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Palliative care for patients with advanced dementia

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Abstract: Dementia is currently the seventh leading cause of death and one of the major causes of disability and dependency among older adults globally. Its final stages are complicated by a multitude of problems that can cause immense suffering. This article explores the interconnection between advanced dementia and palliative care and the role of nurses in providing end-of-life care for these patients.

Keywords: Alzheimer dementia, advanced dementia, end-of-life care, palliative care

DEMENTIA IS CURRENTLY the seventh leading cause of death and one of the major causes of disability and dependency among older adults.¹ Globally, Alzheimer dementia (AD) cases are expected to reach 152 million by 2050.¹ In the US, an estimated 6.2 million people are living with AD, and this number is predicted to double by 2050.² AD is the sixth leading cause of death in the US and the fifth leading cause of death for persons over the age of 65.² Further-

more, deaths from AD are thought to be even more prevalent than recorded due to the underreporting of dementia as a cause of death on death certificates.³⁻⁵

Dementia (or major neurocognitive disorder) is not one disease but describes a cluster of symptoms that mainly affects older adults. These symptoms are not considered a normal part of the aging process and are serious enough to interfere with everyday life. AD is the most

common form of dementia; however, the hallmarks of all dementia diagnoses include evidence of significant cognitive decline from a previous level of functioning in at least one cognitive domain such as learning and memory, language, executive functioning, complex attention, perceptual-motor capabilities, or social cognition. The cognitive deficits do not occur exclusively in the context of delirium and are not better explained by another mental health disorder, such as major depressive disorder or schizophrenia.⁶

Objective signs of dementia help measure the progression of the disease. (See *Stages of dementia*). Over time, the cognitive deficits caused by dementia erode patients' independence in completing activities of daily living.^{2,6} In the mild stages (early stage) of AD, patients can function independently in many areas but often need assistance in tasks of daily living such as traveling to new locations and doing complex tasks like planning dinner for guests or

managing finances. Patients with moderate AD may have difficulties in communicating and performing activities of daily living such as bathing, dressing, and other self-care activities. Patients may occasionally experience incontinence and start exhibiting personality and behavioral changes, such as being suspicious of people around them and acting agitated.²

In the final stages (late-stage) of dementia, also known as advanced or severe dementia, patients are likely to require 24-hour care. Detriments to the patient's physical health become apparent in this stage. Individuals often lose the ability to walk and become confined to bed rest, which spirals into other deteriorative sequelae such as thrombi formation, skin failure, infections, sepsis, and eventually organ failure and death.²

Nurses must recognize when a patient is in the final stages of dementia and provide appropriate interventions to manage the multiple manifestations of this disease. Nurses can advocate for a palliative approach to

care that is focused on promoting patient comfort and quality of life. Furthermore, the nurse's role in advance care planning and assessment of living arrangements as well as their close connection with patients and caregivers enable nurses to guide patients through the end of their life with dignity, respect, and minimal distress.

Prognostication

Nurses must be able to recognize when a patient enters the final stages of dementia in order to coordinate appropriate care and communication with the healthcare team, families, and caregivers. This enables families to have closure and say their good-byes to their loved ones. Prognostic recognition of the final stages of dementia can improve the coordination of intensive palliative care with the healthcare team, resulting in less distress and preventing ineffective treatments. Nurses must have accurate prognostication skills when caring for patients at the end of life whether in the home, hospital, or long-term care (LTC) setting.

Medicare supports hospice service at end of life for patients who are terminally ill and want to change the focus of their care to comfort care for pain and symptom management. Patients with Medicare Part A can get hospice benefits and re-certify for hospice benefits – two 90-day periods followed by an unlimited number of subsequent 60-day period – if their attending physician (if they have one) and the hospice physician certify them as terminally ill, with a medical prognosis of 6 months or less to live if the illness runs its normal course.⁶ The Functional Assessment Staging (FAST) scale has been used to stage dementia and predict 6-month mortality.⁷ Hospice eligibility and recertification typically require a FAST score of 7c and either a concurrent illness associated with advanced dementia, impaired

Stages of dementia

Early stage: This is often overlooked because the onset is gradual.

Common symptoms may include:

- forgetfulness
- losing track of the time
- becoming lost in familiar places.

