

Caring for Patients with Dementia at End of Life

Phyllis Whitehead, PhD, APRN/CNS, ACHPN, PMGT-BC, FNAP^{1,3}

Shareen Gamaluddin, MD⁴

Sarah DeWitt, MD^{1,3}

Christi Stewart, MD^{1,2,3}

Kye Kim, MD^{2,3}

1. Carilion Roanoke Memorial Hospital Palliative Care Service, 1906 Belleview Avenue SE, Roanoke, VA 24014
2. Carilion Center for Healthy Aging, 2001 Crystal Spring Avenue #302, Roanoke, VA 24014
3. Virginia Tech Carilion School of Medicine, 2 Riverside Circle, Roanoke, VA 24014
4. Centra Health Palliative Care Service, 1901 Tate Springs Road, Lynchburg, VA 24501

Keywords: dementia, palliative care or medicine, hospice, end of life

Abstract

Care of the dementia patient continues to be challenging. It is a terminal condition that many times goes undiagnosed leading to improper evidence-based interventions. Healthcare professionals (HCPs) should initiate goals of care conversations early with patients and their families in order to align treatment preferences. Early integration of palliative medicine is an important intervention that can lead to better manage symptoms and lessen the strain on loved ones. Additionally, early enrollment into hospice should be encouraged with loved ones to promote quality of life as defined by the patient.

Introduction

Dementia, or major neurocognitive disorder as it has been recently re-identified in the DSM-V, is a constellation of symptoms indicating a pathologic decline in physical and cognitive function. It is a prevalent disease, with 4% of those >65 years old having dementia and 50% of those >85 years old. Alzheimer's type dementia represents the sixth leading cause of death, and all types of dementia combined represent the third leading cause of death in the United States (US) in 2017. Rates of death due to dementia have been steadily increasing in the US since 2000. ¹ The cost of care for patients with dementia is estimated to be \$236 billion annually (not including loss of productivity and income for caregivers).^{1,2} Despite the widespread and terminal nature of this disease, it is often under-recognized by the medical community. The process of diagnosis, counseling, disease management, staging through disease progression, and care of this patient population at end of life presents unique challenges to the health care community, and represents a major public health challenge in the United States. Dementia, or major neurocognitive disorder, is defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) as described in Table 1. ^{3,4}

Table 1 ^{3,4}

Criteria for Diagnosis of Dementia

1. Decline in one or more cognitive domain:
 - a. Memory
 - b. Language (aphasia)
 - c. Executive function or problem solving
 - d. Complex attention or learning of new information
 - e. Perception-motor (apraxia)
 - f. Social cognition or comporment.
2. Must indicate a decline from a previous level of function.
3. Must interfere with everyday activities
 - a. Lawton Independent Activities of Daily Living scale
4. Decline in medication management, financial management, housekeeping, shopping, using the telephone, laundry, managing transportation, meal preparation

a. Katz Activities of Daily Living scale

5. Decline in bathing, dressing, feeding, transfers, toileting, grooming
6. The deficits and decline cannot be explained by another physical or psychiatric condition (delirium, depression, bipolar disorder, etc.)

(Adapted from DSM-V Criteria)

The various distinct dementia types often overlap in diagnostic criteria and share similar symptoms, making it difficult to differentiate between specific types of dementia outside of a specialty clinic. These similarities become more prominent later in the disease process, and moderate to late stage dementias can often be impossible to clearly diagnose and define. The impact of dementia on morbidity and mortality with other chronic disease such as cardiac, pulmonary or malignancies is often under-represented and overlooked as HCPs develop treatment plans related to disease staging and prognosis.^{5,6}

At this time, the United States Preventative Services Task Force (USPSTF) does not recommend routine screening for dementia due to lack of sufficient evidence to assess the balance of benefits and harms of screening for cognitive impairment in older adults. However, screening is recommended for those with suspected cognitive impairment. There is an 81% disease detection rate with appropriate screening techniques including both medications and advance care planning opportunities.⁴ However, there is an 81% disease detection rate with appropriate screening techniques. Earlier diagnosis allows more treatment opportunities, including both medications and advance care planning opportunities.

Early identification of cognitive impairment can help patients and their HCPs to enact appropriate advance care planning, identify comorbidities and secondary causes of cognitive dysfunction, and discuss initiation of medical therapy. While there are no curative therapies for Alzheimer's disease and other common etiologies of dementia, the goal of pharmacotherapy is to delay the progression of physical and neurocognitive decline in mild to moderate Alzheimer's type dementia.⁷ Not all patients will benefit from medication for dementia, acetylcholinesterase monotherapy compared to placebo or memantine monotherapy may have cognitive and functional benefits in patients with mild to moderate, but no pharmacotherapy is shown to reduce symptoms of moderate to severe dementia. Therefore, delay in start of medication management for delay of disease progression in Alzheimer's dementia may reduce the time period a patient has for potential benefit, if there is to be a response.⁸

There are a wide variety of screening tools available, including the Montreal Cognitive Assessment (MoCA), the Mini-Mental Status Examination (MMSE), the Mini-Cog, the St Louis University Mental Status (SLUMS) Examination and the Short Blessed Test. Informant based screening tests include the Ascertain Dementia 8-Item Informant Questionnaire (AD-8) and the Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE). (Norris) Each of these tests is meant to be utilized for screening of at-risk patients but are not independently diagnostic of a dementia process. A positive

screening test may lead to further evaluation and assessments by specialty providers, such as geriatricians, neurologists, neuropsychologists, and in some areas primary care providers in order to make an accurate diagnosis.

