, bright environment with clear directions.
- Equip doors and gates with safety locks.
- Register the patient for "Safe Return" programs.
- Use calendars, clocks, labels, and newspapers for orientation to time or place.
- Use color-coded or graphic labels as cues for orientation in the home environment.
- Consider a transition of care as the disease progresses.

Nonpharmacologic interventions that have proven to be effective include:

- Music therapy (best data so far)[14]
  - Personalized music
  - Reduces agitation, aggression, wandering, and irritability
- Reminiscence therapy[15]
  - Involves recounting pleasurable experiences
  - Improvement in mood and general behavior
  - Reduction in caregiver distress
- Multisensory stimulation[16]:
  - Improvement in spontaneity, initiative, attentiveness, happiness, and alertness
- Bright light therapy[17]
  - No conclusive results so far
  - Some benefit of bright light during breakfast in reducing agitated behavior
- Simulated presence therapy
  - Audio or video tape of family members
  - Small sample sizes—some benefit in reducing agitation
- Pet therapy[18]
  - Small randomized controlled trials reported reduction in agitation and aggression and increase in socialization
  - Increasing emphasis on robotic pets

MPM

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