

2011 Report
of the
New York State Coordinating Council
for Services Related to Alzheimer's Disease and Other
Dementias

to
Governor Andrew M. Cuomo

And the
New York State Legislature

February 2012

New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias

The New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Council) was established by Public Health Law § 2004-a (enacted by Chapter 58 of the Laws of 2007, Part B, § 25).

The Council was formed to facilitate interagency planning and policy-making, review specific agency initiatives for their impact on services related to the care of persons with dementia and their families, and provide a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for Alzheimer's disease (AD). (Council membership list included later in this document)

The Council is charged with providing reports to the Governor and the Legislature every two years beginning in 2009. Reports, including this one, will set forth the Council's recommendations for policy relating to dementia and include coordination by public and private agencies to meet the needs of persons with Alzheimer's disease and other dementias and their families, this is the second report of this Council.

Once again the Council has gathered expert advice from Council members and others in the field to inform the development of this report.

Council Activity

Since the release of this Council's first report, the Council has had several conference calls as well as electronic communication. Topics at these meetings have included; benefits of early detection; caregiver supports; research updates; and cognitive screening. The Early Detection Subcommittee of the Council also met over the past two years resulting in the recommendations that the Council endorsed and that appear at the end of this report.

2010-11 Council meeting dates:

1/28/10 – The Council met to organize the Early Detection Workgroup, and charged this group with reviewing research and developing recommendations to increase early detection of Alzheimer's disease. State agency members reported on related activity in their agency.

12/20/10 – The Council heard a research update; discussed the benefits of early detection; and reviewed caregiver support data from various sources. State agency members reported on related activity in their agency.

5/12/11 - The Council heard a research update; heard data on screening for cognitive impairment; continued the discussion on the benefits of early detection; and reviewed updated caregiver support data from various sources. State agency members reported on related activity in their agency.

Background

This is the 2011 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias ("the Council"). This report focuses on early detection of Alzheimer's Disease (AD) and other dementias. Since the first report was released, there have been significant policy changes including Federal Health Reform (Patient Protection and Affordable Care Act (ACA)); significant additional research as well as clinical recommendations (new diagnostic criteria) relevant to AD.

Alzheimer's Prevalence and Mortality

The current incidence of AD throughout the United States reflects an aging population. Between 2010 and 2050, the United States is expected to experience a rapid increase in its older population.¹ The number of Americans with AD has risen to 5.4 million persons, with a projection of an increase between 11 and 16 million affected Americans by 2050 and total Medicare spending nationwide for those with Alzheimer's disease has increased to \$93 billion annually.²

Current estimates for the prevalence of AD in New York State reveal a more complex situation. New York is one of the Northeastern states with a large portion of its residents over 65 years of age and currently has a larger number of residents with AD than other sections of the country.³ The rate of increase of those with Alzheimer's residing in New York State will be slower than in the South and West. There was a 3% drop in the incidence of Alzheimer's disease in New York in 2010 from 2000, but expectations are that there will be a 6% increase in the state by 2025, during the period 2000-2025.⁴

Mortality rates also reveal an inconsistent picture. Preliminary statistics from 2009 from the Centers for Disease Control found nationally that between 2008 and 2009, deaths from AD actually decreased by 4.1% and that age adjusted death rates decreased significantly for 10 of the 15 leading causes of death, including AD.⁵ Most recent data indicates that while the disease is still the 6th leading cause of death in the United States, it has risen to 5th among those who are 65 years of age and older.⁶ Researchers acknowledge the weakness of death certificate data, proposing that the number is artificially low based on the immediacy of pneumonia or other conditions.

The Patient Protection and Affordable Care Act (ACA)

The Patient Protection and Affordable Care Act (ACA) created several benefits that impact AD and early detection of cognitive impairment.

As part of ACA there will be a Medicare transitional care pilot project that targets seniors at high risk of reentering the hospital or for nursing home placement and specifically includes those with cognitive impairment. This pilot will provide an opportunity for those with AD to be appropriately served in the community.

The change that will have a significant impact on AD is a new Medicare benefit to provide annual wellness visits for every Medicare beneficiary. This Annual wellness visit will include the detection of cognitive impairment and development of an individual prevention plan. By including detection of cognitive impairment in annual wellness visits, early detection of AD and other diseases and disorders that result in disturbances in cognition, should increase, offering opportunities for addressing the disease and planning for care earlier, when the patient can be an active planning participant.

New Diagnostic Criteria

In April 2011, new diagnostic criteria for AD were published. The new criteria are important because they shift the focus to detecting the disease as early as possible, optimally prior to the onset of dementia symptoms. The new guidelines differ from the 1984 diagnostic criteria in a few key ways. The guidelines:

- Recognize that AD progresses on a spectrum with three stages—an early, preclinical stage with no symptoms; a middle stage of mild cognitive impairment; and a final stage marked by progressive symptoms of dementia. The 1984 criteria addressed only one stage of disease—the final stage of dementia.
- Expand the criteria for Alzheimer’s dementia beyond memory loss as the first or only major symptom. They recognize that other aspects of cognition, such as word-finding ability or judgment, may become impaired first. The 1984 criteria focused on memory loss as the central emerging characteristic of Alzheimer’s dementia.
- Reflect a better understanding of the distinctions and associations between Alzheimer’s and non-Alzheimer’s dementias, as well as between AD and disorders that may influence its development, such as vascular disease. In 1984, these relationships were not well recognized or understood.
- Recognize the potential use of biomarkers—indicators of underlying brain disease—to diagnose AD. However, the guidelines state that biomarkers are almost exclusively to be used in research rather than in a clinical setting. These biomarkers did not exist when the original criteria were developed in 1984, so confirmation of the diagnosis was possible only through autopsy after death.⁷