Determining a prognosis for a patient with dementia is dependent on disease staging. The staging of dementia can be challenging given the wide variety of causes and etiologies, as each specific disease will have a different clinical picture. There exists also a potentially variable rate of trajectory and decline, which may also be impacted by other medical co-morbidities and social determinants, such as financial and community support. However, within the complexity of these disease states, the two standard tools for staging of dementia are the Global Deterioration Scale,³ the Functional Assessment Staging (FAST) scale. These tools can be helpful in informing clinicians, patients and caregivers of the trajectory of illness for a specific patient, and in helping to identify relevant care needs based on disease stage. However, the prognostication of dementia is often problematic due to the complex interaction of health, sociodemographic factors and cognitive function.⁴ Therefore, a singular staging tool, such as the FAST scale or the Global Deterioration Scale, is not enough to independently provide prognostic information for patients with dementia.

There are many other factors that may determine prognosis in those living with dementia. The average duration of life between diagnosis of dementia and death has been reported to be anywhere from 1.1 to 8.5 years.⁹ However, older age, female sex, living alone, receiving home care services, and being prescribed a dementia medication in or before the year of diagnosis were significantly associated with a shorter time from diagnosis to institutionalization. While institutionalization is often considered a negative outcome for those living with dementia, patients who are maintained with nursing level support (extended care facility) tend to have longer survival rates (2.5 years) than those control patients with dementia living independently in the community (1.2 years).¹⁰ There are significant variabilities in and among care settings for those living with dementia, and the setting of care may be impacted by financial resources, community resources, individual family size and resources, cultural and religious backgrounds, sex, age, physical level of function, polypharmacy and medical co-morbidities, and individual variables in how the dementia presents and progresses (such as prevalence of behavioral and psychological symptoms of dementia). These, and other variables will impact care setting, caregiver strain, disease trajectory and overall prognosis.

Clinical Challenges

Dementia, an often slowly progressive disease, is characterized as a pathologic decline in physical and cognitive function. Different types of dementia include Alzheimer's dementia, Lewy body dementia, vascular dementia, frontotemporal dementia, and other mixed dementia. Although mortality for all dementias together is likely higher, Alzheimer's dementia is the sixth leading cause of death in the US according to the CDC.¹ However, it is not always recognized as a terminal condition. It is important to understand the terminal nature of dementia and be able to recognize when a patient is

nearing end-stage. Given the profound physical and cognitive disability that occurs as the disease progresses, it is important to recognize the clinical challenges that can occur in end stage dementia as the final years of life are often characterized by a prolonged trajectory of severe disability.¹¹ The Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) longitudinal study of 323 nursing home residents with advanced dementia found that infections and eating problems were common complications with 41% of residents developed pneumonia, 51% had febrile episode, and 86% developed eating difficulties.¹² Among the 177 patients who died during the study, the proportion of these who developed distressing symptoms such as pain, dyspnea, pressure ulcers, aspiration events increased as they neared end of life.¹² Furthermore, other symptoms such as neuropsychiatric symptoms have been found to also increase in patients with dementia who are nearing end of life.

Advanced dementia can result from a variety of neurodegenerative diseases, and results in a profound physical and cognitive disability that affects memory, cognition, and physical capabilities. As dementia progresses, patients lose the ability to perform instrumental activities of daily living (IADLs) independently. They require increase support including nursing and bedside care.¹³ The Reisburg Functional Assessment Staging (FAST) scale has been used for many years to help prognosticate and determine who is nearing end stage and thus hospice eligible.³ It evaluates patients based on functional status and IADLs. Stage 7 or beyond on the FAST scale indicate that a patient is no longer able to ambulate without assistance, unable to dress and/or bathe with assistance, has urinary and/or fecal incontinence, and is no longer able to express meaningful verbal communication.^{14,15}

Infections are very common in advanced dementia. As dementia progresses, and patients become more bedfast, they are at increased risk of developing complications from advanced dementia such as skin infections and pressure ulcers, difficulty swallowing and aspiration pneumonia, urinary tract infections, and recurrent fevers. When looking at all treatment decisions that are faced in caring for patients with advanced dementia, the decision to treat infections account for roughly 25% of all treatment decisions and are often terminal events.² Because fever and infections are common, antibiotic use has been shown to be highly utilized in patients with advanced dementia.^{6,13} The decision to treat infections requires careful consideration of the patient's goals of care, prognosis, as well as standard infectious disease protocol. Furthermore, appropriate antimicrobial stewardship is important for clinicians to understand and practice. In one study of 241 nursing home residents with advanced dementia, of the residents who died, 42.4% received antibiotics in the last 2 weeks of life.¹² Antibiotic use was found to be seven times higher in the last two weeks of life compared with 6 to 8 weeks before death.¹² This pattern of non-beneficial antimicrobial use within days of death not only leads to financial costs to patients, facilities, and the health care system, but also places patients at high risk of complications and side effects, such as gastrointestinal (GI) upset, clostridioides difficile (C.diff.) infections, and potentially invasive means of medication administration. It also incurs risk of harm in the

nursing home and community setting via the development and spread of antimicrobial resistance.⁷ Antibiotic use was found to be seven times higher in the last two weeks of life compared with 6 to 8 weeks before death.¹⁰ This pattern suggests that infection is a common and expected event at the terminal phase of life for patients with dementia and the use of antimicrobials at this time is unlikely to alter the course of their trajectory and prognosis. Use of antimicrobials may lead to treatment burden at end of life by administration of additional medication, whether orally or intravenously, and could lead to potential side effects of these medications. Additionally, this pattern of antimicrobial use in advanced dementia may increase the risk of development and spread of antibiotic resistance in the community and nursing home setting. It is important to be mindful of antibiotic stewardship as antimicrobials are often started without adequate clinical evidence of an infection.^{16,17} It is important to be mindful of antibiotic stewardship as antimicrobials are often started without adequate clinical evidence of an infection.

