

Chapter 1

Dementia and Chronic Disease in the Elderly



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Main Points

- As dementia progresses, many older adults require assistance performing activities of daily living and instrumental activities of daily living. Assistance from formal and informal caregivers is instrumental in helping the patient manage their health as independently as possible for the longest possible time.
- Many older adults suffer from one or more chronic diseases. In the setting of dementia, they often encounter difficulty performing disease self-management, which may exacerbate their chronic conditions.
- Patient priority-directed care aims to manage disease in a manner that is consistent with patient health outcome goals. Care plans are formulated according to what patients are able and willing to do to achieve their health outcome goals. As dementia progresses, the plan of care will need to be adjusted based on the patient's declining cognitive and functional abilities.
- Medical providers should be aware of and screen for caregiver burden, as well as positive aspects associated with providing care for older adults with dementia.

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Case Vignette: Mr. AC

Mr. AC is an 81-year-old man with past medical history significant for type 2 diabetes mellitus complicated by chronic kidney disease, hypertension, and hyperlipidemia. He lives alone in the community and is independent in his activities of daily living, light housekeeping, and medication management. He quit driving 6 months ago after having two minor accidents within 4 months. The Montreal Cognitive Assessment was performed following the accidents and Mr. AC scored 21/30 points. Of note, he completed 4 years of college and worked as an accountant. On pre-clinic labs, his medical provider notes that Mr. AC's hemoglobin A1C has increased from 6.5% 6 months earlier to 7.8%. Reviewing vital signs, prior to seeing the patient, the provider notes that the patient's blood pressure is poorly controlled, also a new concern. Going into the exam room, the provider is already considering increasing Mr. AC's anti-hypertensive and diabetic regimens.

Introduction

Dementia, also termed major neurocognitive disorder, is characterized by a decline in cognition from a prior level of function, which results in impairment in daily activities. Deficits may be noted in one or more areas of cognition including learning and memory, language, executive function, complex attention, perceptual-motor, and social cognition. Common etiologies of dementia in the elderly population include Alzheimer's disease, vascular dementia, Lewy body disease, Parkinson disease with dementia, and frontotemporal dementia. Reversible or partially reversible causes of dementia are less likely but, as there is the opportunity for improvement following treatment, it is important to evaluate for thyroid abnormalities, vitamin B12 deficiency, neurosyphilis, and normal pressure hydrocephalus.

The prevalence of dementia is staggering with ~50 million individuals living with the disease in 2017 [1]. It is anticipated that this number will double every 20 years and reach 131.5 million by 2050 [1]. As the disease progresses, individuals require increasing care leading to high economic and caregiving costs. In 2010, the estimated worldwide costs of dementia were \$604 billion [2].

Chronic medical conditions are also common in older adults, with three of four individuals aged 65 years or older suffering from at least one chronic condition [3]. Chronic medical conditions are defined as those (1) lasting 1 year or longer and (2) requiring ongoing medical attention or limiting the activities of daily living [4]. Chronic medical conditions are more common in the geriatric population given the growing older adult population. Caring for individuals with chronic medical conditions is associated with a substantial healthcare cost, with those with multiple medical conditions accounting for 93% of total Medicare spending [5].

Older adults suffering from dementia and chronic medical conditions often face a variety of challenges, including changes in their abilities to perform daily

activities and to perform disease self-management. In addition, individuals with dementia will likely require the resources of supported care at some point in the disease trajectory. When caring for patients with dementia, healthcare providers should carefully consider each of these areas, including the impact on the patient and caregiver. The healthcare plan will need to be adapted throughout the course of dementia as disease severity increases and patient goals of care evolve.

Daily Functioning in Dementia

The ability to care for oneself is something most adults take for granted. However, it can be significantly impacted by dementia and chronic conditions. When considering the functional state of an older adult with dementia, it is important to clarify their living situation (i.e., single-family home versus supported living environment, single story dwelling versus need to utilize stairs, living with others versus independently). In addition, providers should confirm if older adults are independent, require assistance, or are dependent in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Table 1.1) [6, 7]. During the course of cognitive decline, older adults often begin requiring increasing assistance with IADLs, often beginning with the need for assistance in financial management as mild cognitive dementia progresses or cognitive issues progress to mild dementia [8]. It is important for providers to recognize that many individuals with cognitive deficits lack insight, or may be entirely unaware, that they are having difficulty managing their IADLs. This can result in significant negative impacts including financial mismanagement, medication errors, and automobile accidents. If possible, it is beneficial for family members or friends to accompany older adults with cognitive concerns to visits so that they can provide corroborating information regarding the individual's daily function. As older adults with dementia begin to have difficulty managing their medications, it can have significant impacts on their overall health and chronic disease self-management. For example, individuals with dementia may take more than the prescribed dose of medication because they forget taking it previously or may fail to take medication. As a result, patients can present with

