



NATIONAL ASSOCIATION OF **CHRONIC DISEASE DIRECTORS**

Promoting Health. Preventing Disease.

Transition Opportunities: Alzheimers Disease: Issues and Ethical Approaches

Background

Alzheimer's Disease in the United States

Currently, 5.4 million Americans have Alzheimer's disease. Among individuals with the disease, 5.2 million are 65 years of age or older and 200,000 are under the age of 65 and living with younger-onset.¹

Alzheimer's disease is fatal and currently recognized as the sixth leading cause of death in the United States. Due to underreporting and underdiagnosing of the disease, a recent major study indicated the disease might be as high as the third leading cause of death in the country. No cure exists and current available medication temporarily treats some of the symptoms, though with varying effectiveness. Currently, no available treatment slows or stops the disease progression.

Over the coming years, researchers predict the United States will see a dramatic demographic shift, with an increasing number of Americans living to older ages, and with older Americans expected to make up 20 percent of the population by the year 2030. The rapid growth in older Americans will also mean more people living with Alzheimer's disease. By 2050, scientists estimate that 13.8 million people will have Alzheimer's disease.²

Alzheimer's disease and other dementias pose an immense financial and social toll on the person with dementia, family caregivers, employers, and the healthcare system, making advanced care and financial planning of utmost urgency.

Alzheimer's Disease & Other Dementias

Alzheimer's disease is the most common cause of dementia, a neurocognitive disorder marked by symptoms including a decline in memory, language, planning, problem-solving, and other cognitive skills that impact an individuals' ability to perform activities of daily living.

Dementia may also be caused by various other conditions, including Vascular dementia, Dementia with Lewy bodies (DLB), Frontotemporal lobar degeneration (FTLD), Parkinson's disease, Creutzfeldt-Jakob disease, among others. All of these conditions are progressive and fatal. In a smaller percentage of

¹ Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2016;12(4).

² Ortman JM, Velkoff VA, Hogan H. An Aging Nation: The Older Population in the United States, Current Population Reports, P25-1140. U.S. Census Bureau, Washington, D.C. 2014. Available at: <http://www.census.gov/content/dam/Census/library/publications/2014/demo/p25-1140.pdf>.

cases, dementia-like symptoms may have reversible causes, such as thyroid disease, vitamin deficiencies, depression, delirium, and medication side effects.

A definitive diagnosis is of utmost importance—for reasons including appropriate treatment, involvement in research, and for advanced planning. However, current studies indicate that only half of people who would meet the diagnostic criteria for Alzheimer's and other dementias obtain a physician diagnosis. For those who do have a diagnosis documented in their medical records, fewer than half report being told of the diagnosis.³

Challenges to Early and Accurate Diagnosis

Early diagnosis has many benefits to the individual with dementia, their family, and the healthcare system as a whole. Significant for both the healthcare industry and the family, they have an increased ability to plan for the future, potentially delaying costly nursing home placement and avoidable hospitalizations. Research shows they are better able to make informed decision, receive higher quality medical care, and have increased access to services, disease education, and social support.^{4 5}

An early diagnosis often increases the ability to participate in research studies. Many scientists believe that medical interventions early in the disease process hold the key to finding effective treatments. Thus, research involvement at this early stage provides potential advantages for the individual by enabling access to the latest medications, and for future progress toward medical interventions meant to slow or stop the progression of dementia.

Despite the many benefits to early diagnosis, barriers remain. In some cases, individuals do not seek out a diagnosis due to lack of knowledge about dementia, fear and stigma, or a belief that dementia is a normal part of aging. Ethical challenges also surround the diagnosis of dementia from the provider perspective, with many primary care physicians failing to disclose a diagnosis. Some of the reasons providers cite include diagnostic uncertainty, time constraints, stigma, fear of causing emotional distress, patient or caregiver wishes, and the lack of disease-modifying treatment. Efforts to educate providers on dementia are of utmost importance for both the future of research and advanced care planning.