Middle stage: The signs and symptoms become clearer and may include:

- forgetfulness of recent events and people's names
- confusion while at home
- increasing difficulty with communication
- needing help with personal care
- behavioral changes, including wandering and repeated questioning

Late stage: Physical signs and symptoms become more obvious and may include:

- becoming unaware of the time and place
- difficulty recognizing relatives and friends
- increased need for assisted self-care
- difficulty walking
- behavior changes that may escalate and include aggression
- serious memory disturbances
- near-total dependence and inactivity

Source: WHO, 2021. www.who.int/news-room/fact-sheets/detail/dementia

nutritional status, or comorbidities that significantly impair the patient's health and functional status. Despite these conditions for enrollment, these hospice criteria are not reliable indicators of a 6-month prognosis.⁸

Other tools are available to help prognosticate the last months and days of life in patients with advanced dementia. A recent systematic review of dementia prognostic models indicated that the best validated prognostic model for advanced dementia is the 12-item Advanced Dementia Prognostic Tool (ADEPT).⁹ Another study found ADEPT to be marginally better than the Medicare Hospice Guidelines and have moderate accuracy to predict 6-month survival in patients with advanced dementia.⁸ However, like the FAST Stage 7c (nonambulatory), the ADEPT score alone is not very suitable for forecasting death.⁹ The ADEPT tool was found to be 68% accurate in predicting death over 6 months, while the FAST scale was 55% accurate in patients living in LTC facilities.⁸ Since these tools are limited, nurses must consider a patient's goals of care as the overarching guide when making end-of-life decisions with their families and surrogates.

Pain

Up to one-half of persons with advanced dementia experience pain in the last 3 months and weeks of life.¹⁰ Recognizing and treating pain in patients with advanced dementia can be challenging because these patients often cannot self-report. The timely recognition of pain in patients with advanced dementia is imperative for effective pain management.¹¹ A recent systematic review reported that behavioral observation assessments of pain are largely inaccurate, with family caregivers overreporting pain and clinicians often underreporting pain.¹¹ Nurses should encourage the use of self-report measures for patients with dementia regardless of

their cognitive ability. Nurses can implement specific adaptations such as using large font sizes and simple terminologies, especially for patients with moderate or advanced dementia, to help elicit self-reports of pain.¹¹ Nurses should use a multifaceted approach to pain assessment that includes a self-report and thorough pain history, physical assessment, and observation of pain behaviors. For those who simply cannot self-report, nurses may use behavioral observation tools to quantify the patient's pain. The behavioral observation tools found to be most effective in the identification of pain in patients with advanced dementia include the Pain Assessment in Advanced Dementia Scale (PAINAD), Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC), Behavioral Pain Assessment Scale for the Elderly Presenting with Verbal Communication Disorders (DOLOPLUS-2 SCALE), and the Elderly Caregiving Assessment 2 (ECPA).¹¹

Scheduled acetaminophen is effective in reducing pain for people with mild to moderate dementia but has a limited role in advanced dementia due to its oral dosing.¹¹ Concentrated oral opioids such as oral concentrated morphine given sublingually are frequently used for severe pain, and nurses should advocate for around-the-clock administration with break-through dosing as needed.¹⁰ Transdermal opioids, such as fentanyl, are not typically used in end-of-life care for patients with advanced dementia, unless the patient has already been prescribed this drug due to pre-existing chronic pain prior to end of life. This method of opioid administration is difficult to titrate due to the long half-life associated with transdermal delivery. Cachexia and fevers also make the transdermal route unreliable, either delivering too much or too little of the drug. For opioid-naïve patients, low doses of

oral or parenteral opioids will likely provide relief. However, nurses may need to request parenteral dosing and continuous opioid infusions for non-opioid-naïve persons and those experiencing severe pain.¹⁰

Dyspnea

Dyspnea is a readily visible but often dismissed symptom at the end of life. Nurses understand that respiratory distress often escalates in the final days of life and coincides with the patient's inability to self-report. The Respiratory Distress Observation Scale (RDOS) is a frequently used tool that nurses use to monitor respiratory distress at the end of life in patients in hospice.¹² The RDOS is used to score the degree of respiratory distress by observing respiratory and heart rates, paradoxical breathing patterns and use of accessory muscles, restlessness, grunting at end-expiration, nasal flaring, and a look of fear. A score greater than or equal to 3 indicates the necessity of both nursing and pharmacologic interventions to reduce dyspnea.¹²

Opioids not only relieve pain but are very effective at relieving dyspnea at the end of life as well.¹³ Excessive respiratory secretions often accompany dyspnea. Nurses can manage this symptom with frequent mouth care, oral suctioning, and administration of anticholinergic agents via sublingual or parenteral routes. If stridor is noted, nurses can work with respiratory therapists to provide inhaled furosemide and anxiolytics as adjunctive therapies.¹³ Inhaled racemic epinephrine can also be administered to patients to relieve stridor; inhaled short-acting beta-2 agonists are ineffective.¹³ Nurses may also independently implement effective nonpharmacologic therapies for dyspnea, such as using fan therapy (which uses a fan to blow air toward the patient's face), maintaining a cool temperature in the patient's room, adjusting the patient's body position, and establish-

ing visitor limitations.¹³ If dyspnea or pain persists despite attempts to reduce symptoms, the nurse should consider the need for an inpatient hospice unit for specialty symptom management.

