Quality Improvement in Neurology: Dementia Management Quality Measurement Set Update

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INTRODUCTION

Dementia is a neurological condition manifested by a substantial decline in multiple cognitive abilities that collectively render a person unable to function at expected levels and progressively impede independent ability to perform everyday activities. For decades, public health officials have warned of the coming 'tsunami' of Alzheimer's disease (AD), and dementia has even been characterized as the dominant scourge of modern times, replacing cancer.(1) Recently, hopeful signs have appeared, including reports from some longitudinal research studies that incidence of dementia is declining(2) and from the federal government that research funding for AD and other dementias will approach $1B in 2017.(3)

The consequential nature of dementia cannot be underestimated. Although not often conceptualized as such, dementia is a terminal disorder.(4,5)According to the 2015 annual statistics available from the Alzheimer's Association, one in nine Americans aged 65 and older has Alzheimer's disease and one in three older adults who dies in a given year has been diagnosed with Alzheimer's disease or another dementing disorder.(6)It is estimated that 14.7% of people older than 70 in the United States have dementia.(7) Alzheimer's disease is listed officially as the sixth leading cause of death in the United States.(6) Further, the monetary cost of dementia in the US ranges from $159–215 billion annually,(7) making it more expensive than heart disease or cancer. In 2014, unpaid caregivers provided nearly 18 *billion* hours of care to people with dementia, often at nontrivial cost to their own health and well-being.(8)

After passage of the National Alzheimer's Project Act (NAPA) of 2011, an Advisory Council for Alzheimer's Research, Care, and Services convened to advise the Department of Health and Human Services; the National Plan it produced in 2012 featured a prominent call for quality measures for the care of patients with dementia. Measurement of quality in care practices and services for persons with dementia and their caregivers remained an integral part of the Advisory Council's work in 2016.(9)

The first set of dementia management quality measures was developed and published in 2013 by the American Academy of Neurology (AAN) under the American Medical Association (AMA) Physician Consortium for Performance Improvement performance measure development model.(10) Previously convened by the AMA, the PCPI Foundation (PCPI) is now an independent foundation comprising multiple organizations focusing on the advancement of measurement science, quality improvement, and clinical registries. The Centers for Medicare and Medicaid Services (CMS) incorporated select measures into the Physician Quality Reporting System (PQRS), at that time the main quality reporting program through which eligible professionals and group practices reported information on the quality of care provided to their patients with Medicare. Measures may be incorporated into CMS' Merit-based Incentive Payment System (MIPS), which replaced PQRS in 2017.

In 2014, AAN and the American Psychiatric Association (APA) assumed joint stewardship of the dementia management measurement set, with the exception of the Cognitive Assessment measure, for which the PCPI retained stewardship. In 2015, the AAN and the APA formed a multidisciplinary Work Group to improve the original dementia management quality measurement set and to identify opportunities to define new quality measures to operationalize delivery of the best possible care for patients with dementia. The Work Group proceeded from the understanding that 'dementia' is a syndrome rather than a disease. Herein, and also throughout the referenced measurement set, 'dementia' is used as an umbrella phrase to encompass the numerous diseases and disorders that cause the symptoms of cognitive and functional decline constituting the dementia syndrome. This update applies to patients in whom the dementia syndrome and its underlying dementing disorder have been identified through a rigorous diagnostic evaluation. Quality measures for the approach to dementia diagnosis and for the characterization of prodromal states such as Mild Cognitive Impairment (MCI) are important and urgently needed, but they lie outside the scope of this measurement set.

OPPORTUNITIES FOR IMPROVEMENT

Providing health care services to patients with dementia poses unique challenges. A key prerequisite for the development of a measure is confirmation that provider performance is not yet ideal, constituting continued room for

improvement. A single measurement set cannot possibly capture all aspects of providing care for patients with dementia and their caregivers. This update focuses on key thematic elements in caring for patients with dementia, regardless of the underlying dementing disease. The original cognitive screening measure was unavailable for update by the Work Group. This should in no way be interpreted as diminishing the importance of annual cognitive assessment, which remains an essential component of quality dementia care management. Indeed, the PCPI opted to retain stewardship of the Cognitive Assessment measure, given its prominence in the measurement landscape. As such, the PCPI will ensure that the measure remains clinically relevant and consistent with the most current evidence, and that the specifications adhere to current industry standards. The measure was recently approved for trial use by the National Quality Forum (NQF), and the PCPI will continue to pursue testing data to facilitate eventual full endorsement by the NQF.(11)

The Work Group developed measures to address nine areas or processes in which quality of care could be improved.

Disclosure of diagnosis: In this setting, disclosure refers both to the diagnosis of the dementia syndrome and an explanation of the specific disease identified through prior diagnostic evaluation as the most likely cause of the dementia. The diagnosis of AD, the disease most commonly causing the dementia syndrome, is disclosed to patients and/or caregivers less than 50% of the time.(6) Withholding the diagnosis of dementia and its underlying specific disease unfairly disadvantages many patients and their families in accessing available services and obtaining assistance to plan for the future.