Early Detection

Clinicians using routine history and physical examination do not typically diagnose dementia during clinic visits. More than 50 percent of people with dementia have never been diagnosed by a physician, including many with mild disease as well as some with moderate dementia. This raises the possibility that screening tests may identify people with undiagnosed dementia, and therefore permits patients and their families to receive care and access support at an earlier stage in the disease process. For dementia screening to lead to improved health outcomes, primary care providers would need to have a brief but accurate and valid screening test to apply during annual wellness visits and other routine care and be trained in its use. A positive screening test could then result in a diagnostic interview and clinical examination consistent with the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM IV)*.⁸

Cognitive Screening Tools

One possible reason for the delay in AD diagnosis may be the previous lack of validated screening tools. Although there are numerous screening tests available, only a few of them have been validated in the populations for which they were intended and have lower accuracy for mild levels of impairment.

One commonly used screening instrument is the Mini-Mental Status Examination (MMSE). Some drawbacks of MMSE are that its accuracy depends upon age, education, and ethnicity of the individual; it is most accurate for whites with at least a high school education and is copyrighted with a charge for its use. Other cognitive screening tests, such as the Short Portable Mental Status Questionnaire, Clock Drawing Test, Modified MMSE, Mini-Cog, Hopkins Verbal Learning Test, and the 7-minute screen are promising, but have not been adequately evaluated in primary care settings. There are also informant-based functional tests, such as the Functional Activities Questionnaire (FAQ), the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), and the Instrumental Activities of Daily Living (IADL) Questionnaire. In these examples a family member or caregiver serves as the “informant”. The primary limitation of these types of tests is that not all patients have caregivers, some functions (e.g. cognition) are not tested and that the instruments require at least some training and skill in administration.⁹

Another tool, the AD8, is a brief informant-based interview that is valid and reliable in differentiating individuals with dementia from those who do not show signs of dementia and is sensitive to the earliest signs of cognitive change as reported by an informant. The AD8 is highly correlated with the CDR (Clinical Dementia Rating), CDR-SB, and other measures of dementia, on objective measures of memory, visuospatial skills, attention, and executive function and biological markers of MCI and AD (MRI, cerebrospinal fluid, and amyloid imaging). As previously mentioned a drawback to the informant-based approach is that informants may not be readily available or accompany the patient to the office. The AD8 has been demonstrated to perform equally as well as a telephone interview as it does during an in-person interview.¹⁰

National Institute of Health is completing a comprehensive review of over 140 published cognitive screening instruments and will be meeting to make recommendations in 2012 that includes all the aforementioned instruments.¹¹

Benefits of Early Detection

Early detection and diagnosis offers many benefits. First and foremost cognitive impairment caused by a reversible condition, such as depression or drug interactions, can be treated or corrected. For those with irreversible cognitive impairment or dementia, a diagnosis provides the person with an opportunity to plan for their future and make decisions they may not be able to make as the disease progresses.

Earlier diagnosis provides for access to information, resources, support and more effective treatment. The support for early diagnosis has been identified by the Alzheimer’s Association and the World Alzheimer Report 2011 into the following broad themes:

1. *Optimizing current medical management*- attention to treatable causes, exacerbating factors, and medication review
2. *Relief gained from better understanding* – validation of concerns, and a framework for understanding the origin and nature of symptoms
3. *Maximizing decision-making autonomy* – the chance to make important decisions about the future while still retaining mental capacity
4. *Access to services* – timely access to medical care, advice, support, all of which require a diagnosis
5. *Risk reduction* – safety at home, driving assessments, anticipating and avoiding adverse effects of medication
6. *Planning for the future* – early retirement, financial planning, safety and security issues
7. *Improving clinical outcomes* – slowing or stabilizing cognitive and functional decline
8. *Avoiding or reducing future costs* – chiefly through delaying or avoiding transition into a care home
9. *Diagnosis as a human right* – both to have access to an accurate diagnosis and to be informed of it, or not, according to preference¹²

Recommendations

1. In light of this information, the Council recommends that all individuals over age 65 (younger if the patient presents with one or more of the 10 Warning Signs¹³) should receive a cognitive screening as: part of regular primary care similar to how individuals are screened for hypertension by measuring blood pressure and other vital signs; part of emergency care; and in any instance they are hospitalized. Screening should include a brief interview with a family member or caregiver (when available and with appropriate consent) using a valid instrument such as the AD8.
2. Key relevant topics should be incorporated into existing pre-service and in-service training for Primary Care Providers; Emergency Department staff; Nurses and other health and allied professionals. Topics should provide information regarding patient's rights, including informed consent regarding screening, as with assessment of all vital signs and other treatment.
3. The NYS DOH Alzheimer's Disease Program should engage Alzheimer's Disease Assistance Centers (ADAC), established education resources and other partners in the design of training modules for different audiences.
4. NYS DOH and other state agencies should explore third party funding opportunities and engage relevant partners in a Public Education campaign. The Alzheimer's Disease Education Fund is one possible source of seed money for this project.
5. Providers should engage patients and where appropriate family members in advance care planning including identifying a health care proxy and discerning the patient's wishes early in the disease process.

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