

Quality Improvement in Neurology: Dementia Management Quality Measures

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OBJECTIVE. To describe new quality measures for clinical dementia management, derived through a standardized, rigorous, evidence-based consensus process, and their suitability for quality improvement activities, pay-for-reporting initiatives, and maintenance of certification requirements.

METHOD. Dementia measures were developed using the American Medical Association–convened Physician Consortium for Performance Improvement® (PCPI) measure development process. Guidelines and consensus papers from 2000 to 2010 using the National Guideline Clearinghouse, the National Quality Measures Clearinghouse, PubMed, and the Cochrane Library were evaluated using the PCPI's framework for determining the acceptability of guidelines and other evidence review documents. Candidate recommendations from each acceptable evidence document were documented, reviewed, and prioritized based on the link to desired outcomes, the level of evidence and strength of recommendation, face validity, feasibility to collect data, and gaps or variations in care. The prioritized recommendation statements were then developed into candidate measures. A work group of experts from representative organizations vetted the measures. A period of public comment was followed by review, approval, or endorsement from the American Academy of Neurology, the PCPI, and other supporting organizations.

RESULTS. The literature search identified 225 relevant recommendation statements from 12 clinical practice guidelines, 1 consensus paper, and 1 systematic review. Systematic assessment resulted in the development of 10 candidate measures. The measures are related to dementia severity staging, cognitive assessment, functional assessment, neuropsychiatric symptom assessment and management, depression screening, safety issues, palliative care, and caregiver education and support.

CONCLUSION. The dementia measures consist of clinical process measures to be performed at the level of the individual practitioner and/or adapted by multidisciplinary practice teams or collaborative care physician models, focusing on accurate and appropriate evaluation and monitoring of disease status and associated symptoms. These dementia measures, when implemented by providers, have the potential to significantly improve care for individuals with dementia.

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Background Information on Dementia

Dementia prevalence rises exponentially with age, approaching 50% by age 85 (Alzheimer's Association, 2012). Dementing disorders are the leading cause of nursing home placement in the United States (Alzheimer's Association, 2012). As the population ages, dementia-attributable mortality is also rising, creating an urgent public health challenge. The total estimated worldwide cost of dementia was \$604 billion in 2010, accounting for approximately 1% of the world's gross domestic product (Phelan, Borson, Grothaus, Balch, & Larson, 2012).

By 2050, the number of individuals aged 65 and older with Alzheimer's disease, the most prominent form of dementia, is projected to be up to 16 million in the United States alone (Alzheimer's Association, 2012).

The current state of practice in the management of people with dementia is highly variable across specialties and across the country. Professional and advocacy organizations have long recommended 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 on 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 among its strategies was the need to "identify high-quality dementia care guidelines and measures across care settings" (see U.S. Department of Health and Human Services, 2013, p. 18). Although other efforts have been made to set quality standards for dementia care, such as those pioneered by RAND in its geriatric care series *Assessing Care of Vulnerable Elders* (ACOVE; Feil, MacLean, & Sultzer, 2007), implementation has not been embraced by practitioners, health care systems, or insurers. In ACOVE, dementia is considered one of three "geriatric syndromes" or conditions common in the elderly that are not captured under disease management guidelines. Separate quality indicators were developed for the ambulatory patient (usually with mild to moderate dementia) and the patient with advanced dementia and poor prognosis (Feil et al., 2007). A recent systematic review reported that of the three geriatric syndrome sets, the dementia quality indicators had the lowest adoption rate, with an interquartile range of 11%–35% across studies (Askari et al., 2011).

A new measurement set for dementia management 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) is described in this article.¹ The measurement set was developed by an interdisciplinary Dementia Work Group (DWG) representing the stakeholder physician organizations, patient advocacy groups, and other relevant stakeholder groups concerned about the care of patients with dementia. The measures were designed to identify and define a set of quality measures to improve

the clinical management of patients with a diagnosis of dementia, to enhance the support given to their caregivers, and to improve patient outcomes. The measures primarily target underemphasized aspects of the evaluation and longitudinal management of patients with dementia focusing on fundamental aspects of quality care that can be implemented broadly. Standardized assessment of dementia care quality will support quality improvement initiatives to promote care that is safe, timely, effective, efficient, equitable, and patient centered.

