

Quality Improvement in Neurology: Dementia Management Quality Measures (Executive Summary)

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This article represents the efforts of an interdisciplinary work group, the Dementia Measures Work Group (DWG), composed of representatives of diverse national organizations who convened specifically to define optimal standards of dementia care for individual practitioners as well as multidisciplinary teams. The DWG measurement set 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 for tracking patient-centered outcomes. In addition, it specifies annual reassessment and updating of interventions and care plans for dementia-related problems that affect families and other caregivers as well as patients.

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Editorial Note

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Because so many of us today are part of the “sandwich generation” (Miller, 1981)—concurrently caring for children *and* aging parents—an alarming statistic may have significance for us: Approximately every 4 seconds, an older adult will develop dementia. That number is estimated to nearly double over the next 20 years, to almost 65.7 million in 2030 and 115.4 million in 2050 (World Health Organization & Alzheimer’s Disease International, 2012). Therefore, we can reasonably assume that we may be caring for a person with dementia at some point in our lives.

The pain and consuming sadness that family members face as they watch their loved one deteriorate both cognitively and physically can be overwhelming. Forgetfulness and loss of memory are often attributed to a normal aging process, but for people experiencing dementia, behavioral changes and functional limitations can progress quickly, eventually leading to the inability to perform even basic daily tasks and self-care. To provide both preventative and compensatory skilled intervention that will maximize function and preserve quality of life for people with dementia, occupational therapy should be an integral part of any

health care dementia team. However, what constitutes appropriate and optimal dementia care has challenged medical and health care personnel for several years. Until recently, interventions have been described as “inconsistent, often suboptimal, and largely unplanned” (Odenheimer et al., 2013, p. 704).

In collaboration with *Neurology* and the *Journal of the American Geriatrics Society*, the *American Journal of Occupational Therapy* is proud to publish “Quality Improvement in Neurology: Dementia Management Quality Measures” in this issue. Although previous groups have tried to establish systematic standards of care for dementia, none thus far have been widely accepted or utilized. This article represents the efforts of a new interdisciplinary work group, the Dementia Measures Work Group (DWG), composed of members from diverse national organizations such as the American Academy of Neurology (AAN), the American Geriatrics Society, the American Medical Directors Association, the American Psychiatric Association, and the American Medical Association–convened Physician Consortium for Performance Improvement[®], who convened specifically to define optimal standards of dementia care for individual practitioners as well as multidisciplinary teams.

The article articulately describes the gaps in dementia care and the opportunities available for improvement. The DWG performed an exhaustive literature search of clinical practice guidelines and dementia reviews to identify 10 performance measures that should serve as the foundation

for quality dementia intervention. The measures were developed after a thorough examination of randomized controlled trials and effectiveness studies.

Occupational therapy can greatly contribute to the dementia team and to improving the health of people with dementia; the second and third quality measures listed are cognitive assessment and functional status assessment, skills that are integral to the occupational therapy process. The guidelines represent a systematic, comprehensive approach to dementia care and management and should be used as a standard of care when working with this patient population. Our focus on functional independence and meaningful activity will preserve our place on the dementia health care team for years to come. We thank the AAN for allowing us to publish such an important resource and encourage our readers to disseminate this work to other health care professionals and teams working with the dementia population.

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Executive Summary

Professional and advocacy organizations have long urged that dementia be recognized and properly diagnosed (Ashford et al., 2006, 2007). With the passage of the National Alzheimer’s Project Act (NAPA; Pub. L. 111–375) in 2011, an Advisory Council for Alzheimer’s Research, Care and Services was convened to advise the U.S. Department of Health and Human Services. In May 2012, the Council produced the first National Plan to Address Alzheimer’s Disease, and prominent in its recommendations was a call for quality measures suitable for evaluating and tracking dementia care in clinical settings (see U.S. Department of Health and Human Services, 2013). 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; Feil, MacLean, & Sultzer, 2007), implementation has not been widely embraced by practitioners, health care systems, or insurers.

In this Executive Summary (full report available at www.neurology.org and online at <http://ajot.aotapress.org>; navigate to this article and click on “Supplemental Materials”), we report on a new measurement set¹ 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 (AAN), the American Geriatrics Society (AGS), the American Medical Directors Association (AMDA), the American Psychiatric Association (APA), and the American Medical Association (AMA)–convened Physician Consortium for Performance Improvement[®] (PCPI[®]). Both the ACOVE measures and the measurement set described here apply to

¹Dementia measurement set approved by the American Academy of Neurology 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.