Table 1.1 Activities of daily living and instrumental activities of daily living

Activities of daily living	Instrumental activities of daily living
Bathing	Ability to use telephone
Dressing	Shopping
Toileting	Food preparation
Transferring	Housekeeping
Continence	Laundry
Feeding	Mode of transportation
	Responsibility for own medications
	Ability to handle finances

apparent poor control of chronic conditions (i.e., hypo or hyperglycemia, hypo or hypertension) leading providers to assume that adjustments are needed to the medication regimen. However, prior to adjusting medications, it is important for providers to evaluate for cognitive issues, especially deficits in executive function, which may be making it difficult for older adults to take their medications or engage in other self-care tasks as directed. In cases where cognitive issues are making it difficult for the patient to follow instructions, it is often helpful to simplify the treatment (i.e., changing from short-acting insulin with meals to an oral hypoglycemic) or, as the dementia progresses, enlisting the help of caregivers or visiting nurses to assist with medication management.

While older adults who require assistance with IADLs are often able to remain in their homes with appropriate supports, it is much more challenging for an individual to remain independent once they require assistance with ADLs. Dependence in basic ADLs, especially loss of continence, is a common reason for older adults to be transitioned to a long-term care facility with 65% of caregivers citing the older adult's "need for more skilled care" as the reason for institutionalization [9]. In cases where transfer to a supported care environment is not consistent with the patient/family goals, it is important for providers to work with caregivers to obtain appropriate home supports (i.e., visiting nurses, nonskilled services) as well as simplify medical care as consistent with patient goals for the ease of both the older adult and caregiver.

Management of Chronic Medical Conditions in Older Adults with Dementia

Providers caring for older adults with comorbid dementia and chronic medical conditions often face challenges regarding declining ability to perform disease self-management, modification of disease management based on patient priorities, and challenges regarding surrogate decision-making. However, consistent consideration of the patient's cognitive deficits and overall goals during formulation of the medical plan will enable providers to provide individualized, patient-centered care to older adults with dementia.

As cognitive deficits progress in older adults with mild cognitive impairment or dementia, they often encounter increasing challenging with disease self-management. This is because, from a cognitive perspective, self-management is a complicated task requiring complex physical, emotional, and cognitive abilities [10]. Lorig and Holman have organized self-management into five core processes: (1). problem solving – identifying problems and generating solutions, (2). decision-making – acting in response to changes in disease condition, (3). finding and utilizing appropriate resources, (4). working with healthcare professionals to make decisions about treatment, and (5). taking action [11]. Cognitive impairment can result in difficulties with all these processes, leading to significant negative impacts on chronic disease self-management. In addition, older adults with dementia often lack awareness of increasing difficulties with self-care tasks and medical providers

often over-estimate a patient's ability to manage their health until the dementia is significantly progressed [10]. Instead of assuming an older adult is non-adherent or has poor disease control, providers should evaluate for underlying cognitive impairment as a contributor to suboptimal management of chronic health conditions. In individuals with known dementia, providers should continuously evaluate the impact cognition is having on disease self-management and adjust treatment decisions accordingly throughout the course of cognitive decline.

When caring for an older adult with dementia and chronic comorbidities, it is important for providers to continually adjust medical care to ensure it is aligned with patient priorities. When possible, this should occur in conjunction with the older adult, but, as dementia progresses, patient priority-directed decision-making will often occur in conjunction with the surrogate decision maker. Patient priority-directed care – an alternative to disease-based care which often results in care that is fragmented and lacking accountability, of uncertain benefit and potential harm, burdensome, and may not focus on the patient priorities – aims to manage disease in a manner consistent with patient health outcome goals (e.g., function, social activities, symptom relief) [12]. Care plans are developed based on what patients are able and willing to do to achieve their health outcomes goals. While health outcome goals are often consistent over time, for example, an individual identifying remaining as independent as possible as a personal value, specific sub-goals regarding this and the impact of healthcare will change as dementia progresses. In the scenario of remaining independent, an individual may transition from a complex insulin regimen to oral hypoglycemics when diagnosed with mild cognitive impairment and later require assistance from family to organize a pill box as their dementia progresses.