Education and support of caregivers: Persons with dementia become highly dependent on others, particularly as cognitive functioning worsens and behavioral symptoms emerge. Whether taken on by a single individual or shared among several members of the broader support community for the person with dementia, the caregiver role can be extremely stressful and takes a toll on general and mental health alike.(12) Clinicians have knowledge of methods and resources to assist caregivers, and sharing this knowledge is an essential aspect of providing good clinical care.

Functional assessment: In routine practice, persons with dementia may not be assessed regularly for changes in their ability to perform both basic and instrumental activities of daily living.(13) Frequent and comprehensive assessments allow health care providers to track these changes and make timely interventions aimed at supporting function or mitigating disability.

Screening for behavioral and psychiatric symptoms: Behavioral and psychiatric symptoms, including depression, are very common in dementia, are major sources of disability and distress, and are frequently neither detected nor appropriately treated.(14,15) Regular screening for, and management of, these symptoms will improve the quality of life for patients and reduce caregiver burden.

Screening for safety concerns: Screening for safety concerns is a major unmet need for patients with dementia.(13) Injuries associated with falls, accidents, and aggression have serious adverse impact on the quality of life of patients and caregivers. It is possible to reduce the risk of these outcomes through simple preventive measures. Opportunities to introduce these preventive measures may be overlooked if health care providers fail to screen for safety risks, paying specific attention to discrete risk domains.

Screening for driving safety: The onset of dementia often correlates with deterioration in driving skill and increased risk of accidents.(16) Health care providers are often reluctant to raise the issue of driving safety because they feel incompetent to assess it and because patients frequently resist such discussions.(17) Screening for driving safety at regular intervals will identify potential deficits and create opportunities to review reasonable options for remaining mobile in the community.

Advance care planning: Growing evidence indicates that patients want to engage in advance care planning to ensure that their end-of-life wishes are met,(18) but few patients with dementia are engaged in these discussions.(17) Persons with dementia without advance directives face unfairly increased risks of burdensome end-of-life transitions.(19)

Screening for pain: Pain is frequently unrecognized, undertreated, and poorly managed in elderly persons, particularly those with dementia.(20)

Treatment of dementia: Guideline-adherent pharmacologic treatment of dementia occurs in as few as one-third of primary care practices.(15)

METHOD

The AAN and APA formed the Work Group for the purpose of updating and modifying the original dementia management quality measure set using the AAN measure development process. Details of the full measure development process are available online.(21) The AAN and APA leadership team sought a broad representation of key stakeholders. Members were selected through a competitive process by the leadership team evaluating relevant and substantive experience in quality measurement, dementia care, or both. The selected Work Group comprised 26 members from 21 organizations (a list of members and contributing organizations follows this article), including physician, patient, caregiver, advanced practice provider, psychologist, payer, and nursing representatives. Insights provided by patient and caregiver representatives proved invaluable. All members disclosed potential conflicts of interest and were instructed to abstain if a potential conflict could be perceived during voting.

The Work Group's overarching priority was to conceptualize the best possible care for patients with dementia and their caregivers and to operationalize optimal processes for delivering such care. Candidate measures were reviewed and edited prior to a vote to approve, reject, or abstain from moving the proposed measure forward. Measures were refined

through an iterative, consensus-based process before, during and after the in-person meeting. Within this overall construct, measure feasibility and usability were given high priority, with the goal of minimizing reporting burdens. During this process, the Work Group also reviewed each of the original measures, evaluating whether current evidence still supported them, whether gaps in care continued, and whether links to desired outcomes have been described. This measurement set has been approved by the Work Group, the AAN Quality and Safety Subcommittee, the AAN Practice Committee, the AAN Institute Board of Directors, the APA Performance Measurement Committee, the APA Council on Geriatric Psychiatry, the APA Council on Quality Care, the APA Joint Reference Committee, and the APA Board of Trustees.

Further information on the measure development process and evidence used for these measures is provided in a data supplement that accompanies the online version of this executive summary. Additionally, individual measure specifications are included with numerator, denominator, exceptions, and timeframe for the measure. Denominator exceptions occur when a clinical factor necessitates removal of the patient from the denominator, and they require a clear rationale for exception on the grounds of medical, patient, or system reasons. When applicable, explicit exceptions are noted with rationale; precise specification of exceptions should foster ease of use in future conversion to electronic measures. In cases where assessment tools (i.e. screening tools for Behavioral and Psychiatric Symptoms of Dementia (BPSD)), are required to satisfy the measure, options for reliable and validated tools are provided in a nonprescriptive manner. Efforts were made to harmonize updated measures with extant measures whenever possible; details on measure harmonization are included in the individual measure specifications.