One of the hallmarks of advanced dementia is the onset and progression of eating difficulties. Nutritional support is the one of the most common treatment decisions faced by patients and their caregivers.¹⁰ There are different causes of eating problems in patients with advanced dementia, however oral and pharyngeal dysphagia as well as an inability to perform the task of eating are the most common causes of eating difficulties.¹⁰ Other causes that lead to eating difficulties can include depression, loss of taste or smell, and poor dentition. The Choosing Wisely Campaign, an initiative of the American Board of Internal Medicine (ABIM) Foundation, does not recommend percutaneous feeding tubes in patients with advanced dementia.¹² Studies have found that feeding tubes do not improve survival of patients with dementia, nor do they prevent aspiration pneumonia, or improve healing.^{10–12,17} Feeding tubes in fact, are attributed to increased complications including use of physical and pharmacological restraints, distress and delirium, as well as development of pressure ulcers.^{12,18,19} Careful hand feeding remains the recommended, evidence-based approach to provide nutrition to those patients with advanced dementia and feeding problems.¹² Ongoing, routine oral care is crucial with patients with advanced dementia for comfort and minimizing aspiration risks.^{12,13,18}

Patients with advanced dementia are at high risk for neuropsychiatric symptoms which are often be more troubling and distressing than cognitive symptoms. These neuropsychiatric symptoms include hallucinations, delusions, paranoia, wandering, agitation or aggression, depression, apathy, disinhibition and sleep disturbances.^{20,21} The presence of one or more of these symptoms are common in patients with advanced dementia which increases with disease severity leading to increased functional and cognitive impairment. Additionally, the presence of neuropsychiatric symptoms often hasten or lead to nursing home placement as families and caregivers have difficulty caring safely for the patient at home. Particularly, the presence of delusions and/or hallucinations have been shown to be associated with increased risk of overall decline, with hallucinations, although less frequent, are more highly associated with increased institutionalization and mortality.^{5,20,21}

Agitation, aggression, and other behavioral abnormalities that occur in patients with dementia can be caused by several underlying factors. Identifying and treating these underlying issues can be an effective way of treating the agitation and aggression. For many dementia patients with new behavioral changes, this could indicate a new infection, medication toxicity, fever, pain, fear, confusion, poor sleep, or other uncontrolled symptom.^{5,20–22} It is important to identify and treat the underlying cause as there is no single approach or medication that can be expected to treat the symptom of agitation without addressing what is actually causing it. It is important to note that physical restraints are rarely indicated in treatment of patients with dementia and should only be used for those that are an imminent risk of physical harm to themselves or others. By carefully treating the possible sources of agitation as well as promoting an environment that decreases chance of wandering, falls, and delirium, the use of restraints can be minimized.^{5,7,14,20,21}

Advance Care Planning

The Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* recommends that clinicians encourage advance care planning (ACP) conversations throughout an individual's lifespan, including childhood if they have capacity to do so, and document as appropriate.²³ ACP is a process that encourages persons of all ages dealing with serious illness to understand, identify, and share their values, goals, and preferences regarding future medical care.²⁴

Because seriously ill patients with dementia lose their decision-making capacity, the HCP may have to rely on loved ones to advocate for the patient's wishes.²⁵ State laws vary in the extent to which they authorize proxy decision making; they also differ as to which family members have priority in the decision making.²⁶ Thus, the HCP should be familiar with the state's surrogate decision-making laws and regulations. The HCP should initiate family meetings early within the disease trajectory, so the patient can appoint a surrogate decision maker for health care decisions and share care preferences with the surrogate. ACP conversations should occur to ensure surrogates understand the patient's priorities of care in order to align treatment plans.^{27,28} HCPs should start early with ACP conversations and they should be ongoing as the patient's condition progresses.²⁹

Patient and family meetings are crucial interventions in establishing goals of care for patients. During the patient and family meeting, the HCP needs to provide an accurate summary of the medical care to date, the potential medical treatment options that may be considered in the future especially the use of artificial hydration and nutrition at end of life, and the potential outcomes, including prognosis.^{30,31}

In the acute care setting, the HCP should summarize what the medical teams are recommending as the best care option(s), while focusing on the patient's preferences and values. For example, "In light of what we have talked about so far, what do you

think your loved one would want to do?" The goals of the meeting are to minimize the surrogate decision maker's burden of responsibility and to remain focused on the patient's wishes, not the decision maker's wishes.^{23,32} Once ACP decisions have been made it is crucial to document treatment preferences in one of the many Advance Directive documents such as Five Wishes, POLST/POST/MOST and DDNAR to mention a few. These documents need to be shared with all HCPs and facilities.^{33,34}

With the majority of deaths occurring in acute care settings, where the focus of care is on active, curative treatment and not on managing symptoms or establishing realistic goals of care, HCPs must be able to advocate for seriously ill patients and their loved ones. Patients need HCPs who are skilled in the science of palliation and skilled ACP as well as the art of holistic healing. With the ever-changing healthcare environment, HCPs are essential in providing specialized interventions to meet the diverse needs of acute care patients.³⁵

Palliative and Hospice Care

As of 2019 Alzheimer's and other dementias were the 6th leading cause of death worldwide.² The symptom burden in advanced dementia is complex and involves not only cognitive decline, but physical symptoms such as pain, dyspnea, infections, communication difficulties, and behavioral challenges. Given these complexities the majority of those with advanced dementia live in institutionalized settings and subsequently die in these facilities.

