Case Management: the Patient with Dementia

What We Know

Dementia is a progressive, degenerative, neurologic disorder characterized by loss of cognitive function, changes in mood and behavior, and functional decline. Symptoms are typically irreversible. Dementia is not part of the normal aging process.\(^{(1,6,9,11,16)}\)

- Alzheimer’s disease (AD) accounts for 60–80% of cases of dementia. Other causes of dementia include cerebrovascular disease (causes vascular dementia), Lewy body disease, frontotemporal degeneration, Pick’s disease, Parkinson disease, Creutzfeldt-Jakob disease, Huntington disease, brain tumors, chronic alcohol abuse, multiple sclerosis, drug and other toxic exposures, and infections of brain structures (e.g., syphilis, HIV infection/AIDS, encephalitis). Symptoms of stroke, hypoxia, hydrocephalus, metabolic disturbances, head injury, and nutritional deficiencies can manifest as dementia but are causes of cognitive impairment unrelated to dementia etiology.\(^{(1,3,11,16)}\)

- Dementia is a public health issue that affects about 50 million individuals worldwide.\(^{(16)}\) An estimated 5.7 million persons in the United States have AD. Of these patients, 5.5 million are 65 years of age and older and approximately 200,000 are under 65 years of age. Nearly two-thirds of persons with AD are female.\(^{(1)}\)

- Because of the increasing number of older adults in the population (i.e., people aged 65 years and older) and particularly the increasing number of the oldest-old (i.e., those aged 85 years and older), by 2050, the annual increase in new cases of AD and other dementias in the U.S. is projected to more than double.\(^{(1)}\)

- Number of persons in the U.S. aged 65 years or older with AD is expected to reach 13.8 million.\(^{(1)}\)

- Worldwide prevalence of dementia is expected to increase to 152 million.\(^{(16)}\)

- Although older age is the most important risk factor for dementia, dementia is not an inevitable consequence of aging. Additional risk factors include genetic factors, depression, low educational attainment, cognitive inactivity, and social isolation.\(^{(1,16)}\)

- Protective factors include regular exercise, avoiding tobacco and harmful use of alcohol, weight control, eating a nutritious diet, and maintaining healthy blood pressure, cholesterol, and blood glucose levels.\(^{(1,16)}\)

- Short-term memory loss is usually the first clinical sign of dementia. Other early signs of dementia include word-finding difficulty progressing to aphasia, difficulty performing familiar tasks, personality changes, uncharacteristic behavior, mood swings, poor judgment, confusion, and disorientation.\(^{(3,11)}\)

- As dementia progresses, the patient experiences worsening of preexisting symptoms, inability to perform ADLs, disrupted sleep, inability to learn new information, hallucinations, delusions (including delusions of persecution), confabulation, inattention, poor concentration, wandering, and lack of interest in the outside world. Patients with severe dementia become immobile, unable to recognize themselves or others, and completely dependent on others for ADLs.\(^{(11)}\)
Treatment for dementia is limited to temporarily relieving symptoms. Currently, there is no cure and no way to slow the progression of the disease. Therapy can involve the following:\(^{(1,4-6,11)}\)

- **Pharmacotherapy**
  - The primary class of medication are cholinesterase (AChE) inhibitors (donepezil, rivastigmine, galantamine) that work to relieve cholinesterase deficiency, a chemical messenger involved in memory and judgement
  - An N-Methyl-D-Aspartate antagonist (NMDA), memantine, has been approved by the U.S. Food and Drug Association for use alone or in combination with AChE inhibitors
  - Antidepressants are prescribed for patients with comorbid depression and psychotropic medications when behavioral modification therapy fails
- **Behavioral modification therapy to manage dementia-related behaviors\(^{(11)}\)**
- **Computerized memory training\(^{(1)}\)**
- **Cognitive stimulation\(^{(1)}\)**
- **Caregiver intervention programs\(^{(6)}\)**
  - All caregivers of patients with dementia should receive comprehensive training on effective patient care interventions to manage dementia
- **Residential support (e.g., in-home care)\(^{(1-6)}\)**
- **Diet.** There is no special nutritional therapy for dementia; however, brain-imaging scans of older adults and persons with dementia demonstrate a significantly decreased uptake of glucose. Therefore, the prescription medical food caprylidene can be prescribed. Caprylidene is metabolized into ketone bodies that is readily used by the brain with glucose uptake is impaired\(^{(3)}\)
  - Structured routines and physical activity have been shown to decrease patient stress while maintaining cognitive functioning

