

# Quality improvement in neurology

## Dementia management quality measures



Germaine Odenheimer, MD  
 Soo Borson, MD  
 Amy E. Sanders, MD, MS  
 Rebecca J. Swain-Eng, MS  
 Helen H. Kyomen, MD, MS  
 Samantha Tierney, MPH  
 Laura N. Gitlin, PhD  
 Mary Ann Forcica, MD  
 John Absher, MD  
 Joseph Shega, MD  
 Jerry Johnson, MD

Correspondence to  
 American Academy of Neurology:  
[quality@aan.com](mailto:quality@aan.com)

Professional and advocacy organizations have long urged that dementia be recognized and properly diagnosed.<sup>1,2</sup> With the passage of the National Alzheimer's Project Act<sup>3</sup> in 2011, an Advisory Council for Alzheimer's Research, Care, and Services was convened to advise the Department of Health and Human Services. In May 2012, the Council produced the first National Plan to address Alzheimer disease and prominent in its recommendations is a call for quality measures suitable for evaluating and tracking dementia care in clinical settings.<sup>4</sup> Although other efforts have been made to set dementia care quality standards, such as those pioneered by RAND in its series *Assessing Care of Vulnerable Elders (ACOVE)*<sup>5</sup>, implementation has not been widely embraced by practitioners, health care systems, or insurers. In this Executive Summary (full manuscript in appendix e-1 on the *Neurology*<sup>®</sup> Web site at [www.neurology.org](http://www.neurology.org)), we report on a new measurement set for dementia management developed by an interdisciplinary Dementia Measures Work Group (DWG) representing the major national organizations and advocacy organizations concerned with the care of patients with dementia. This effort was led by the American Academy of Neurology, the American Geriatrics Society, the American Medical Directors Association, the American Psychiatric Association, and the American Medical Association–convened Physician Consortium for Performance Improvement (PCPI). Both the ACOVE measures and the measurement set described here apply to patients whose dementia has already been identified and properly diagnosed.

Though similar in concept to ACOVE, the DWG measurement set differs in several important ways: it includes all stages of dementia in a single measure set, calls for the use of functional staging in planning care, prompts the use of validated instruments in patient and caregiver assessment and intervention, highlights the relevance of using palliative care concepts to guide care prior to the advanced stages of illness, and provides evidence-based support for its recommendations and guidance on the selection of instruments useful in tracking patient-centered outcomes. In addition, the DWG measurement set specifies annual reassessment and updating of interventions and care plans for dementia-related problems that affect families and other caregivers as well as patients. Here, we first provide a brief synopsis of why major reforms in health care design and delivery are needed in order to achieve substantive improvements in the quality of care, and then list the final measures approved for publication, dissemination, and implementation.

**OPPORTUNITIES FOR IMPROVEMENT** Health care for persons with dementia is inconsistent, often suboptimal, and largely unplanned. Peer-reviewed studies of dementia care document inconsistency in outpatient care,<sup>6,7</sup> high rates of potentially preventable episodes of acute care,<sup>8,9</sup> and increased numbers of locus of care transitions.<sup>10</sup> These findings suggest that much of the health care for patients with dementia is reactive and unsystematic. Ambulatory care is driven largely by chronic conditions, for which

### GLOSSARY

**ACOVE** = Assessing Care of Vulnerable Elders; **DWG** = Dementia Measures Work Group; **EHR** = electronic health record; **ICD-9** = *International Classification of Diseases*, ninth revision; **MU** = Meaningful Use; **PCPI** = Physician Consortium for Performance Improvement; **PQRS** = Physician Quality Reporting System.

Supplemental data at  
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From the Department of Geriatric Medicine (G.O.), University of Oklahoma College of Medicine, Oklahoma City; Veterans Affairs Medical Center (G.O.), Oklahoma City, OK; Department of Psychiatry and Behavioral Sciences (S.B.), University of Washington, School of Medicine, Seattle; Department of Neurology (A.E.S.), Albert Einstein College of Medicine, Bronx, NY; American Academy of Neurology (R.J.S.-E.), Minneapolis, MN; Department of Psychiatry (H.H.K.), McLean Hospital and Harvard Medical School, Boston, MA; American Medical Association (S.T.), Chicago, IL; Center for Innovative Care in Aging (L.N.G.), Community Public Health, School of Nursing and Department of Psychiatry, Division of Geriatrics and Gerontology, Johns Hopkins University, School of Medicine, Baltimore, MD; Division of Geriatric Medicine (M.A.F., J.J.), University of Pennsylvania, Perelman School of Medicine, Philadelphia, PA; Absher Neurology (J.A.), Greenville, SC; and Department of Geriatrics and Palliative Medicine (J.S.), University of Chicago, IL.

