

Palliative Care for Dementia

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KEYWORDS

• End of life • Palliative care • Hospice • Dementia • Dying

KEY POINTS

- The population with dementia will represent a group with specific end-of-life care needs that will require better access to hospice and palliative services.
- End-of-life care in dementia has special considerations in addressing behavioral disturbances and maintaining attention to goals of care.
- Unique problems in the care of the patient with dementia at the end of life may be related to refractory delirium (confusion) and cachexia (failure to maintain weight).

INTRODUCTION

With the increase of the elderly population and increasing burden of dementia care, one may consider the need for palliative and hospice services as an urgent public health priority, particularly given that Alzheimer's disease is now the sixth leading cause of death in the United States.¹ This public health need is underscored by the severe burden of emotional distress endured by family caregivers and the potential for relief afforded by appropriate end-of-life services in dementia.^{2,3} End-of-life services have been historically created for the context of cancer care, with less of a focus on dementia, although this has changed considerably in recent years. For example, in 1995, less than 1% of hospice patients were observed to have a primary diagnosis of dementia,⁴ whereas almost 15% of all hospice enrollments in 2014 were in the context of dementia care.⁵ Despite this reassuring rapid increase, there remain challenges in ensuring that patients with dementia are given the chance for the best possible care at the end of life.

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Management of dementia is complicated by neuropsychiatric symptoms such that the longitudinal care of a psychiatrist or other mental health provider is often a central part of the primary care of the patient and a major source of family support. Given the importance of continuity of care at the end of life, the involvement of psychiatry in palliative and hospice services affords a critical opportunity for growth. For example, a recent European consensus document has outlined recommendations for optimal palliative care for dementia and included continuity of services as among its top major domains of high-quality care.⁶ Further, within the top domain, an explicit recommendation included attention to behavioral care within a comprehensive care setting. To achieve the best care for both our patients suffering from dementia as well as their caregivers, it is necessary to achieve 2 goals, one is to improve access for persons with dementia, and the second is to engage providers with psychiatry expertise to be involved in those services. This article addresses how issues in prognostication in dementia may affect the first goal. The article then reviews how psychiatry expertise may be used for the specific clinical issues that require attention in dementia care at the end of life.

PROGNOSTICATION

Difficulties with prognostication is one of the greatest barriers to access to end-of-life services in the content of dementia, given the absence of highly predictable metrics in estimating survival relative to other medical conditions.⁷⁻¹⁰ The lack of clear metrics and variable outcomes in survival time creates significant difficulty for families, patients, and even clinical care providers to conceptualize dementia as a terminal condition.^{11,12} The recent European consensus notes in its primary recommendation that dementia can realistically be regarded as a terminal condition and “recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.”⁶ Although there is great heterogeneity in its early stages, all dementias move toward a stereotypic terminal stage of inexorable functional decline, frailty, cachexia, and medical complications, with median survival about 5 years from diagnosis.¹¹ In this regard, end-stage dementia is strikingly similar to advanced cancer or congestive heart failure. One means of conceptualizing end-stage dementia is a condition of “brain failure,” with all the characteristics associated with other major organ failure (eg, advanced liver failure or congestive heart failure).¹³ When viewed as progressive major organ failure, it may help to reduce the likelihood of inappropriately viewing dementia as purely a deficit in memory function, which does not adequately reflect the global dysfunction and deterioration of advanced disease.

Traditionally, the course of end-stage dementia has been characterized as one of slow, steady decline, but Sachs and colleagues⁷ have suggested that the more likely scenario is one of slow progression punctuated by recurrent health crises. In this regard, the actual pattern may be more akin to that seen in end-stage chronic obstructive pulmonary disease or congestive heart failure, where small disruptions in health status may result in severe symptoms. The crises seen in end-stage dementia may be more variable given that there is a risk for instability in the face of minor perturbations in fluid status, infections, or aspiration. Consequently, these crises may include episodes of aspiration pneumonia, urosepsis, dehydration, delirium, or falls. Medical decision making gains importance during these crises and the importance of a palliative approach comes to the fore when there is a risk for aggressive interventions (hospitalization, artificial nutrition and hydration). Recurrent crises offer an important opportunity to engage with the patient and family decision makers about appropriate

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