Polypharmacy and specific pharmacologic agents

Persons with advanced dementia often take medications for their chronic diseases that are no longer beneficial. Nurse and caregiver administration of these medications often becomes an overwhelming task and a source of anxiety. Nurses should be cognizant of the frequency of inappropriate polypharmacy in patients with advanced dementia. Between 54% and 86% of patients with advanced dementia in LTC facilities receive at least one medication of questionable benefit, including lipid-lowering drugs, sex hormones, cholinesterase inhibitors, cytotoxic chemotherapy, antiplatelet agents, and immunomodulators.¹⁴

Currently, there is no standard definition of polypharmacy. Some publications describe polypharmacy as the presence of prescribed medications over a threshold number of four or five.¹⁵ There is more agreement recognizing the association between polypharmacy and potentially inappropriate prescribing (PIP) in older adults.¹⁶ The multiple tools designed to determine medication appropriateness for older adults do not consider those with a dementia diagnosis, such as the Beers criteria, the Screening Tool of Older Person's Prescriptions (STOPP), and the Screening Tool to Alert Doctors to Right Treatment (START).^{16,17} For detailed information about polypharmacy for this patient population, nurses can reference the criteria identified by Holmes, et al., and Parsons, et al., which characterize medications based upon their appropriateness for use in patients with advanced dementia needing

palliative care: never appropriate, rarely appropriate, sometimes appropriate, or always appropriate. These criteria represent the only current and available system for identifying PIP in people with advanced dementia who may need a palliative approach.^{17,18}

FDA-approved medications such as donepezil, rivastigmine, galantamine, and memantine are indicated to control behavioral symptoms and reduce cognitive decline in the early or moderate stages of dementia.

Nurses can suggest the discontinuation of these medications when the patient reaches advanced dementia because their usefulness may have ended.¹⁹

On June 7, 2021, the US FDA approved the clinical use of aducanumab, the first new drug for Alzheimer disease in 18 years.²⁰ Aducanumab is an amyloid beta-directed antibody indicated for the treatment of Alzheimer disease administered by I.V. infusion. Unfortunately, the indication for the medication excludes the advanced stage of dementia.²¹ Therefore, nurses can reassure the families of patients with advanced dementia that their loved one is not missing out on any new potential therapies.

Mood and behavioral issues

Behavioral issues are higher in patients with dementia (76%) than without (38%).²² The overall frequency of behavioral issues increases from 67% in mild dementia to 76% in moderate dementia and to 88% in advanced dementia.²² Nurses can monitor patients for signs and symptoms of depression, agitation, apathy, fearfulness, and psychosis, which are often difficult to diagnose and manage.²² Nurses can use the neuropsychiatric inventory to quantify 12 behavioral symptoms and assess for concerning behavioral is-

ues in people with dementia.²³ In patients with advanced dementia, nurses may observe depression and symptoms such as anorexia, apathy, low energy, limited communication, and insomnia. These symptoms are often partially related to chronic diseases and medications.^{24,25} Nursing

administration of antidepressant medications may be indicated in a patient with high clinical suspicion of depression; however, there is no strong evidence to recommend the routine use of antidepressants in persons with advanced dementia.²⁶

Nurses may also observe behavioral issues such as aggression, motor agitation, delusions, hallucinations, and combativeness in patients with advanced dementia often associated with caregiver and family distress.²⁷ The cornerstone for the treatment of these symptoms includes nurses' use of nonpharmacologic approaches such as redirection, education and support for caregivers, environmental redesign, exercise, massage, and music therapy.²⁸

Administration of antipsychotics has been part of the routine management of behavioral issues in palliative care despite limited research to support this practice and no FDA approval for this indication.²⁹ Nurses must be aware that the use of first-, second-, and third-generation antipsychotics are associated with an increased risk of death, stroke, and transient ischemic attack.³⁰ These patients' surrogate decision-makers and healthcare teams must have an honest conversation about the risk and benefits of these medications.