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Dementia measurement set approved by the AAN Board of Directors on October 31, 2011, and by the full membership of the American Medical Association–convened Physician Consortium for Performance Improvement on October 31, 2011.

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prevention, early recognition, and timely treatment can be delayed in the setting of dementia, leading to exacerbations of other chronic conditions. Proactive outpatient care and care coordination could reduce avoidable emergency room visits and hospital admissions and potentially avert negative impacts on patients and caregivers that arise from preventable health crises.

**Ethnic and socioeconomic disparities are important influences on the quality of dementia care.** These influence the rate and quality of dementia diagnoses, the stage of decline at which diagnosis occurs, the use of antidementia medications, the quality and type of end-of-life care, and the use of community-based supportive services.<sup>11</sup> While beliefs about dementia's origins and significance may contribute to some of these health care disparities, many quality issues affect minority and mainstream populations alike: a lack of knowledge of what constitutes good dementia care, inadequate resources, insufficient insurance coverage, low access to knowledgeable professionals, and institutional barriers. All contribute to the need for improvements in health care design.

**Partnership with caregivers is integral to improving care.** Several different models of integrated care for dementia have been described and have been shown to improve utilization of community-based services, reduce the use of CNS-active medications that may worsen cognition, increase family caregivers' competence and reduce their stress, and enhance the capacity of practice environments to provide dementia-specific care.<sup>6,10,12-16</sup> Focus is increasingly turning toward nonpharmacologic modes of management for mood and behavioral problems due to the newly questioned value of antidepressant medications for depression in dementia,<sup>17-19</sup> the modest efficacy of antipsychotic medications for behavioral problems<sup>20</sup> and the increased risks of cardiovascular events and mortality associated with their use, the cognitive toxicity of anticholinergic medications,<sup>21</sup> and recognition of the risks of falls and other adverse outcomes associated with use of benzodiazepines in the elderly.<sup>22</sup> Caregivers are essential partners in health care management as well as implementation of nonpharmacologic interventions that complement health care; their knowledge, well-being, and sustained engagement with health care providers are critical to the success of both medical and psychosocial components of care.

**The well-being and behavioral stability of patients with dementia is strongly influenced by the well-being of their caregivers.** Caregivers for individuals with dementia require individualized attention and assistance in order to function at their best. Unmanaged caregiving stress adversely affects health,<sup>22-24</sup> increases caregiver mortality risk,<sup>25</sup> and promotes behavioral decompensation in

patients with dementia. However, models for providing integrated care for caregivers and patients together have not gained traction outside specialized settings. Interventions targeting improvement in caregivers' coping with dementia-related behaviors and functional deficits can be effective.<sup>12,26-29</sup> However, these interventions are not typically covered under Medicare and other insurance plans, and, when such interventions are locally available and used by caregivers, their effects may not be apparent to medical providers, integrated into the overall patient care plan, or tracked as components of quality of care.

**Comprehensive integrated care and quality improvement initiatives must be explicit and practical.** Despite the quality promise of comprehensive dementia management, provider productivity standards and current billing and reimbursement systems discourage its adoption and undermine its consistency. Although a great deal of dementia care is actually done through work with caregivers, the patient must be present in order for most physician services to be reimbursed under Medicare, regardless of whether the patient is able to participate actively in his or her own care. Moreover, there may be differential handling of "neurologic" and "psychiatric" codes for the same dementing condition: *ICD-9* code 331.0 identifies Alzheimer disease and is reimbursed as a medical code; *ICD-9* code 294.1 denotes senile dementia and is a psychiatric code reimbursed by some plans under a mental health benefit for which coverage may be more limited. Measuring dementia care activities by providers and health systems will create a solid data resource for redesigning payment and coding structures so that they reflect the work providers need to, and actually, do to provide high quality of care for persons with dementia.

**DEMENTIA MANAGEMENT QUALITY MEASURES** In dementia care, desired outcomes include preserving, to the maximum possible extent, cognitive and functional abilities, reducing the frequency, severity, and adverse impact of neuropsychiatric and behavioral symptoms, sustaining the best achievable general health, reducing risks to health and safety, and enhancing caregiver well-being, skill, and comfort with managing the patients with dementia in partnership with health care providers. Clinical performance measures would ideally include patient-level outcomes as well as processes of care. However, the progressive nature of most dementing diseases, the heterogeneity of comorbid conditions and the medical and other management requirements, and the multiplicity of factors that influence outcomes in dementia make development of reliable patient-reported outcome measures impracticable. In their place, assessing the quality of dementia care must rely on measuring care processes that

**Table** Measure title and description of the final 10 dementia measures (measures copyrighted by the American Medical Association, 2012)