Although many experts in the field characterize Alzheimer disease and other progressive dementias as terminal illnesses, medical professionals and family members have difficulty viewing dementia as an illness from which one dies. It wasn't until 1994 that The National Center for Health Statistics even ranked Alzheimer's disease as a cause of death. The lack of recognition of dementia as a terminal disease stems from a couple different factors. The prolonged nature of functional decline in a dementia patient can prevent the correlation of the disease with the end result of death. In a stage IV cancer patient, once functional deterioration starts, there is a fairly short (weeks to months) and predictable pattern of decline to death. In this case the progression of disease, particularly if there has been cessation of treatments, can be clearly identified as the direct cause of death.^{36,37}

In dementia patients however, the time from diagnosis to death is much longer and varied. In Alzheimer's dementia the length of survival after diagnosis is typically several years.^{2,38} Several factors contribute to this less predictable disease trajectory including differences in social supports after the diagnosis, timing of the diagnosis, additional medical comorbidities at the time of diagnosis, as well as the underlying etiology of dementia. Additionally, even though secondary complications of advanced stage dementia include infection, apraxia, dysphagia, malnutrition, decreased mobility, and non-healing wounds – these secondary complications ultimately become identified as

the primary cause of death.³⁹ Thus aspiration pneumonia is characterized as the terminal event, not the dementia.

In general, as dementia progresses toward end stage, the frequency and severity of these complications also increases. This in turn leads to increased symptom burden, debility, and caregiver strain. Palliative care is an excellent source of support for these patients and their caregivers. Palliative care is specialized medical care for people living with a serious illness. The focus is on providing relief from the symptoms and stress of the illness with a goal of improving quality of life for both the patient and the family.

However, patients with dementia are less likely to be referred to palliative services compared to those without a dementia diagnosis. This can result in under recognition and treatment of symptoms such as pain as well as lead to unwanted burdensome interventions.⁴⁰ Factors identified as barriers to accessing palliative services include the current structure of healthcare, education, and perceptions of caregivers as well as healthcare personnel, and communication between patients, family and providers.

The health systems in the United States, particularly Medicare, have financial incentives and reimbursement structures that are acute care oriented.² This reimbursement structure does not benefit the provision of palliative care services to people with dementia, particularly in the nursing home setting.⁴¹

Staff shortages and time limitations add to the burden of care in nursing homes. As a patient's cognitive and communication abilities decline, it can become harder to assess symptoms, like pain for example. Patients with dementia can have difficulties with recall, sensory interpretation, and verbal expression. As the disease advances reporting of something simple such as pain must be gathered from the patient's report as well as caregiver report, and direct patient observation.²

Lack of continuity across care settings is also significant. The average Medicare beneficiary sees seven physicians in four different practices annually, with communication and coordination of care between physicians often suboptimal.⁴² Having continuity of care is key to understanding the patient's progression and stage of dementia. This subsequently aids in recognizing and appropriately managing acute illness and as well as chronic conditions which should lead to palliative medicine consultation to better manage symptoms and assist in goals of care conversations.

While palliative care can be utilized further upstream in the course of illness, hospice is available as a support once reaching end stages of a disease. In general, to qualify for hospice services a patient must have an expected prognosis of 6 months or less to live and be ready to forego treatments aimed at cure and/or prolongation of life.¹ A hospice team of interdisciplinary professionals address physical, psychosocial, and spiritual distress of the dying person and their family.

In the United States, Medicare has specific eligibility guidelines for hospice enrollment. For dementia patients must meet the following requirements to be eligible for hospice in Table 2.

Table 2 ^{3,4,43,44}

Hospice Eligibility Criteria

<p>1. Be Stage 7A or beyond on the Functional Assessment Staging (FAST) scale as well as all the following:</p> <ul style="list-style-type: none"> ○ Unable to ambulate independently (assistance is needed) ○ Unable to bathe/dress self without assistance ○ Incontinent of bowel and bladder; intermittent or constant ○ No consistent meaningful verbal communication
<p>2. Must have had at least one of the following complications in the prior year:</p> <ul style="list-style-type: none"> ○ Aspiration pneumonia ○ Pyelonephritis or other upper urinary tract infection ○ Septicemia ○ Multiple decubitus ulcers \geq stage 3 ○ Recurrent fever after treatment with antibiotics ○ Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin <2.5 g/dL

Subsequently referrals to palliative or hospice are often not prompted until there is a trigger from disease complications such as infection, fall/fracture, decubitus ulcers leading to escalation of care to an acute or intensive care unit level setting. Given the lack of accurate and standardized referral, some have advocated hospice services should be driven by patients' preference to focus care on quality of life and comfort rather than on estimates of life expectancy.¹ Currently the majority of dementia patients enrolling in hospice utilize services well under the 6 month expected prognosis. In 2018 15.6% (177,490) of Medicare hospice beneficiaries carried a principal admitting diagnosis of dementia. The mean length of stay was 105 days with a median of just 55 days.