Caregiving

Caregivers provide 18.1 billion hours of unpaid assistance to people with Alzheimer's and other dementias, valued at \$221.3 billion in 2015. Caregivers of people with dementia often provide more extensive assistance than those caring for people with other conditions. The disease has unique challenges, which include disorientation, loss of judgement, and loss of the ability to communicate. Personality and behavior changes, the eventual need for 24-hour supervision, the increasing need for assistance with all activities of daily living and with medical tasks, and the impact on employment and finances to pay for care, all place an enormous toll on caregivers.

Caregivers do often report positive reactions to caregiving, but many also experience declines in their own emotional and physical health, combined with an increased risk of chronic conditions and death.

³ Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2015;11(3)332+.

⁴ Barrett AM, Orange W, Keller M, Damgaard P, Swerdlow RH. Short-term effect of dementia disclosure: How patients and families describe the diagnosis. *J Am Geriatr Soc* 2006;54(12):1968-70.

⁵ Campbell P, Wright J, Oyeboode J, Job D, Crome P, Bentham P, et al. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry* 2008;23(10):1078-85.

Health care costs associated with caregiving are estimated to amount to a striking \$10.2 billion in the United States for 2015.

Families often take on a huge financial burden to care for an individual with dementia. For many, it affects their employment, whether they take a leave of absence, go in late or leave early, or quit their job in order to provide care. In other cases, people contributing to care costs have needed to increase their hours of employment, postpone retirement, or return to work in order to cover the increased costs.

Cost of Care and Community Care Trends

Alzheimer's disease is one of the costliest chronic diseases. Total payments in 2016 for all individuals with Alzheimer's disease and other dementias are estimated at \$236 billion, with Medicare and Medicaid covering \$160 billion, and out-of-pocket spending covering \$46 billion. Total annual payments for people with Alzheimer's disease and other dementias are expected to increase to more than \$1 trillion in 2050.⁶

Older people with Alzheimer's disease and other dementias utilize health care services to a greater extent than others—with more hospital stays, skilled nursing facility stays, and home health care visits than older adults without dementia. According to one major study, people living with dementia in the community were more likely to have a preventable hospitalization, avoidable emergency department visits, placing a heavy toll on the Medicare and Medicaid system.⁷

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services by older adults. Two types of programs have demonstrated the potential to reduce avoidable health care and nursing home use: caregiver support programs in the community and collaborative care models that include geriatricians, social workers, nurses, and medical assistance to improve care coordination.

Opportunities for the new administration:

1. One of the frequently noted issues is the need to develop advance directives at the point of diagnosis or before to respect the autonomy of the patient. CMS can prioritize development of advance directives at time of diagnosis (or update existing advance directives) through incentives in rate setting and specific coverage guidance.
2. Physicians and other health professionals report discomfort with discussing dementia with patients and caregivers. HRSA can provide extensive training on communicating this difficult diagnosis and discussing predictable sequela as a preface to developing a fully informed advance directive and helping families prepare.
3. NIH to prioritize research on ethical issues related to Alzheimers Disease, from early stage questions of life changes to late stages and respecting autonomy.
4. Often providers report regulatory limitations on following ethical approaches. Some of these perceptions are true and others reflect misinformation about rules. HHS ASPE can study and

⁶ Alzheimer's Association. 2016 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2016;12(4).

⁷ Rudolph JL, Zanin NM, Jones RN, Marcantonio ER, Fong TG, Yang FM, et al. Hospitalization in community-dwelling persons with Alzheimer's disease: Frequency and causes. *J Am Geriatr Soc* 2010;58(8):1542-8.

report on statutory and regulatory obstacles to ethical approaches and common misconceptions.

5. IOM and President's Commission on Bioethics to publish recommendations for professionals and others to assure ethical treatment.
6. The new President can propose funding states through CDC to develop State Plans to address Alzheimers Disease and other dementias, which will include ethical approaches to public awareness, diagnosis, prevention, treatment, and community-clinical linkages, for caregivers and patients, strengthen surveillance and collect national data on cognition through multiple channels resulting in fully informed individual decisions and policymakers. This model has been successful in public health approaches to address other chronic conditions such as diabetes nd heart disease.

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