Urinary tract infections (UTIs) and pneumonia

UTIs are commonly misdiagnosed and mistreated in older adults and overly diagnosed in patients with



dementia, leading to increased costs, hospitalizations, and inappropriate antibiotic use without increased survival.³¹⁻³³ In 2019, the Infectious Disease Society of America updated its 2005 Guidelines on Asymptomatic Bacteriuria (AB).³⁴ These new guidelines direct that patients with delirium but no urinary or systemic symptoms be assessed for other causes of delirium instead of being given AB treatment. Recommendations to curb antimicrobial misuse in patients with AB include not testing urine when other causes for infection are possible, canceling urine cultures if the urine dipstick for urine leukocyte esterase and nitrite is negative, avoiding urinary catheterization, and not providing antimicrobials in clinically stable, nonfebrile older adults who do not have acute, local genitourinary symptoms.³⁵

Many patients with advanced dementia receive care in LTC facilities. For these patients, nonlocalizing signs and symptoms such as acute confusion, delirium, falls, or foul-smelling urine may cause healthcare providers to suspect symptomatic UTI. However, nurses should be aware that these are not valid indicators and may lead to unnecessary testing and antimicrobial use.³⁶ Nurses should monitor for acute, localizing genitourinary symptoms in this population to support the diagnosis of symptomatic UTI.³⁶ For patients with indwelling urinary catheters, nurses should monitor for fever as it is a common presentation of symptomatic UTI. Nurses in LTC should understand that bacteriuria is always present in this group of patients and therefore urine should not be cultured.³⁶ Patients in LTC who are not receiving palliative care are more likely to be transferred to the hospital due to infection.³⁷ For patients who do not wish to be transferred to a hospital, the nurse should advocate for a palliative approach to manage UTIs. This may include

administering phenazopyridine to suppress bladder spasms and antipyretics if fever is present.³⁸

Pneumonia is frequently an immediate and underlying cause of death in patients with dementia and is the second most common infection at the end of life in terminally ill patients in hospice.³⁹ Patients with dementia develop pneumonia more frequently when certain risk factors are present. These risk factors include older age, male sex, underlying cerebrovascular disease, chronic pulmonary disease, heart failure, use of antipsychotics, and proton pump inhibitors.^{39,40} Patients with dementia also have higher hospital readmission rates and higher short-term risk of death after pneumonia, especially for patients taking antipsychotics.³⁷ Nurses should know that antimicrobial use for pneumonia in patients who are terminally ill, including patients with advanced dementia, does not provide consistent symptom management nor does it improve survival.^{34,40} In fact, it leads to the emergence of multidrug-resistant bacteria in LTC settings.^{34,40} For palliative purposes, dyspnea associated with pneumonia responds well to opioids; antitussives may ease the symptoms of cough; otic drops can relieve pain from otitis media; and finally, fever has long been alleviated with the use of antipyretics.³⁷

Cachexia

Neuroinflammation, impaired glucose and insulin homeostasis, mitochondrial dysfunction, and oxidative stress have been cited as common precursors to cachexia.⁴¹ Weight loss associated with cachexia has multiple causes. Nurses should monitor patients for anorexia and reduced food intake, hypothalamic feeding dysregulation, changes in smell perception, behavioral changes, dysphagia, and certain comorbidities such as recurring pneumonia and hypoalbuminemia.⁴² The inability to main-

tain sufficient fluid and calorie intake with 10% weight loss during the previous 6 months or serum albumin <2.5 g/dL (normal, 3.4 to 5.4 g/dL) should indicate that the patient with dementia is entering the end of life.⁴²

Despite the perceived need to provide artificial nutrition for persons with advanced dementia, enteral feedings significantly increase the risks of pneumonia and pressure injuries, do not improve survival, and may even hasten death.⁴³ Furthermore, there is no evidence that withholding artificial nutrition or fluids causes increased thirst or hunger in patients with advanced dementia.⁴³ Nurses can help educate and comfort families who choose not to artificially feed their loved ones in the advanced stages of dementia, easing anxiety and guilt.

Complications associated with enteral feeding, coupled with the lack of efficacy, have led to a consensus that feeding tubes in patients with advanced dementia are contraindicated.⁴⁴ Careful hand feeding is preferred and supported by the American Geriatrics Society and the American Board of Internal Medicine's Choosing Wisely Campaign.⁴⁵⁻⁴⁷ Because of intentional efforts to educate healthcare providers and the public about the negative effects of feeding tubes in patients with advanced dementia, a significant reduction in their use in LTC settings occurred during the years of the educational drive. This concerted effort led to a drastic reduction from nearly 12% in 2000 to less than 6% in 2014.⁴⁸

Delirium

Delirium at the end of life is common, affecting up to 75% of persons during their final weeks of life, and is an independent predictor of mortality.^{49,50} Delirium has three subtypes: hyperactive, hypoactive, and mixed. The hyperactive form can be observed as acute agitation, confusion, restlessness, and reversal

of the sleep pattern. The hypoactive form can be observed as decreased psychomotor activity. The mixed form of delirium is observed as a combination of both hyperactive and hypoactive forms.⁵¹ Validated screening tools for delirium include the Confusion Assessment Method (CAM), the Nursing Delirium Screening Scale, and the 4AT.