Both the ACOVE and the DWG measurement set presented here assume that patients have already been properly diagnosed with dementia, and neither addresses the need to improve dementia detection and diagnosis. Although similar in concept to ACOVE, the DWG dementia measurement set was developed using the nationally recognized PCPI process for measure development and differs from ACOVE in several important ways: It includes all stages of dementia, emphasizes the value of functional assessment and staging in planning care, prompts the use and documentation of validated measures in patient and caregiver assessment and intervention, and highlights the need to move palliative care upstream into outpatient care management beginning at the time of diagnosis. In addition, the DWG measurement set explicitly calls for annual reassessment and updating of care planning and interventions for dementia-related problems that affect the caregiver as well as the patient. The use of practical, evidence-based quality measures may stimulate the consolidation of clinical, educational, and policy initiatives for progressive improvement in dementia care at the practice level.

Reason for Prioritizing Dementia: Gaps in Care

The dementia care management gap presents significant challenges for persons with dementia and their caregivers. According to a study analyzing the quality of medical care provided to vulnerable community-dwelling older patients, patients with dementia received the recommended quality of care only about 35% of the time (Wenger et al., 2003). Quality of care was assessed by clinical performance on nine dementia quality indicators. Another study assessed 18 dementia care processes drawn from existing guidelines to characterize contemporary care patterns for dementia within one U.S. metropolitan area. Quality of care was quantified by analyzing medical records and caregiver surveys ($n = 378$; Chodosh et al., 2007). Adherence to the 18 individual care processes ranged from 9% to 79%; notably, 11 of the 18 care processes had an adherence rate of less than 40% (Chodosh et al., 2007). For example, functional decline is universal in

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.

dementia but often overlooked by health care providers, even though interventions such as physical activity can ameliorate decline (Andel et al., 2008; Heyn, Abreu, & Ottenbacher, 2004; Wang, Larson, Bowen, & van Belle, 2006).

Similarly, depression is substantially more common in persons with dementia compared with cognitively intact persons but is underdiagnosed and often inadequately treated (Chodosh et al., 2007; Heyn et al., 2004; Wang et al., 2006; Wenger et al., 2003). Other neuropsychiatric symptoms also are frequently overlooked by providers, even though they may represent undiagnosed medical conditions amenable to treatment and, if unmanaged, are associated with more rapid cognitive decline and nursing home placement (Hodgson, Gitlin, Winter, & Czekanski, 2011; Spalletta et al., 2010; Yaffe et al., 2002). Finally, caregiver education about the underlying disease process and management of neuropsychiatric symptoms remains suboptimal. Improvements in caregiver knowledge may decrease unwarranted interventions near the end of life (Grossberg et al., 2010).

Opportunities for Improvement in Dementia Care

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; Drasković, Vernooij-Dassen, Verhey, Scheltens, & Rikkert, 2008; Perry et al., 2010; Reuben et al., 2010), high rates of potentially preventable episodes of acute care (Bynum et al., 2004; Phelan et al., 2012), and increased number of transitions in care for persons with dementia (Callahan et al., 2012). These findings suggest that much of health care for patients with dementia is unsystematic and potentially chaotic. Ambulatory care is driven largely by chronic conditions, for which prevention, early recognition, and timely treatment can be delayed in the setting of dementia. This can lead 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 arising from preventable health crises.

Ethnic and socioeconomic disparities are also important influences on the quality of dementia care. They 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 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 cognition-impairing medications, increase family caregivers' competence and reduce their stress, and enhance the capacity of practice organizations 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 evidence of limited effectiveness of antidepressant medications for depression in dementia (Banerjee & Wittenberg, 2009; Gitlin, Kales, & Lyketsos, 2012; Nelson & Devanand, 2011), modest efficacy (Vigen et al., 2011) for behavioral problems in dementia and increased cardiovascular and mortality risk associated with antipsychotics (Kales et al., 2012), central nervous system toxicity of anticholinergic medications (American Geriatrics Society 2012 Beers Criteria Update Expert Panel, 2012), and recognition of the risks of falls and other adverse outcomes associated with the use of benzodiazepines in older adults (Fick & Resnick, 2012). Caregivers are essential partners in health care management as well as in implementing nonpharmacological interventions. Their knowledge, well-being, and sustained engagement with health care providers are critical to the success of both medical and psychosocial components of care for persons with dementia.