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 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 (Chodosh et al., 2007; Reuben et al., 2010), high rates of potentially preventable episodes of acute care (Bynum et al., 2004; Phelan, Borson, Grothaus, Balch, & Larson, 2012), and increased numbers of locus of care transitions (Callahan et al., 2012). These findings suggest that much of health care for patients with dementia is reactive and unsystematic. Ambulatory care is driven largely by chronic conditions, for which 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.

Ethnic and socioeconomic disparities 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 (Cooper, Tandy, Balamurali, & Livingston, 2010). 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 central nervous system-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 (Borson, Scanlan, Watanabe, Tu, & Lessig, 2006; Boustani, Sachs, & Callahan, 2007; Callahan et al., 2011, 2012; Mittelman, Haley, Clay, & Roth, 2006; Reuben et al., 2010; Vickrey et al., 2009). Focus is increasingly turning toward nonpharmacological modes of management for mood and behavioral problems due to the newly questioned value of antidepressant medications for depression in dementia (Banerjee & Wittenberg, 2009; Gitlin, Kales, & Lyketsos, 2012; Nelson & Devanand, 2011), the modest efficacy of antipsychotic medications for behavioral problems (American Geriatrics Society 2012; Beers Criteria Update Expert Panel, 2012) and the increased risks of cardiovascular events and mortality associated with their use, the cognitive toxicity of anticholinergic medications (Vigen et al., 2011), and recognition of the risks of falls and other adverse outcomes associated with use of benzodiazepines in the elderly (Fick & Resnick, 2012). Caregivers are essential partners in health care management as well as implementation of nonpharmacological 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 Are Strongly Influenced by the Well-Being of Their Caregivers.

Caregivers for individuals with dementia require individualized attention and assistance to function at their best. Unmanaged caregiving stress adversely affects health (Fick & Resnick, 2012; Schulz et al., 2012; Vitaliano, Murphy, Young, Echeverria, & Borson, 2011), increases caregiver mortality risk (Schulz & Beach, 1999), 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 (Cooper et al., 2012; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; McCurry, Logsdon, Vitiello, & Teri, 1998; Mittelman et al., 2006; Teri et al., 2003). 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 "neurological" and "psychiatric" codes for the same dementing condition: The *ICD-9* code 331.0 identifies Alzheimer's 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 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 five categories relevant to therapeutic decision making: (1) assessment of the person with dementia post diagnosis (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 Table 1. For the full measure specifications, visit the PCPI Web site at www.physicianconsortium.org. Readers interested in examples of how to meet individual measures are referred to this Web site.

Conclusion

The DWG measures have the potential to dramatically impact 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 Physician Quality Reporting System (PQRS) measures list (Centers for Medicare and Medicaid Services, 2013b). 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 organization and all clinical disciplines providing health care for affected patients. In addition, Measure 2, Cognitive Assessment, is included in the clinical quality measure list for Meaningful Use (MU) 2. MU is a Medicare and Medicaid Electronic Health Record (EHR) incentive program designed to offer financial incentives for the "meaningful use" of certified

Table 1. Measure Title and Description of the Final 10 Dementia Performance Measures

Measure Title	Description
1. Staging of Dementia	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-mo period
2. Cognitive Assessment	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-mo period
3. Functional Status Assessment	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-mo period
4. Neuropsychiatric Symptom Assessment	Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of neuropsychiatric symptoms is performed and the results are reviewed at least once in a 12-mo period
5. Management of Neuropsychiatric Symptoms	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-mo period
6. Screening for Depressive Symptoms	Percentage of patients, regardless of age, with a diagnosis of dementia who were screened for depressive symptoms within a 12-mo period
7. Counseling Regarding Safety Concerns	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-mo period
8. Counseling Regarding Risks of Driving	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-mo period
9. Palliative Care Counseling and Advance Care Planning	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
10. Caregiver Education and Support	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-mo period

Note. Full specifications are available on the Physician Consortium for Performance Improvement Web site at www.physicianconsortium.org. Readers interested in examples of how to meet the measurement requirements are referred to this document. Readers are also referred to Appendix e-1 in the full article, online at www.neurology.org. Copyright © 2012 by the American Medical Association. Reprinted with permission.

EHR technology to improve patient care (Centers for Medicare and Medicaid Services, 2013a).

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.

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