For both hospice and palliative programs there is a need for continued education. There is often a lack of professional knowledge about these services, when to utilize, and their availability. Given the misconceptions and negative associations, families are resistant and mistrusting to the idea of palliative or hospice interventions. If identified and used appropriately both palliative and hospice address care needs of a vulnerable population. Palliative medicine and hospice teams treat not only the patient but provide support and education for the caregivers in mitigating the challenges of caring for a patient with advanced dementia.^{5,45-47}

Psychosocial and Financial Challenges

End-of-life (EoL) care for persons with dementia occurs in various clinical settings ranging from homes to hospitals and long-term care facilities. While transition among different care settings at EoL remains an issue in dementia care, one study found that persons with severe dementia were less likely to be transferred between care settings in the last three months of life and less likely to die in hospital.⁴⁸ Regardless of caregiving settings, providing their caregivers and families with psychosocial support is important. For instance, when a patient is in an assisted living facility, memory care program or skilled nursing facility, the family needs to be updated on the patient's medical status continuously. A multi-method qualitative study, the Supporting Excellence in End-of-Life Care in Dementia (SEED) identified seven key components of good EoL care in dementia. Two of them, relevant to psychosocial challenges, are timely planning discussions with family and recognition of end of life and provision of supportive care as discussed above.⁴⁰ A thematic study utilizing in-depth interviews to investigate families' experiences with EoL care for the people with dementia indicates that it is important healthcare professionals inform and support families to help them make decisions about EoL care and preferences regardless of care settings.⁴⁹

Families will need assistance with providing activities of daily living (ADLs) and supervision of their loved ones diagnosed with dementia. Providing personal care for these patients will be for a prolonged and uncertain time period. Complicating the situation even further, many of these families are elderly and in poor health themselves. Therefore, it is important to include education about expenses incurred by caregiving in terms of paying privately for ADLs, home health, and lost income from time off work to name a few challenges.

Especially, when a patient is actively dying, families need to be clinically apprised on the patient's status to minimize their distress. Additionally, clinicians should be responsive to their emotional and psychosocial needs. Shanley et al indicate that at this stage, they may feel exhausted and alone.⁵⁰ Additionally, clinicians need to pay attention to the needs of families in a culturally sensitive manner. Communication concerning disclosure, truth telling, and decision making should be respectful of their cultural preferences.⁵¹

The cognition of individuals with dementia at EoL necessitates a surrogate decision maker or other appropriate party to make medical decisions for them. An expectation that medical decisions are made by their families, which increases the burden on their families and becomes one of the reasons why clinicians need to proactively discuss EoL decisions with patients and families early in the diagnosis. Family needs education regarding clinical conditions of patients at EoL and treatment options, such as diminished oral intake, infections as discussed in "clinical challenges". Oftentimes, family members may have to deal with ethically charged concerns for prolongations of dying and inappropriately aggressive care.⁵² versus preferred palliative or comfort care.⁵³ Ethical care is often operationalized in clinical settings. There are several clinical considerations with the potential to improve care provisions. Loved ones should be

educated on the trajectory of advanced dementia including loss of interest in eating and ability to safely swallow, ongoing infections such as urinary tract, aspiration pneumonia and other indignities that can be managed with proper care.⁵⁴

Families need to be educated regarding the issues with caregiver burden and emotionally and spiritually supported during these challenging periods in which their loved ones undergo the EoL stage of their medical illness. If clinically indicated, the clinician has a responsibility to advise and encourage family caregivers to seek professional care. Clinicians have a responsibility to recognize caregiver burden. Caregiver assessment and intervention should be tailored to the individual circumstances and contexts in which caregiver burden occurs.^{55,56} Importance of spiritual support for family caregivers needs to be addressed in a culturally sensitive manner and if appropriate, referred to spiritual counsellors.⁵⁷

Addressing grief related issues as a psychosocial intervention is recognized as an integral part of EoL care. Caregiver grief is ongoing for the family throughout the illness trajectory. Ambiguous loss arises from a perceived mismatch between the physical and psychological presence of a person with chronic physical illness and causes great difficulty in identifying and using effective coping skills. It is largely influenced by the individual's perceptions of their relationship, resources, and the degree of stress.⁵⁸ Especially, inconsistent behaviors of the person with dementia causes significant boundary ambiguity of the family system, which prevents family from defining their situation, coping with, and managing it.^{59,60}

Dementia involves a series of losses over many years in the patient and family. The family experiences multiple losses such as roles, companionship, and financial well-being prior to the patient's eventual death. This type of grief, anticipatory grief, causes adverse mental consequences among caregivers. One study indicates there is a strong correlation between anticipatory grief and depression among spousal caregivers.^{14,61} Considering mental health consequences of the bereaved family caregivers, preparation of these changes is an important priority in caring for them.^{14,62} Information and education on grief and the availability of professional services needs to be available to families before and after the death of the patient, as culturally appropriate and desired.

For most of individuals with dementia aged over 65 or older, Medicare is the primary source of health care coverage. As of 2018, estimates suggest that 5.4 million individuals have Alzheimer's disease and related dementias (ADRD) in the United States, of whom 96% are 65 years or older. If current prevalence rates and population trends continue, the number of older Americans with ADRD will more than double by midcentury, with projections of 11 million to more than 13 million individuals with diagnosed ADRD by 2050.⁶³ One study indicates that persons with ADRD and mild cognitive impairment (MCI) incurred significantly higher Medicare expenditure than matched controls even before they received a formal diagnosis. Medicare expenditure of persons with ADRD and MCI may start to increase at least 12 months before their diagnosis, peak during the first few months immediately after diagnosis and decrease

afterward but remains at a higher level than before diagnosis. These findings highlight the importance of early diagnosis and indicate the need for complex case management to coordinate care transition for individuals with these conditions.⁶⁴ Interestingly, one earlier study shows that total Medicare expenditure is higher primarily around the time of diagnosis due to costly assessment by specialists including geriatricians, geriatric psychiatrists, neurologists, neuropsychologists, medical dementia work ups, imaging studies, and medications.^{1,65}