Surrogate decision makers play an important role in the care of older adults with dementia as decision-making capacity declines and the severity of dementia increases [13]. Early in the disease process, it is typical for family to support the older adult in decision-making through rewording medical explanations, talking through risks/benefits, and helping them to consider various treatment options [14]. As dementia progresses, or older adults experience other life-threatening conditions, surrogates often assume the role of primary decision maker with approximately one in three older Americans requiring a surrogate to make decisions at the end-of-life [15]. In advanced dementia, surrogates will be required to make all medical decisions. Common decisions made by surrogates on behalf of older adults with dementia near the end-of-life included transfer to the hospital, diagnostic testing, and feeding tube placement [16]. Even in advanced dementia, many surrogates report that it is difficult to limit treatment and evaluation, but 80% reported finding guidance from previously completed advance directive documents helpful in decision-making [16]. This highlights the importance of completing advance directives, including choosing a surrogate decision maker and documenting end-of-life wishes, when adults with cognitive issues still have capacity to make these decisions. Additionally, aligning care with patient priorities can help surrogates feel confident that they are supporting the previously identified values of the older adult through their healthcare decisions.

Supported Care in Dementia

For many older adults, remaining as independent as possible, within the bounds of their cognitive and physical functionality, is important to their sense of self. Early in the course of cognitive decline, many older adults will continue to be able to manage their daily activities and healthcare needs with minimal, if any, assistance. As the disease progresses, increasing support with ADLs, IADLs, and disease self-management will be required, and many individuals will need supported care. Supported care options for older adults with dementia include adult day programs, in-home caregiving, assisted living facilities, long-term care facilities, and hospice care.

Adult day programs can be based on a medical model, social model, or combined model [17]. Services offered typically include assistance with ADLs, care of psychosocial health, meals, and interactive programs [18]. Some adult day programs also include resources to address medical needs (i.e., nursing, physical therapy). Studies have identified benefits of adult day programs for individuals with dementia as well as their informal caregivers. Attendees have increased socialization, independence, and stimulation while caregivers benefit from respite and decreased feelings of isolation and worry [19]. Fields et al. also determined that adult day programs can prepare caregivers for future institutionalization of their loved one with dementia thus leading to an easier care transition [20].

In-home caregiving can be provided by informal or formal caregivers. Informal caregivers are unpaid individuals, often a family member or close friend, who assist the older adult with daily activities and medical tasks. In the United States, approximately 34.2 million individuals provide unpaid care to an adult aged 50 years or older on an annual basis, with 15.7 million informal caregivers assisting an older adult with dementia [21]. Formal caregivers, typically through home health services, often include nurses and physical therapists. Nursing assistance with disease monitoring and medication monitoring can be beneficial to older adults living independently with early cognitive decline or in assisting informal caregivers in caring for loved ones with more advanced disease.

As dementia progresses, many older adults will require a degree of services that cannot be provided at home and transition to an assisted living or long-term care facility. About 47.8% of long-term care residents have a diagnosis of dementia [22]. Factors associated with long-term care placement include behavioral and psychological symptoms of dementia, poorer cognition, impairment in ADL performance, and increased caregiver burden. In addition, the effects of community support services were variable with the highest level of placement occurring in individuals with the highest and lowest amounts of community services [23]. Toot et al. speculate that a high level of services is likely related to a high level of patient need [23]. However, a low degree of community support services may reflect minimal need or an unrecognized level of unmet need.

