Dementia, Prognosis, and the Needs of Patients and Caregivers

Alzheimer disease and other types of dementia are common in older patients, especially those older than 85 years of age (1). While several studies suggest that life expectancy is shortened in patients with dementia, we know less about the prognosis of dementia than that of other life-threatening illnesses, such as cancer or congestive heart failure (2). Developing a better understanding of the impact of dementia on life expectancy is important because accurate prognostic estimates can inform the goals of care for older people. For example, when a physician knows her patient has a poor prognosis, she may avoid recommending care that is of little benefit in the last years of life, such as cancer screening tests, and focus on minimizing the burden of symptoms (3).

In this issue, Larson and colleagues (4) provide new information about the prognosis of Alzheimer disease. They followed 521 patients enrolled in a managed care organization after the diagnosis of Alzheimer disease. Across all age groups, patients with the disorder had considerably reduced survival times than would be expected from U.S. Census life tables. In fact, Alzheimer disease reduced life expectancy by about half. Furthermore, several clinical indicators, including worse cognition, significant functional impairment (such as gait disturbance), or major comorbid conditions (such as diabetes or heart failure), distinguished which newly diagnosed patients were likely to fare worse than average.

Clinicians should be able to apply the findings of this rigorous, carefully conducted study to their patients with newly diagnosed dementia. The authors examined patients in a “real-world” setting and collected prognostic information that would generally be available to primary care clinicians. They enrolled patients when their symptoms first came to clinical attention, and few patients were lost during the follow-up period.

In applying the study’s results to patients, however, we must recognize a subtle but clinically important distinction. The study examines survival after a diagnosis of Alzheimer disease, which is not necessarily the same as survival after onset of the disease. Since cognitive decline is often insidious, identifying the precise time when a patient first meets diagnostic criteria for dementia is difficult without frequent cognitive testing. This complicates the interpretation of such risk factors as gait disturbance or the severity of cognitive impairment. It is not clear whether patients with these risk factors have worse survival because they have more aggressive forms of dementia or because these risk factors signify patients whose dementia was diagnosed at a later point in its natural history.

Yet another detail complicates the task of identifying prognostic indicators: The diagnosis of dementia is not entirely a biological event—social and other medical factors play a role in determining the point at which loss of cognition becomes obvious. The diagnosis of dementia often occurs when a family member notices that a patient’s cognitive problems cause impaired functioning in day-to-day activities. The frequency of contact with other people and family members’ alertness to changes in cognition and willingness to get involved will affect the time of diagnosis. In addition, the point at which someone notices cognitive impairment reflects the patient’s ability to compensate. Noncognitive factors, such as worsening of other chronic diseases, declines in functional status, loss of social support, or depression, may lead to the diagnosis of dementia because they compromise the patient’s ability to compensate. These factors may lead to the diagnosis of dementia at an earlier point in its natural history; however, they are prognostically important in their own right and may partially account for the poor prognosis of patients receiving a diagnosis of dementia. As cognitive screening becomes more widespread, physicians must become skilled at taking into account the interplay of social factors, comorbid conditions, and their attendant effects on day-to-day functioning, and the natural history of dementia.

Patients receiving a diagnosis of dementia through cognitive screening rather than by an evaluation prompted by the concerns of the patient or caregiver are likely to have a considerably longer life expectancy than the patients in Larson and colleagues’ study. This phenomenon does not mean that screening and early treatment improve prognosis. Rather, it is an example of lead-time bias, in which screening appears to increase survival time but in fact only increases the length of time a person lives with a diagnosis. In other words, screening identifies the disease at an earlier point in its natural history, without necessarily altering its course (5). Clearly, the life expectancy of a patient newly diagnosed with dementia may vary depending on the events precipitating the diagnosis. This observation notwithstanding, the finding of Larson and colleagues that patients receiving a diagnosis of dementia have substantially decreased life expectancies appears robust.

The poor prognosis of many patients with dementia has important implications for their care. From our knowledge of the prognosis and clinical course of dementia, we know that a diagnosis of dementia is a sentinel event that signifies progressive loss of independence and increasing demands on caregivers. A dementia diagnosis should prompt a clinician to define a patient’s palliative care needs by carefully considering the best way to sustain the quality of life for both the patient and the caregiver.

Clinicians may be alert to the palliative care needs of patients with metastatic cancer but may not realize that a dementia diagnosis is also a sentinel event for planning end-of-life care. Patients with malignant conditions have a relatively short period of declining health before death (6, 7), but in patients with dementia, health declines over a
long period, and it is difficult to determine when they have entered the last months of life and become eligible for Medicare coverage of hospice care (6, 8). This observation may explain why fewer patients with dementia receive a referral to hospice than patients with cancer (9). Certainly, physicians should consider hospice referral for patients with dementia whose illness has features that suggest very limited life expectancy, such as in ability to ambulate, eat, or communicate without assistance; decubitus ulcer; and recurrent pneumonia (10, 11). However, patients with dementia and their caregivers often have significant needs for palliative care services long before the patient is eligible for hospice. Many patients with dementia are not able to obtain the palliative services they need, such as assistance with activities of daily living, day health services, and respite care. As a result, caregivers shoulder most of the burden of caring for a patient with dementia (12–16).

Despite limitations posed by our health system, primary care clinicians can help patients with dementia by helping them to formulate plans for palliative care. The plan should focus on the comfort and quality of life for both patients and caregivers. Physicians and caregivers should identify surrogate health care decision makers and assess the patient’s preferences for care at the very end of life (17, 18). In some cases, patients may express preferences that should cause clinicians to reconsider the balance of benefit and harm of life-prolonging care (11, 17). However, many patients with dementia want life-prolonging care, and palliative care planning should accommodate them. In any patient with an ultimately fatal, chronic disease, offering life-prolonging and palliative care at the same time is often appropriate.

Larson and colleagues’ article can help patients, caregivers, and clinicians to establish priorities in their respective roles. Some patients with dementia and their caregivers will be distressed to learn that dementia is associated with reduced life expectancy. However, we suspect that progressive cognitive and functional decline will remain their primary concerns. Thinking of dementia as a progressive, chronic disease may help clinicians reset their priorities to focus on palliative care planning and to assess their patients’ preferences for care. This type of thinking is necessary for good care of patients with dementia, but it is not enough. Unfortunately, the U.S. health care system places many barriers in the way of good palliative care (6). Our duty to our patients extends to advocating changes that will give patients and caregivers better access to the care they need.

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