Case Study

Mr. Johnson, a disabled businessman was transferred to a dementia unit via a memory disorder clinic at a local Veterans Affairs Medical Center. He was a married 55-year-old physically fit veteran. His wife was no longer able to care for him at home due to a rapidly declining cognitive function along with behavior symptoms. He was diagnosed as suffering from frontotemporal dementia at age 51 and could no longer function at work. Upon admission to the unit, his wife and the interdisciplinary treatment team agreed upon his treatment goals to be stabilization of his behavior symptoms and focus on his comfort and quality of life. Over a period of several months, his basic activities of daily living deteriorated quickly to the point where he required help to be fed and bathed. Due to his sensitivity to psychotropic agents, his behavior symptoms were not adequately stabilized, and his care became a significant challenge to the nursing team. His two daughters were so devastated to see their father's changes that they stopped coming to visit him. Mrs. Johnson joined a grief group therapy run by a psychiatrist in charge of unit. His daughters were referred to see a local psychotherapist. When he developed aspiration pneumonia, he was not transferred to the acute medical unit and was cared for on the unit that managed his symptoms such as dyspnea, pain, anxiety, and delirium. As he was actively dying, he was moved to a room specifically designed for EOL care. His family was able to come and stay by his bedside. His favorite music was played, and aromatherapy was also provided for comfort. His wife and children stayed overnight at his bedside and they were with him when he died peacefully early the next morning. The wife and children expressed appreciation to the staff and shared that the patient died as he had shared with them during their advance care planning sessions years ago.

Conclusion

Caring for patients with dementia continues to be challenging for both healthcare professionals (HCPs) and their loved ones. It is imperative that HCPs initiate goals of care conversations early with the patient to understand treatment preferences. Additionally, early integration of palliative medicine can better manage symptoms and lessen the strain on loved ones. Palliative medicine practitioners should be a standardized part of the treatment team.

Early enrollment into hospice should be discussed with loved ones as a treatment intervention in promoting quality of life for these patients and their loved ones.

Additionally, modifying hospice dementia eligibility criteria to allow for earlier enrollment and longer coverage is needed. Additionally, improved social support for caregivers is vital for keeping patients at home and during the transition to facilities. It is time to change policy and social welfare systems in our country to allow for proper care of patients diagnosed with dementia and to support their caregivers.

HCPs can and should provide more comprehensive care and support for their patients diagnosed with dementia. By expanding palliative medicine and hospice services to provide more social, nursing and medical interventions, care of the dementia patient will improve. Partnerships with palliative medicine and hospice is crucial when caring for patients with dementia and their loved ones.

References

1. Kramarrow EA, Tejada-Vera B. Dementia Mortality in the United States, 2000-2017. *Natl Vital Stat Reports*. 2019;68(2).
2. Burns RB, Waikar SS, Wachterman MW, et al. Trends in Hospital-Based Specialty Palliative Care in the United States From 2013 to 2017. *J Pain Symptom Manage*. 2018;10(1):774-780. doi:10.1111/jocn.13925
3. Reisberg B. Functional assessment staging (FAST). *Psychopharmacol Bull*. 1988;24(4):653-659.
4. Endsley S, Main R. Palliative Care in Advanced Dementia. *Am Fam Physician*. 2019;99(7):456-458.
5. Bartley MM, Suarez L, Shafi R, Baruth JM, Benarroch A, Lapid MI. Dementia care at end of life: Current approaches. *Curr Psychiatry Rep*. 2018;20(7):50.
6. Ernecoff NC, Lin FC, Wessell KL, Hanson LC. Quality of life with late-stage dementia: Exploring opportunities to intervene. *J Am Geriatr Soc*. 2019;67:1189-1196.
7. Burns RB, Waikar SS, Wachterman MW, Kanjee Z. Management options for an older adult with advanced chronic disease and dementia. *Ann Intern Med*. 2020;173:217-225.
8. Hunt LJ, Covinsky KE, Yaffe K, et al. Pain in Community-Dwelling Older Adults with Dementia: Results from the National Health and Aging Trends Study. *J Am Geriatr Soc*. 2015;63(8):1503-1511. doi:10.1111/jgs.13536
9. Todd S, Barr S, Roberts M, Passmore AP. Survival in dementia and predictors of mortality: A review. *Intern J Geriatr Psychiatry*. 2013;28(11):1109-1124.
10. Joling KJ, et al. Time from diagnosis to institutionalization and death in people with dementia. *Alzheimer's Dement*. 2020;16(4):662-671.
11. Hanson LC, Kistler CE, Lavin K, et al. Triggered palliative care for late-stage dementia: A pilot randomized trial. *J Pain Symptom Manage*. 2019;57(1):10-19.