Dementia is the sixth leading cause of death in the United States, and the number of individuals dying of this disease is anticipated to continue increasing over the coming decades [24]. Enrollment of individuals with dementia in hospice, which

provides clinical and psychosocial services to Medicare beneficiaries who have an expected life expectancy of <6 months, has increased significantly from 3.3% of hospice beneficiaries in the late 1990s to 14.8% in 2014 [25, 26]. Despite this increase, a significant number of terminal dementia patients are not enrolled in hospice due to barriers including difficulty recognizing dementia as a terminal condition, estimating prognosis, and accessibility of hospice in long-term care facilities [27]. Due to these challenges, patterns of hospice use in individuals with hospice differ from those with other terminal illnesses. Those with dementia tend to be enrolled in hospice for a very short (≤ 1 week) or a very long (>6 months) period, and are more likely to be disenrolled prior to death [26, 27]. Overall, family members of older adults with dementia are positive regarding the support received through hospice, and providers should consider if a hospice referral is appropriate in individuals with advanced dementia.

Caregiving in Older Adults with Dementia

Informal caregivers, an integral component of care for older adults with dementia and other comorbid chronic conditions, providing 83% of help, are far larger than compensated care services [28]. About 23% of older adults with dementia receive care from three or more informal caregivers, and only 8% do not receive informal care. The three primary reasons informal caregivers cite for providing care to a loved one with dementia are 1. the desire to keep the individual at home, 2. proximity to the individual with dementia, and 3. a perceived obligation as spouse or partner. Informal caregivers of older adults with dementia assist with an average of two ADLs and five IADLs. In addition, they are more likely to monitor health of the care recipient, critical for management of comorbid disease, compared to caregivers of individuals without dementia (79 versus 66 percent) [29].

When providing care for older adults with dementia and chronic diseases, providers should also be aware of the impact of caregiving on family and friends. As dementia worsens, the increasing amount of care and supervision required can result in increased stress and depression, declining caregiver health, and financial hardships due to employment gaps and out-of-pocket expenses. About 59% of family caregivers of older adults with dementia rate the stress of caregiving as high or very high and 40% suffer from depression. As individuals with dementia reach the end-of-life, 59% of caregivers reported feeling “on duty” 24 hours per day and 72% reported feelings of relief when the person with dementia died [30]. Medical providers should regularly screen for caregiver stress using a validated tool, such as the Caregiver Burden Inventory, as well as refer them to appropriate support resources including social work, the Alzheimer’s Association, and local Area Agencies on Aging [31]. In addition to supporting dementia caregivers, it may be helpful to work with the caregiver to identify positive caregiving experiences. Commonly identified positive aspects of caregiving include 1. a sense of personal accomplishment and gratification, 2. feelings of mutuality in a dyadic relationship, 3. an increase in family cohesion and functionality, and 4. a sense of personal growth and purpose in live [32].

Case Vignette Continued: Mr. AC

Entering the exam room, Mr. AC's provider is concerned regarding his worsening blood pressure and diabetes management. In the past, the patient was meticulous with recording his blood glucose levels and was aware of the indication for each medication in his regimen. In conversation with Mr. AC, the provider discovered that he was checking blood glucose levels only intermittently and his log was disorganized. In addition, the patient seemed confused regarding his medications. Based on these findings, the provider is concerned that the worsening control of Mr. AC's chronic medical conditions is secondary to difficulty in disease self-management related to progression of his cognitive decline. A repeat Montreal Cognitive Assessment is performed, and the patient's score has decreased to 17/30. He scores 0/5 points on the visuospatial/executive portion. The provider arranges for a visiting nurse to assist with medication management. In addition, with permission from Mr. AC, the provider contacts the patient's daughter to discuss concerns regarding the increasing impact of the patient's cognitive issues on his ability to perform IADLs and perform disease self-management. The daughter verbalizes that she will be able to check on her father more frequently and assist as needed. When Mr. AC returns to clinic 3 months later, his daughter accompanies him. The patient verbalizes his appreciation for the home skilled services and increased assistance from his daughter. His blood pressure is once again well controlled and his hemoglobin A1C is improved to 6.6%.

Conclusion

As it progresses, dementia has significant impacts on the ability of individuals to perform their ADLs, IADLs, and chronic disease self-management. Providers should consider services such as adult day programs, visiting nurses, or more supported care environments, which can assist the older adult with dementia in managing their comorbid chronic diseases in a manner which is aligned with their care priorities. When dementia becomes advanced, hospice services can be beneficial in supporting the patient and family members. As important members of the health-care team, informal caregivers should be screened on a regular basis for caregiver stress and referred for supportive services as appropriate.

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