The World Health Organization published a global action plan in response to dementia, which presented seven action areas with target goals to be met by 2025 to reduce the disability and dependency of dementia worldwide, including:\(^{(15)}\)

- Establish dementia care as a public health policy
- Improve education about dementia to reduce stigmatization and discrimination
- Reduce dementia risk by educating about life-style factors
- Organize and develop health and social care for dementia patients that integrates dementia treatment into primary care
- Provide support (evidence-based information, training programs, respite services, and resources) for caregivers
- Improve epidemiology data collection regarding dementia
- Increase funding for dementia research and innovation

The manifestations of dementia are often emotionally and financially devastating for patients, their family members, and other caregivers. Management is challenging for healthcare clinicians and caregivers both in the home-care setting and in long-term care facilities\(^{(1,2,3,4,11)}\)

- More than 16 million family members and other unpaid caregivers provided an estimated 18.6 billion hours of care valued at nearly $244 billion to persons with AD and other dementias in 2019\(^{(1)}\)
  - An estimated 86% of dementia caregivers have provided care for at least the past year and 57% have provided care for at least 4 years\(^{(1)}\)
- Dementia caregiving tasks are many and include
  - helping with ADLs, including assisting with bathing, dressing, grooming, toileting, and managing incontinence; performing household chores; providing transportation; arranging for doctor’s appointments; and managing finances and legal affairs\(^{(1)}\)
  - helping the patient take his or her medications correctly\(^{(1)}\)
  - managing behavioral symptoms, including aggressive behavior, wandering, depressed mood, anxiety, and agitation\(^{(1)}\)
  - finding and using support services\(^{(1)}\)
  - arranging for paid in-home, nursing home, or assisted living care\(^{(1)}\)
  - hiring and supervising paid caregivers\(^{(1)}\)
  - managing other health conditions (e.g., cancer, diabetes mellitus), if present\(^{(1)}\)
  - providing emotional support\(^{(1)}\)
• Dementia caregivers should be supported and offered education and training to allow them to develop the skills necessary to care for their family member with dementia. They should also be provided with information about coping strategies to maintain their own physical and psychological well-being.(6,11)

Case management (CM) is “a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost-effective outcomes”(12)

• CM programs provide assessment, information, planning, referral, care coordination, and/or advocacy for family caregivers.(1,6)

• CM is commonly used for organizing and coordinating patient-centered care with the goal of promoting long-term, in-home care for patients with dementia as an alternative to early admission to long-term care, while improving the mental health of family caregivers.(1,6,10)