12. Greenfield SM, Gil E, Agmon M. A bridge to cross: Tube feeding and the barriers to implementation of palliative care for the advanced dementia patient. *J Clin Nurs*. 2020;8. doi:10.1111/jocn.15437
13. Ernecoff NC, Zimmerman S, Mitchell SL, et al. Concordance between Goals of Care and Treatment Decisions for Persons with Dementia. *J Palliat Med*. 2018;21(10):1442-1447. doi:10.1089/jpm.2018.0103
14. Sampson EL, Candy B, Davis S, et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med*. 2018;32(3):668-681.
15. Reisberg B, Ferris SH, DeLeon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry*. 1982;139(9):1136-1139.
16. Ernecoff NC, Zimmerman S, Mitchell SL, et al. Concordance between goals of care and treatment decisions for person with dementia. *J Palliat Med*. 2018;21(10):1442-1447.
17. Ernecoff NC, Lin FC, Wessell KL, Hanson LC. Quality of Life with Late-Stage Dementia: Exploring Opportunities to Intervene. *J Am Geriatr Soc*. 2019;67(6):1189-1196. doi:10.1111/jgs.15794
18. Ernecoff NC, Wessell KL, Hanson LC, et al. Does receipt of recommended elements of palliative care precede in-hospital death or hospice referral? *J Pain Symptom Manage*. 2020;59(4):778-786.
19. Berry SD, Rothbaum RR, Kiel DP, Lee Y, Mitchell SL. Association of clinical outcomes with surgical repair and hip fracture vs nonsurgical management in nursing home residents with advanced dementia. *JAMA Intern Med*. 2018;178(6):774-780.
20. Harman SM. Psychiatric and Palliative Care in the Intensive Care Unit. *Crit Care Clin*. 2017;33(3):735-743. doi:10.1016/j.ccc.2017.03.010
21. Trachsel M. Title: The Ethical Importance of Assessing End-of-Life Care Preferences in Patients with Severe and Persistent Mental Illness. *Am J Geriatr Psychiatry*. 2017;26(1):98-99. doi:10.1016/j.jagp.2017.09.026
22. Burns RB, Waikar SS, Wachterman MW, Kanjee Z. Management Options for an Older Adult With Advanced Chronic Kidney Disease and Dementia: Grand Rounds Discussion From Beth Israel Deaconess Medical Center. *Ann Intern Med*. 2020;173(3):217-225. doi:10.7326/M20-2640
23. Scott J, Owen-Smith A, Tonkin-Crine S, et al. Decision-making for people with dementia and advanced kidney disease: A secondary qualitative analysis of interviews from the Conservative Kidney Management Assessment of Practice Patterns Study. *BMJ Open*. 2018;8(11). doi:10.1136/bmjopen-2018-022385
24. Ouchi K, George N, Revette AC, et al. Empower Seriously Ill Older Adults to Formulate Their Goals for Medical Care in the Emergency Department. *J Palliat*

- Med.* 2018;22(3):267-273. doi:10.1089/jpm.2018.0360
25. Sellars M, Clayton JM, Detering KM, Tong A, Power D, Morton RL. Cost and outcomes of advance care planning and end-of-life care for older adults with end-stage kidney disease: A person centred decision analysis. *PLoS One.* 2019;14(5).
 26. Stewart R, Dimmock A, Green M, et al. An analysis of recruitment efficiency for an end-of-life advance care planning randomized controlled trial. *Am J Hosp Palliat Med.* 2019;36(1):50-54. doi:10.1177/1049909118758158
 27. Whitehead PB, Ramalingam N, Carter KF, Katz K, Harden S. Nurse Practitioners' Perspectives on the Patient Preferences About Serious Illness Instrument. *J Hosp Palliat Nurs.* 2016;18(4):332-341. doi:http://dx.doi.org/10.1097/njh.0000000000000256
 28. Whitehead PB, Carter KF. A model for meaningful conversation in serious illness and the patient preferences about serious illness instrument. *J Hosp Palliat Nurs.* 2017;19(1). doi:10.1097/NJH.0000000000000307
 29. Lakin JR, Benotti E, Paladino J, Henrich N, Sanders J. Interprofessional Work in Serious Illness Communication in Primary Care: A Qualitative Study. *J Palliat Med.* 2019;XX(Xx):1-13. doi:10.1089/jpm.2018.0471
 30. Johnston FM, Neiman JH, Parmley LE, et al. Stakeholder Perspectives on the Use of Community Health Workers to Improve Palliative Care Use by African Americans with Cancer. *J Palliat Med.* 2019;22(3):302-306. doi:10.1089/jpm.2018.0366
 31. Huang C-HS, Crowther M, Allen RS, et al. A Pilot Feasibility Intervention to Increase Advance Care Planning among African Americans in the Deep South. *J Palliat Med.* 2016;19(2):164-173. doi:10.1089/jpm.2015.0334
 32. Hole B, Hemmelgarn B, Brown E, et al. Supportive care for end-kidney disease: An integral part of kidney services across a range of income settings around the world. *Kidney Int Suppl.* 2020;10:e86-e94.
 33. Dillon E, Chuang J, Gupta A, et al. Provider Perspectives on Advance Care Planning Documentation in the Electronic Health Record: The Experience of Primary Care Providers and Specialists Using Advance Health-Care Directives and Physician Orders for Life-Sustaining Treatment. *Am J Hosp Palliat Med.* 2017;34(10):918-924. doi:10.1177/1049909117693578
 34. Hole B, Hemmelgarn B, Brown E, et al. Supportive care for end-stage kidney disease: an integral part of kidney services across a range of income settings around the world. *Kidney Int Suppl.* 2020;10(1):e86-e94. doi:10.1016/j.kisu.2019.11.008
 35. Scott J, Owen-Smith A, Tonkin-Crine S, et al. Decision-making for people with dementia and advanced kidney disease: A secondary qualitative analysis of interviews from the Conservative Kidney Management Assessment of Practice Patterns study. *BMJ Open.* 2018;8(e022385).