The Well-Being and Behavioral Stability of Patients With Dementia Are Strongly Influenced by the Well-Being of Their Caregivers

Caregivers themselves must receive clinical attention and assistance to function well. Unmanaged caregiving stress adversely affects health (Schulz et al., 2012; Vitaliano, Murphy, Young, Echeverria, & Borson, 2011), increases caregiver mortality risk (Cooper et al., 2012; Schulz et al., 2012), 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 (Brodaty & Arasaratnam, 2012; Cooper et al., 2012; Gitlin, 2012; Gitlin et al., 2010; McCurry, Logsdon, Vitiello, & Teri, 1998; Mittelman et al., 2006; Schulz & Beach, 1999; Teri et al., 2003). However, these interventions are not typically covered under Medicare and other insurance plans, and when they are locally available, financially and geographically accessible, 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 care quality.

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 or other clinician 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: *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 that 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 care for persons with dementia.

Disparities

Dementia itself can be considered a source of health care disparities: High-quality care from knowledgeable providers is less widely available than for other chronic conditions for which simple outcome measures are available. In addition, ethnic differences, often marked, have been demonstrated in the rates and quality of dementia diagnosis, stage at which diagnosis occurs, appropriate use of antidementia medications, quality and type of end-of-life care, and use of community-based supportive services for dementia (Connolly, Sampson, & Purandare, 2012; Froehlich, Bogardus, & Inouye, 2001; Hargrave, Stoeklin, Haan, & Reed, 2000). However, lack

of knowledge about dementia and resources available for patients and families, limited access to and quality of resources, and insurance coverage constraints also contribute (Dilworth-Anderson & Gibson, 1999; Neighbors et al., 2007; Sleath, Thorpe, Landerman, Doyle, & Clipp, 2005). These disparities present significant opportunities to improve the quality of care.

Methods

The dementia measure development process followed the PCPI process for measure development (American Medical Association, 2009). Measure development was a collaborative effort hosted by the PCPI together with the AAN, AGS, AMDA, and APA. The steps in the measure development process required submitting the topic for selection, completing an evidence-based literature search, constructing draft measures and technical specifications, convening a multidisciplinary work group to review candidate measures, soliciting public comments during a 30-day period, refining the final measures and corresponding technical specifications, and obtaining approvals from the expert panel work group and finally the full membership of the PCPI. In addition, the measurement set was reviewed by the AMA Performance Measurement Advisory Group (PMAG) to assign Current Procedural Terminology (CPT[®])–II codes and was approved by the AAN Board of Directors on October 31, 2011.

Topic Selection for Measure Development

The AAN nominated the topic of Alzheimer's disease for quality measurement development to the PCPI in February 2009. The topic was selected for development and expanded to include all dementias. Dementia was chosen because it is a high-impact condition; is one of the top-20 Medicare conditions for which a paucity of measures exist; is a clinical priority for neurology, psychiatry, and geriatric medicine; has an evidence base for measure development as enumerated in clinical practice guidelines; and has demonstrated gaps in care with room for improvement. Given the nature of the syndrome and pivotal role that family members and other individuals play in care management, dementia as a topic area also fostered development of measures that addressed key priority gap areas in the performance measure landscape, such as patient and family engagement, patient safety, and palliative and end-of-life care.

Work Group Formation

A cross-specialty and multidisciplinary work group was convened by soliciting a broad representation of key

stakeholders and inviting nominations for members from physician and nonphysician associations, patient and caregiver advocacy organizations (e.g., Alzheimer's Association), health plans, and large group employers. The final work group consisted of 22 members (see the Acknowledgments for a list of work group members and contributing organizations): 5 geriatricians, 4 neurologists (including 2 geriatric neurologists), 4 geriatric psychiatrists, 1 hospice and palliative care physician, 1 internist, 1 family physician, 1 radiologist, 1 social worker, 1 nurse, 1 occupational therapy representative, 1 health plan representative, and 1 patient organization representative. The group sought to include a neuropsychologist, but no nominations were received. All group members completed a profile and material interest disclosure statement. The work group was convened according to the PCPI conflict of interest policy (American Medical Association, 2010), which prohibits participation by any individuals who have a *material interest* as that term is defined by the policy.

Evidence-Based Literature Search Strategy

A comprehensive literature search strategy to identify published guidelines, consensus papers, relevant existing quality measures, research regarding gaps in care, and unexplained variations in care and costs of care from 2000 to 2010 was conducted using the National Guideline Clearinghouse, the National Quality Measures Clearinghouse, PubMed, and the Cochrane Library. Supplementary Internet searches were carried out on relevant dementia Web sites.