• Although methodologically rigorous clinical trials on dementia care management are lacking, successful dementia care in-home programs are based on models of collaborative approach to care that include the following components:(1,2,5,8,13,14)
  • Discussions should be scheduled with the patient and/or caregivers regarding financial costs of the provision of in-home care; a financial advisor can be included to educate on the financial effects of care.(1)
    – Factors to consider include whether full-time care, part-time care, short-term stays, adult day care programs, and/or respite care are desired and appropriate
    – Establishing time intervals for reevaluation of financial assets is recommended
  • Advance directives and power of attorney should be discussed and formally established.(2)
  • Individualized patient care needs are identified and computer-assisted assessment is used to determine a personalized array of intervention modules.(13)
    – Case managers should revise the CM care plan in collaboration with the patient and caregivers, as necessary
  • Task delegation with specific instructions and definitions should be provided to caregivers.(13)
  • Environmental adjustments should be made to the home to promote patient safety and reduce risk of injury (e.g., keeping lights on at night, maintaining simple activity schedule, using reminders, lists, notes).(2)
  • High-quality personal care assistance should be provided to preserve the patient’s dignity and comfort; caregivers are often educated to allow the patient to set the pace and provide brief and simple cues for patient guidance. Specific interventions include:(2)
    – Frequent orientation to time, person, place, circumstances, time, date, and reality and use of familiar objects to support orientation (e.g., clock, calendar, daily schedule)
    – Use of positive feedback to support patient’s appropriate thinking and behavior
    – Communicate with simple explanations and face-to-face interaction. Speak slowly and do not shout in patient’s ear
    – Discourage patient’s suspicions of others, express reasonable doubt and impact of personal negative effects of such thoughts when client voices delusional thoughts about others
    – Distract patient from discussing non-reality based thinking; focus on real people and events
    – Monitor client safety for indications of delusional thinking revealing intention for violence
  • Medication management should be managed by an interdisciplinary conference with a primary care provider, psychologist, neurologist/psychiatrist and registered nurse (RN) case manager; written and verbal instructions, including information on potential adverse effects, should be given to caregivers.(8,13)
    – The goal of medication management is to use the least amount of medication to achieve the maximum patient benefit
  • Physical exercise should be performed to promote health and maintain strength and stamina, and can help prevent wandering.(5)
  • Adequate nutrition and hydration promote satisfactory caloric intake and hydration; meal planning should include patient input as much as possible (for more information, see Quick Lesson About ... Dementia and Nutrition)
    – Oral intake and weight should be monitored and documented regularly
  • Receiving necessary healthcare services is important to maintain optimal health and includes arranging transportation to medical appointments; the case manager can accompany the patient to appointments and should communicate regularly with healthcare providers.(13)
  • Behavioral interventions should be performed to address signs and symptoms of dementia.(8,13)
Caregivers should be educated in effective and therapeutic communication strategies and adjustment of environmental factors to promote patient safety (for more information, see Evidence-Based Care Sheet: Dementia: Communication). An individualized regimen for giving prescribed psychotropic and other medications should be established.

- Caregivers should be educated about what information and documentation is necessary for the case manager to be able to evaluate the patient and to identify subtle changes in patient status and function, maintain continuity of care, and evaluate outcomes on subsequent visits. 

- Although the majority of patients prefer to remain in their homes, homecare is complex and extremely costly. Currently, the Agency for Healthcare Research and Quality is researching the most effective care interventions for people with dementia.

Evidence regarding the effectiveness of CM for patients with dementia and their family members is mixed. A systematic review of high intensity CM programs focused on patients with dementia report significant benefits to caregivers and patients.

The authors of a systematic review of studies of the effectiveness of support workers (e.g., case managers, care workers, counseling support workers) on persons with dementia found too much heterogeneity among studies to draw overall conclusions. They were able to identify the following shared components of support worker models that demonstrated a positive effect on caregiver burden and improved QOL: long-term intervention, face-to-face contact, individualized education and support, use of multidisciplinary teams, collaborative input, health/clinical background of support workers, ongoing follow-up, and interprofessional collaborations.

The authors of a systematic review evaluated 54 studies and found evidence that family physician-case manager collaboration can address the needs of the patient-caregiver dyad. They found that some needs (e.g., education on the disease) are well addressed, while others (e.g., early diagnosis, legal issues, financial issues) are often overlooked. The authors of a meta-analysis pooled data from 16 randomized controlled trials with 10,372 participants. They found that community-based care coordinating interventions resulted in significant improvements in both patient behavior (measured using the Neuropsychiatric Inventory) and caregiver burden. Nurse case managers had a more dramatic positive effect on caregiver QOL than case managers from other professional backgrounds.

What We Can Do

- Become knowledgeable about CM for patients with dementia so you can accurately assess your patients’ personal characteristics and health education needs; share this information with your colleagues
- Collaborate with multidisciplinary care teams in your facility according to facility protocols to identify, diagnose, treat, and provide CM for persons with dementia
- Assist patients with dementia and their caregivers with creating an in-home CM program, as appropriate
- Provide emotional support to caregivers of persons with dementia and refer them to the National Alliance for Caregiving; for more information, see https://www.caregiving.org/

References