Measure title	Description
<b>No. 1: Staging of dementia</b>	Percentage of patients, regardless of age, with a diagnosis of dementia whose severity of dementia was classified as mild, moderate, or severe at least once within a 12-month period
<b>No. 2: Cognitive assessment</b>	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results are reviewed at least once within a 12-month period
<b>No. 3: Functional status assessment</b>	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of functional status is performed and the results are reviewed at least once within a 12-month period
<b>No. 4: Neuropsychiatric symptom assessment</b>	Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and the results are reviewed at least once in a 12-month period
<b>No. 5: Management of neuropsychiatric symptoms</b>	Percentage of patients, regardless of age, with a diagnosis of dementia who have one or more neuropsychiatric symptoms who received or were recommended to receive an intervention for neuropsychiatric symptoms within a 12-month period
<b>No. 6: Screening for depressive symptoms</b>	Percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12-month period
<b>No. 7: Counseling regarding safety concerns</b>	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled or referred for counseling regarding safety concerns within a 12-month period
<b>No. 8: Counseling regarding risks of driving</b>	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who were counseled regarding the risks of driving and the alternatives to driving at least once within a 12-month period
<b>No. 9: Palliative care counseling and advance care planning</b>	Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who 1) received comprehensive counseling regarding ongoing palliation and symptom management and end-of-life decisions and 2) have an advance care plan or surrogate decision-maker in the medical record or documentation in the medical record that the patient did not wish or was not able to name a surrogate decision-maker or provide an advance care plan within 2 years of initial diagnosis or assumption of care
<b>No. 10: Caregiver education and support</b>	Percentage of patients, regardless of age, with a diagnosis of dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes and were referred to additional resources for support within a 12-month period

Full specifications are available on the Physician Consortium for Performance Improvement Web site at [www.physicianconsortium.org](http://www.physicianconsortium.org). Readers interested in examples of how to meet the measurement requirements are referred to this document. Readers are also referred to the full manuscript for this article in appendix e-1.

have been associated with positive outcomes in a rapidly evolving evidence base. The DWG measurement set consists of 10 separate, auditable quality measures. These measures are inclusive of the multiple stages of illness and can be viewed in 5 categories relevant to therapeutic decision-making: 1) assessment of the person with dementia postdiagnosis (measures 1–4 and 6), 2) management of neuropsychiatric symptoms (measure 5), 3) patient safety (measures 7 and 8), 4) palliative care and end-of-life issues (measure 9), and 5) caregiver issues (measure 10). For most measures, care quality is indicated by the proportion of eligible patients whose documented care meets the identified goal. Situations in which the use of a particular quality measure may not be appropriate for a particular patient (e.g., counseling regarding risks of driving for a patient who does not drive) are specified with an exception to the measure. A brief summary of each measure is found in the table. For the full measure specifications, visit the PCPI Web site at [www.physicianconsortium.org](http://www.physicianconsortium.org). Readers interested in examples of how to meet individual measures are referred to this Web site.

**DISCUSSION** The DWG measures have the potential to dramatically affect practice and improve the quality of care provided to patients with dementia. In fact, all of these measures, except measure 9, were selected for the 2012 and 2013 PQRS measures list.<sup>30</sup>

PQRS provides an incentive payment to eligible professionals who demonstrate provision of high quality care for specified conditions, and can accelerate adoption of dementia care quality standards across all types of practice organizations and all clinical disciplines providing health care for affected patients. In addition, measure number 2, Cognitive Assessment, is included in the clinical quality measure list for Meaningful Use (MU) 2. MU is a Centers for Medicaid & Medicare Services electronic health record (EHR) incentive program designed to offer financial incentives for the meaningful use of certified EHR technology to improve patient care.<sup>31</sup>

The emphasis on dementia management in this measurement set recognizes the enormous challenge dementia presents to individual patients and their caregivers, health care providers, public health, and government and private insurers. While patients, caregivers, and health professionals await more effective disease-modifying treatments for patients with dementia, adherence to the measures outlined here will improve the quality of life for patients and caregivers with dementing illnesses.

#### **AUTHOR CONTRIBUTIONS**

Germaine Odenheimer: drafting/revising the manuscript, study concept or design, analysis or interpretation of data, accepts responsibility for conduct of research and final approval; co-leadership of the team of authors. Soo Borson: drafting/revising the manuscript, study concept or design,

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This podcast begins and closes with Dr. Robert Gross, Editor-in-Chief, briefly discussing highlighted articles from the October 22, 2013, issue of *Neurology*. In the second segment, Dr. Jeff Burns talks with Dr. Amy Sanders about her paper on dementia management quality measures. Dr. Adam Numis then reads our e-Pearl of the week about Leber hereditary optic neuropathy. In the next part of the podcast, Dr. Mark Keegan focuses his interview with Dr. Alasdair Coles on alemtuzumab treatment of

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