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Review Article

Palliative Care as a Primary Therapeutic Approach in Advanced Dementia: A Narrative Review

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ABSTRACT

Purpose: The goal of this narrative review was to identify and summarize the ways in which palliative care could benefit patients who have advanced dementia.

Methods: This case-based discussion article examines current literature on palliative care for dementia.

Findings: Dementia is an incurable, progressive disease that affects millions of subjects. The prevalence has grown in the last decade and is projected to continue on this trajectory. In the later stages of dementia, subjects require increasing levels of care due to severe cognitive and functional impairment. Although the field of palliative medicine focuses on improving the quality of life of patients with life-limiting illnesses, many patients with advanced dementia do not receive palliative care services.

Implications: Palliative care has been shown to improve patient and caregiver satisfaction, quality of life, and symptom burden at the end of life. Patients with advanced dementia would benefit from increased access to palliative care. (*Clin Ther*. 2014;36:1512–1517) © 2014 Elsevier HS Journals, Inc. All rights reserved.

Key Words: palliative care, dementia, Alzheimer's disease, geriatrics, geriatric psychiatry.

INTRODUCTION

Dementia, regardless of subtype, is an incurable neurodegenerative disease, characterized by progressive impairment in cognition and functional status. Although patients may live for decades after the initial onset of symptoms, it is ultimately a terminal diagnosis. In 2012, ~5.2 million people in the United States had a diagnosis of Alzheimer's disease (AD); by 2025, that number is expected to reach 6.7 million.[1] In 2010, AD was the fifth leading cause of death in Americans aged >65 years, reflecting an increase of 38.7% from 2000 to 2010.[2] Worldwide, an estimated 44.4 million subjects have dementia, and by 2030, there will be a projected 75.6 million people with the disease.[3] Despite the prevalence, patients with dementia are, as a whole, underrepresented within the palliative care population.

Palliative care focuses on improving patients' quality of life by alleviating the symptom burden of life-limiting illnesses. The palliative care population includes patients who are terminally ill and have ≤6 months to live (hospice-eligible patients), those who are terminally ill but have a life expectancy >6 months, and those who have a life-limiting illness but are not imminently dying. Palliative care may be delivered alongside potentially curative treatments, at any stage in the disease process. Patients can receive services in outpatient clinics, nursing facilities, and hospitals, as well as at home.

Palliative care has been shown to increase quality of life in patients, families, and caregivers; decrease medical costs; and reduce hospital usage.[4–8] In the case of cancer, early access may extend survival.[9–11] A palliative care approach to dementia moves the focus of medical care from estimated prognosis to quality of life. Currently, the goal of dementia treatment is not

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to cure but to slow progression and alleviate symptoms that interfere with quality of life. Such symptoms include behavioral problems, functional decline, sleep disorders, and eating difficulties; these symptoms not only cause distress for patients but also negatively affect caregivers and family members.

Formally introducing dementia patients to palliative care can help ameliorate such symptoms and enhance additional aspects of management, including delineating goals of care for patients, providing caregiver support, and managing long-term care planning options. A palliative approach can help reduce the medical burden placed on patients from multiple medications, procedures, and hospitalizations. It can also help patients and families explore their own expectations about the disease process and ideas of symptom management.

This case-based discussion article examined the current literature on palliative care for dementia.

STAGES OF DEMENTIA AND IMPACT ON TREATMENT DECISIONS

In its early to moderate stages, dementia is often seen as a chronic syndrome, rather than as a primary life-limiting disease. The consequence of this perception is that medical decisions are made in isolation, without consideration of how treatments may impact the specific vulnerabilities of a patient with dementia. In particular, dementia (especially AD) is associated with cognitive impairment, memory loss, and problems with language expression and comprehension, all of which can have significant effects on treatment outcomes.

When a patient with a life-limiting cancer diagnosis is being considering for a medical treatment, the presence of the cancer would prompt a number of questions. How will the treatment affect the cancer? How will the presence of cancer impact recovery from or tolerability of the procedure? What is the patient's overall prognosis, and how does that influence the feasibility of the particular treatment?

Similarly, in patients with dementia, there should be a consideration of staging: patients with early-stage AD are typically able to reason through issues of some complexity and make their own medical decisions, but they may not recall the process or their decision; they would need reminders as well as preservation of their process through a written or videotaped record. Patients with more advanced disease may tolerate the medical procedure in question but may encounter complications due to an inability to sit still, to say they are in pain, or to remember not to touch an indwelling line or catheter.

Prognostication in dementia is an inexact science, most studied in patients with AD, and largely based on functional and cognitive decline. AD is generally described based on mild, moderate, and severe disease stages; those patients who fall into the severe category experience profound cognitive impairment, require assistance with all aspects of personal care, and experience neurologic dysfunction such as gait instability, incontinence, and difficulty swallowing. Survival time after diagnosis of AD ranges from 4 to 8 years on average, often depending on the stage of disease at diagnosis.[12–16]

In the United States, Medicare hospice eligibility for dementia is based on the Functional Assessment Staging Tool. Once patients meet criteria for stage 7c, they are presumed to have a prognosis of ≤ 6 months and thus are hospice eligible. However, several studies investigating the accuracy of dementia prognostic tools have found that the Functional Assessment Staging Tool did not reliably predict 6-month mortality.[17,18] This finding is problematic in that dementia patients who have poor prognostic indicators may nevertheless be ineligible for the Medicare Hospice Benefit. Access to early palliative care can assist patients and families with end-of-life planning before the onset of advanced dementia, especially important given the prognostic difficulties in late-stage dementia.

PALLIATIVE MANAGEMENT OF MEDICAL CONCERNS IN ADVANCED DEMENTIA

Mrs. B., a 96-year-old, formerly fiercely independent woman, had several years of strokes, which caused increasing cognitive impairment and functional decline. Her last hospitalization, after another major stroke, was prolonged when she developed pneumonia and sepsis. Once at home, she began having occasional episodes of bradycardia that resulted in acute confusion and dizziness. She had previously expressed a desire to stay out of hospitals and focus on comfort care, but the episodes concerned her family, and they wondered if she should be hospitalized for evaluation.

Hospitalizations are associated with poor outcomes in patients with advanced dementia. Both age and