Evidence-Based Evaluation Supporting Development and Writing of Measures

Each relevant full-text guideline or consensus paper was screened against the PCPI framework for determining the acceptability of guidelines and other evidence review documents (American Medical Association, 2009). Guidelines developed by national American physician organizations and federal agencies were preferred for use in measure development. However, guidelines and other evidence documents developed by non-American organizations, as well as nonphysician organizations, were also acceptable and were evaluated for consideration. Each guideline or other evidence document had to disclose potential conflicts of interest for all individuals participating in or sponsoring the development of the document. The recommendation statements and their corresponding level of evidence (as defined by the guideline developers' rating scheme methodology) were then extracted from eligible guidelines and consensus papers. Candidate

recommendations were documented, reviewed, and prioritized on the basis of the link to desired outcomes, the level of evidence and strength of recommendation supporting the intervention, face validity, feasibility to collect data, and gaps or variations in care. Measure specifications were carefully drafted to include a full measure description, a numerator, a denominator, and applicable exceptions.

Use of the Measures

The dementia measures indicate how often a process or outcome of care is applied, thus offering opportunities for performance quality improvement of providers, health systems, and health plans. Nine of the 10 measures are in use by the Centers for Medicare and Medicaid Services (2012, 2013b) Physician Quality Reporting System program for 2012 and 2013. 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 EHR technology to improve patient care (Centers for Medicare and Medicaid Services, 2013a). Supporting information on how to calculate the reporting rate and performance rate are available in the full measurement set on the PCPI Web site (www.physicianconsortium.org).

Results

The literature and evidence search identified 225 recommendation statements from 12 clinical practice guidelines, 1 consensus paper, and 1 systematic review (American Medical Directors Association, 2009; American Psychiatric Association, 2007; California Workgroup on Guidelines for Alzheimer's Disease Management, 2008; Doody et al., 2001; Dubinsky, Stein, & Lyons, 2000; Knopman et al., 2001; Lorenz et al., 2008; National Collaborating Centre for Mental Health, Social Care Institute for Excellence, & National Institute for Health and Clinical Excellence, 2007; National Consensus Project for Quality Palliative Care, 2009; National Quality Forum, 2006; Petersen et al., 2001; Qaseem, Snow, Cross, et al., 2008; Qaseem, Snow, Shekelle, et al., 2008; U.S. Preventive Services Task Force, Agency for Healthcare Research and Quality, 2003) across the continuum of care for patients with dementia from screening and early detection through long-term care issues. Existing indicators for dementia (Chow & MacLean, 2001; National Committee for Quality Assurance, 2008) and end-of-life or palliative care (American Geriatrics Society, Physician Consortium for Performance Improvement, & National Committee for Quality Assurance, 2008;

National Committee for Quality Assurance & Physician Consortium for Performance Improvement, 2008; Wenger & Rosenfeld, 2001) were also reviewed. Review of the recommendation statements resulted in eight candidate measures based on a prioritization strategy focused on the recommendation statement's clinical importance, link to desired outcomes, evidence base, level of evidence, gaps in care associated with the recommendation, and validity and feasibility to implement the recommendation in practice in a quality measure. The work group revised the draft measures and proposed two additional measures at the face-to-face meeting on April 8, 2010. The set of all 10 measures was posted for a 30-day public comment period. According to staff of the AMA, 720 individual comments were received from 73 medical specialty societies, health care professional organizations, physicians, health care professionals, insurers, and other interested parties, which resulted in further refinement of the draft measures. The final 10 measures were approved by the work group and were reviewed by the appropriate bodies of the five lead

collaborating organizations, where required, including the AAN board of directors and the full membership of the PCPI. Approval from these groups was achieved on October 31, 2011. The dementia measurement set will be revised periodically with an extensive review every 3 years.

Brief measure titles and measure statements for each of the 10 dementia performance measures are listed in Table 1. The full measure specifications are available from the PCPI Web site at www.physicianconsortium.org. The measure statement contains the denominator and numerator for each measure. The appropriate exceptions for each measure are found in the full measure specifications.