36. Goebel JR, Ferolito M, Gorman N. Pain Screening in the Older Adult With Delirium. *Pain Manag Nurs*. 2019;20(6):519-525. doi:10.1016/j.pmn.2019.07.003
37. Sullivan NM, Blake LE, George M, Mears SC. Palliative Care in the Hip Fracture Patient. *Geriatr Orthop Surg Rehabil*. 2019;10:215145931984980. doi:10.1177/2151459319849801
38. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med*. 2004;19(10):1057-1063.
39. Sommerbakk R, Haugen DF, Tjora A, Kaasa S, Hjermland MJ. Barriers to and facilitators for implementing quality improvements in palliative care – results from a qualitative interview study in Norway. *BMC Palliat Care*. 2016;15(1):61. doi:10.1186/s12904-016-0132-5
40. Bamford C, Lee R, McLellan E, et al. What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatr*. 2018;18:302-317.
41. Erel M, Marcus EL, Dekeyser-Ganz F. Barriers to palliative care for advanced dementia: A scoping review. *Ann Palliat Med*. 2017;6(4):365-379.
42. Amjad H, Carmichael D, Austin AM, Chang CH, Bynum JP. Continuity of care and health care utilization in older adults with dementia in fee-for-service Medicare. *JAMA Intern Med*. 2016;176(9):1371-1378.
43. Gleason LJ, Benton EA, Alvarez-Nebreda ML, Weaver MJ, Harris MB, Javedan H. FRAIL Questionnaire Screening Tool and Short-Term Outcomes in Geriatric Fracture Patients. *J Am Med Dir Assoc*. 2017;18(12):1082-1086. doi:10.1016/j.jamda.2017.07.005
44. Bansal AD, Leonberg-Yoo A, Schell JO, Scherer JS, Jones CA. Ten Tips Nephrologists Wish the Palliative Care Team Knew about Caring for Patients with Kidney Disease. *J Palliat Med*. 2018;21(4):546-551. doi:10.1089/jpm.2018.0087
45. Hill E, Savundranayagam MY, Zecevic A, Kloseck M. Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care. *Am J Alzheimers Dis Other Demen*. 2018;33(5):284-291.
46. Eisenmann Y, Golla H, Schmidt H, Voltz R, Perrar KM. Palliative care in advanced dementia. *Front Psychiatry*. 2020;11:699.
47. DeVleminck A, Morrison RS, Meier D, Aldridge MD. Hospice care for patients with dementia in the United States: A longitudinal cohort study. *J Am Med Dir Assoc*. 2018;19(7):633-638.
48. Meeussen K, Van den Block L, Echteld M, et al. Older people dying with dementia: A nationwide study. *Int Psychogeriatrics*. 2012;24(10):1581-1591.
49. Bolt S, van der Steen J, Schols J, Zwakhalen S, Meijers J. What do relatives value most in end-of-life care for people with dementia? *Int J Palliat Nurs*. 2019;25(9):432-442.

50. Shanley C, Russell C, Middleton H, Simpson-Young V. Living through end-stage dementia: The experiences and expressed needs of family carers. *Dementia*. 2011;10(3):325-340.
51. Bradley N, Lloyd-Williams M, Dowrick C. Effectiveness of palliative care interventions offering social support to people with life-limiting illness—A systematic review. *Eur J Cancer Care (Engl)*. 2018;27(3):1-12. doi:10.1111/ecc.12837
52. Hewison A, Lord L, Bailey C. "It's been quite a challenge": redesigning end-of-life care in acute hospitals. *Palliat Support Care*. 2015;13(3):609-618. doi:10.1017/S1478951514000170
53. Costa-Requena G, Espinosa Val MC, Cristòfol R. Caregiver burden in end-of-life care: advanced cancer and final stage of dementia. *Palliat Support Care*. 2015;13(3):583-589. doi:10.1017/S1478951513001259
54. Yeaman P, Ford J, Kim K. Providing quality palliative care in end-stage Alzheimer disease. *Am J Palliat Care*. 2013;30(5):499-502.
55. Paladini A, Fusco M, Coaccioli S, Skaper SD, Varrassi G. Chronic Pain in the Elderly: The Case for New Therapeutic Strategies. *Pain Physician*. 2015;18(5):E863-76. <https://www.ncbi.nlm.nih.gov/pubmed/26431140>.
56. Delgado-Guay M, Ferrer J, Rieber AG, et al. Financial Distress and Its Associations With Physical and Emotional Symptoms and Quality of Life Among Advanced Cancer Patients. *Oncologist*. 2015;20(9):1092-1098. doi:10.1634/theoncologist.2015-0026
57. Byrne M. Spirituality in palliative care: What language do we need? Learning from pastoral care. *Int J Palliat Nurs*. 2007;13(3):118-124.
58. Hinkle LJ, Fetting LP, Carlos WG, Bosslet G. Twelve tips for just in time teaching of communication skills for difficult conversations in the clinical setting. *Med Teach*. 2017;0(0):1-6. doi:10.1080/0142159X.2017.1333587
59. Kapust L. Living with dementia: The ongoing funeral. *Soc Work Heal Care*. 1982;4:79-91.
60. Shippee ND, Shippee TP, Mobley PD, Fernstrom KM, Britt HR. Effect of a Whole-Person Model of Care on Patient Experience in Patients With Complex Chronic Illness in Late Life. *Am J Hosp Palliat Med*. 2018;35(1):104-109. doi:10.1177/1049909117690710
61. Theut S, Jordan L, Ross L, Deutsch S. Caregiver's anticipatory grief in dementia: A pilot study. *Int J Aging Hum Dev*. 1991;33(2):113-118.
62. Hebert R, Dang Q, Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *J Palliat Med*. 2006;9(3):683-693.
63. Fishman P, Coe N, White L, et al. Cost of dementia in Medicare managed care: A

- systematic literature review. *Am J Manag Care*. 2019;25(8):e247-e253.
64. Lin P, Zhong Y, Fillit H, Chen E, Neumann P. Medicare expenditures of individuals with Alzheimer's Disease and related dementias or mild cognitive impairment before and after diagnosis. *J Am Geriatr Soc*. 2016;64(8):1549-1557.
 65. Lamb V, Sloan F, Nathan A. Dementia and Medicare are life's end. *Health Serv Res*. 2008;43(2):714-732.