Acute change or fluctuating courses are often not useful in assessing a patient with advanced dementia.^{49,52} Rather, family input has been found to be the most useful source of information. Current delirium prevention guidelines have unclear efficacy in patients with advanced dementia, and the implementation of these guidelines is often challenging.⁵³

The most important aspects in the management of patients with delirium should be focused on the resolution of underlying medical problems (such as pain or infection), nonpharmacologic strategies, and avoiding PIP.⁵⁴ If nonpharmacologic strategies have been ineffective and the patient with delirium is considered a risk to themselves or others, medications such as haloperidol and atypical antipsychotics (olanzapine, risperidone, quetiapine) could be administered.⁵⁵

Advance care planning

Advance care planning is a process in which patients and families, together with their healthcare providers, identify acceptable care preferences for when the patient is unable to communicate their wishes.⁵⁶ It should occur incrementally over time, not elicited suddenly or during a serious illness.⁵⁷ Last-minute decisions often lead to misaligned treatment goals, increased costs, repeated hospitalizations, and inadequate symptom control.^{58,59} Failure to acknowledge the progressive course of dementia and lack of ongoing advance care planning discus-

sions with a consistent provider contribute to increased suffering for patients with advanced dementia.⁵⁸⁻⁶¹

Nurses often know the patient and family best and can act as a liaison between families and coordination of palliative care needs. When surrogates of persons with advanced dementia choose palliative care at the end of life, hospitalizations are not indicated unless comfort needs could not be met in the current location.⁶² Hospice should be recommended at this time.

Institutionalization

The cost of dementia care is greatly increased if the patient is institutionalized. A recent study reviewed 9,230 people with dementia and 24,624 matched controls from family physicians' electronic records linked with national administrative databases and found the median time from documented diagnosis until institutionalization and death for people with dementia was 3.9 and 5.0 years.⁶³ Patients with dementia who have been institutionalized can expect to spend \$100,000 more than persons without dementia in their last 5 years of life.⁶⁴ Patients in LTC and their families can expect to pay \$247 to \$280 per day or \$90,155 to \$102,200 per year for a semiprivate or private room.⁶⁵ Medicaid is the only public program that covers lengthy LTC facility admissions. Private LTC insurances can offset many costs, although it was purchased by only 7.5 million Americans in 2020.⁶⁶

Caregivers

An alternative to institutionalization is home care with paid or unpaid caregiver support. In 2019, 18.6 billion hours of care were provided to patients with dementia by approximately 16.3 million unpaid caregivers. It is estimated that more than 83% of care for persons with advanced dementia is provided by

unpaid caregivers, at an estimated monetary value of \$244 billion.^{2,67}

These caregivers are at risk for significant employment and health consequences associated with the caregiving role and have increased stress and depression.² Barriers to self-care for informal caregivers include factors such as being a woman, of minority ethnicity, increased length and duration of caregiving, and decreased functional status of the patient with dementia.⁶⁸ Nurses should monitor for and intervene when caregiver stress is high. Some positive aspects of caregiving noted by informal caregivers include "making a difference" and fulfilling obligations.⁶⁹ Positive caregiver experiences are attributed to access to medical counseling and formal and informal care support and are impacted when the caregiver understands the impact of caregiving and that they deserve self-care.⁶⁸ Nurses must emphasize caregivers' positive role and provide support. Still, almost 50% of local aging services do not offer family caregiver interventions, and resources for self-care in communities remains limited, especially for ethnically diverse caregivers.^{1,68}

Conclusion

Advanced dementia is a common cause of death and suffering. Its course is plagued with physical, financial, and psychosocial complications that affect the quality of life of patients and caregivers. Palliative care for patients with advanced dementia can bring physical and psychological respite to those affected, as well as address the emotional and financial aspects of caring for these patients. Being front and center in providing palliative care for patients with advanced dementia, nurses must be aware of the different disease stages, appropriate interventions, and other aspects of care such as advance care planning to ensure quality end-of-life care. ■

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