An example is provided to illustrate the use of one of the dementia measures. For Measure 8, Counseling Regarding Risks of Driving, the eligible patient population (denominator) is all patients with a diagnosis of dementia, regardless of age, as defined by relevant *ICD-9* or *ICD-10* codes, who have one of the eligible clinical encounters. The dementia syndrome is a broad category that represents a large number of specific disorders. Therefore, several

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.

ICD-9 and *ICD-10* codes are relevant for this measure. For example, *ICD-9* codes 290.0 (Senile dementia, uncomplicated), 331.0 (Alzheimer's disease), and 331.82 (Dementia with Lewy bodies) and *ICD-10* codes F01.50 (Vascular dementia without behavioral disturbance), G30.9 (Alzheimer's disease, unspecified), and G31.83 (Dementia with Lewy bodies) are some of the diagnosis codes eligible for this measure. Several CPT codes pertinent to mental health care were revised or newly created and implemented on January 1, 2013. These CPT codes take into consideration a variety of elements in combination, including the type of evaluation or interventions, condition severity, and time needed to render a service, as well as the acuity and interactive nature of the interventions. The 2013 CPT codes 90832 or 90833 may be relevant for Measure 8. The full list of applicable *ICD-9*, *ICD-10*, and CPT codes is available in the full measure specifications found on the PCPI Web site.

If the patient is eligible for the measure, to complete the measure the clinician must document in either the medical record or the EHR that they counseled the patient about the risks of driving and the alternatives to driving (numerator) at least once during the 12-month measurement period. In the medical record, this may be documented by the CPT-II code 6110F. This measure has one type of eligible exception: a medical reason (e.g., patient is no longer driving). The medical exception should be documented in the medical record and the result coded as 6110F-1P. More information on how to calculate exceptions is available in the full measure specifications and in previously published measures (Cheng et al., 2010).

Discussion

The dementia measurement set was designed to improve the care of persons with dementia. The DWG's principal focus was to provide a set of evidence- or guideline-based clinical performance measures that will improve the care and quality of life of persons with dementia. The set of 10 dementia quality measures (see Table 1) represents a comprehensive approach to the management of a person with dementia and features quality improvement initiatives in areas of patient management previously underemphasized in dementia care. The goal was to establish measures that were patient and family centered and that would be used by a broad range of providers in primary and specialty services, reflecting the multidisciplinary care common to many patients with dementia. Physicians in the medical specialties of neurology (geriatric and/or behavioral), psychiatry, geriatrics, internal

medicine, family practice, and palliative care are likely to find these measures useful in improving care for patients with dementia. Allied health professionals, nonphysician practitioners, and other nonphysician clinicians will also benefit from familiarity with the measures.

The measurement set consists of clinical process measures to be performed at the level of the individual practitioner focusing on accurate and appropriate evaluation and monitoring of disease status and associated symptoms. 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). These measures support the efficient delivery of high-quality health care in many of the Institute of Medicine's six specific aims for improvement developed around the need for health care to be safe, effective, patient centered, timely, efficient, and equitable. Widespread adoption of these measures has the potential to improve the quality of care for patients with dementia at multiple stages of disease and levels of health care delivery.

Several significant challenges and considerations were addressed throughout the development process. First, an inclusive process was established by inviting a broad range of organizations to participate in the development and vetting of the measures. Second, nuances in dementia management may arise based on the specific cause of dementia, and therefore core aspects of dementia management common to most dementias, regardless of cause, were identified. Third, the measurement set did not include measures relevant to establishing the diagnosis of dementia. Issues of cognitive screening, application of diagnostic criteria for the dementia syndrome and its constituent diseases, and evaluations necessary to determine the diagnosis were beyond the scope of the current measurement set. Fourth, the lexicon of dementia is currently in flux, transitioning from a static threshold model that required impairments in memory and at least one additional cognitive domain plus functional decline (American Psychiatric Association, 2000) to a dynamic disease stage model that permits diagnosis of the underlying etiology even before the dementia syndrome is fully present (Jack et al., 2011). Other changes in dementia medical care that will likely affect the enduring utility and need for reappraisal of these measures include the forthcoming fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, which considers major (i.e., dementia) and minor (i.e., mild cognitive impairment)

neurocognitive disorders, and the 2013 mandated adoption of the *ICD-10* in the United States.

Other challenges were germane to the choice and utility of measures. The development of clinical outcome measures in addition to the process measures described here was also considered. However, given the progressive nature of dementia and the paucity of interventions available to change its course, the development of reliable and comprehensive patient-level clinical outcome measures for dementia is deemed unrealistic at the present time. Given the inexorably progressive and degenerative disease course experienced by the overwhelming majority of patients with dementia, coupled with the lack of disease-modifying therapies, determination of target outcomes in this setting was particularly challenging. Common “outcome” metrics, such as survival/mortality or treatment response, apply only in nontraditional ways to this patient population. The goals of management, particularly for patients with advanced cognitive impairment, focus on improving the quality of life for patients and caregivers, maintaining optimal function, and providing maximum comfort (Herrmann & Gauthier, 2008).

The final quality measures are based on a number of clinical practice guidelines and primarily target under-emphasized aspects of the evaluation and management of patients with dementia and address the provision of effective and patient-centered care. The care processes measured in the DWG set are supported by evidence from traditional randomized efficacy trials as well as effectiveness and quality improvement studies. Drawing from outcome measures used in these studies, the DWG measurement set offers examples of validated outcome measures that could be used to satisfy the performance criteria. The suggested measures are not restrictive, and the list is not exhaustive; providers may choose other outcome measures if valid, reliable, and comparable to those included as examples. Finally, the denominator exceptions that specify who should be excluded from consideration were a critical issue that had to be resolved before the measures were finalized for implementation in actual practice settings.

The question of whether to base a measure on the use of medications approved for the treatment of Alzheimer’s disease, such as cholinesterase inhibitors (CEIs) or N-methyl-D-aspartate receptor antagonists (NMDAs), in the treatment of dementia was carefully examined. Clinical practice guidelines have recommended that CEIs be considered for all patients with mild to moderate Alzheimer’s disease but have also emphasized that the decision to initiate such therapy should be derived from individualized patient assessment and be based on a thorough discussion of the potential risks and benefits. CEIs may stabilize cognitive

decline: In clinical trials, their use has produced modest but statistically significant improvements in cognition and global status for a substantial subset of patients (Coin et al., 2012). However, most trials have been brief in duration and have defined outcomes by statistical significance rather than clinical relevance. CEIs are considered first-line pharmacotherapy in some dementias, such as Alzheimer’s disease, and may be helpful in some other dementia types. However, CEIs may be detrimental in other conditions, such as frontotemporal dementia.

NMDAs have been recommended for use in moderate to severe Alzheimer’s disease, but as with the CEIs, their benefit is modest and they carry the potential for adverse effects. In addition, the potential effectiveness of CEIs and NMDAs may vary by stage of dementia and may not be appropriate for some patients with negligible benefit or the potential for causing harm. Given these uncertainties in the risk–benefit ratio, the use of CEIs or NMDAs is not addressed in the measurement set (Baker & Qaseem, 2011). This decision should not be interpreted as an endorsement of therapeutic nihilism surrounding the use of cognitive enhancers for dementia but rather as an acknowledgment that use of these therapies is better decided on the basis of the clinician’s judgment than encouraged through performance measurement.

The progressive and debilitating nature of dementing illnesses makes palliative care and end-of-life issues a critical component of decision making. Planning for care at the end of life is essential at every stage of ongoing care because of the chronically progressive nature of the illness. Defining and documenting the goals of care as established by the patients themselves can occur only early in the course of illness. Families, caregivers, or proxy decision makers who witness or participate in these goal setting discussions will feel more confident about making critical decisions on diagnostic interventions or nutritional strategies as patients decline.

Currently, all the measures in the dementia measurement set apply to the individual treating clinician, and he or she is held accountable for the measure. However, future measure development will likely focus on system-level quality measures that would make a health care system or an interdisciplinary team (including a physician, nurse or nurse practitioner, occupational therapist, social worker, or others) accountable for the care provided to the patient.

Conclusion

The emphasis on dementia management in this measurement set recognizes the enormous challenge dementia presents to public health, government and private insurers,

health care providers, individual patients, and their caregivers. While patients, caregivers, and health care professionals await more effective medical treatments for dementing diseases, adherence to the measures outlined here and building individualized care plans for patients based on them will improve the quality of life and potentially the health of patients with dementing illnesses and their caregivers. These measures are a blueprint for improving the quality of care of patients with dementia. Whereas all measures tap important elements of long-term management of dementia, they can be applied by health care practices, health care systems, and health care plans collectively as a set or used individually for improving specific aspects of care or for specialized competency-based training, such as maintenance of certification or other education programs.

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