The AAN and APA will update these measures on an ongoing basis every three years, allowing the measurement set to provide a working framework for measurement, rather than a long-term mandate.

RESULTS

The updated measurement set addresses a small but important subset of the priorities inherent in high quality dementia care. The cochairs and facilitators reviewed 249 abstracts, identifying 23 guidelines to serve as the measures' evidence base. The Work Group ranked 11 candidate measures for review at the face-to-face meeting, where, after review of evidence and gaps in care, nine measures were finalized. The public comment period resulted in over 150 comments from 25 individuals or organizations. Each measure is designated for both quality improvement and accountability purposes. Each measure applies at the individual practitioner (physician or other health care professional), practice, and system (hospital or other health care setting) levels, and is applicable in outpatient, inpatient, emergency department or urgent care, or postacute care facility settings. Table 1 includes measure titles and a brief description of each of the nine process measures; full measure specifications are available in the data supplement that accompanies the online version of this executive summary.

The Work Group review resulted in decisions to retire or reconfigure three measures (Table 2), to reaffirm six with modifications, and to develop and approve three entirely new measures. Consensus supported retirement of the staging measure on the grounds that dementia stages constitute artificial constructs with little intrinsic meaning. The Work Group concluded that there is value in continued assessment of disease progression, but patients and caregivers may be better served simply by hearing whether dementia is mild, moderate, or severe. This rather more qualitative algorithm, while still a 'staging' of sorts, is less formal and has face validity that is easy to grasp for clinician and caregiver alike. Functional assessment is retained in the new suite of measures. The depression screening and management of neuropsychiatric symptoms measures were subsumed into an updated measure on screening and management of BPSD.

Six measures were retained with modifications. For example, in the driving safety measure, the exception for patients with dementia who had already stopped driving was removed in response to reports that the exception had caused confusion in pay-for-reporting programs. In the caregiver education measure, new exceptions were created for patients without caregivers, caregivers with prior training and/or certification, and patient/caregiver dyads already connected with existing supports. For the functional status measure, additional clarity was provided on how to meet assessment requirements. The safety measure was modified to specify dual risk domains related to self/others or the environment. The previously separate measures for assessment and management of neuropsychiatric symptoms were unified in a single measure devoted to evaluation and management of BPSD; this measure also incorporated the previous stand-alone measure on depression screening.

Finally, three new measures were developed. The first addresses disclosure of the dementia diagnosis, for both the dementia syndrome and the most likely etiologic dementing disorder. The second focuses on assessing the vulnerable population of patients with dementia for pain. The third is a measure for treatment, emphasizing pharmacologic treatment, when appropriate, within treatment rubrics that also by necessity incorporate nonpharmacologic behavioral and lifestyle modifications. This measure encompasses pharmacologic and nonpharmacologic treatment strategies because FDA-approved pharmacologic treatments are available for only a select subset of dementing diseases and even these are symptom- rather than disease-modifying agents.

The Work Group discussed, but opted not to develop, several measures or measure components. Additional elder abuse and violence screening were considered as potential components of the safety measure, but it was ultimately determined that these concerns were beyond the scope of the safety measure and duplicative of existing measures. The

TABLE 1. 2015 Dementia Management Measurement Set Update

Measure Title	Measure Description
Disclosure of Dementia Diagnosis[a]	Percentage of patients with a diagnosis of a qualifying dementing disorder or disease whose diagnosis has been disclosed to them and, if available, their primary caregiver.
Education and Support of Caregivers for Patients with Dementia	Percentage of patients with dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND were referred to additional resources for support in the last 12 months.
Functional Status Assessment for Patients with Dementia	Percentage of patients with dementia for whom an assessment of functional status was performed at least once in the last 12 months.
Screening and Management of Behavioral and Psychiatric Symptoms Associated with Dementia (BPSD)	Percentage of patients with dementia for whom there was a documented screening for behavioral and psychiatric symptoms, including depression, and for whom, if screening positive, there was also documentation of recommendations for management in the last 12 months.
Safety Concern Screening and Follow-Up for Patients with Dementia	Percentage of patients with dementia or their caregiver(s) for whom there was a documented safety screening in two domains of risk: dangerousness to self or others and environmental risks, and for whom, if screening positive, there was documentation they were provided with recommendations for their mitigation, which may include referral to other resources, in the last 12 months.
Driving Screening and Follow-Up for Patients with Dementia	Percentage of patients with dementia for whom there was a documented screening for driving risks and for whom, if screening positive, there was also documentation they were informed of alternatives to driving in the last 12 months.
Advance Care Planning and Palliative Care Counseling for Patients with Dementia	Percentage of patients with dementia who 1) have an advance care plan or surrogate decisions maker documented in the medical record or documentation in the medical record that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan AND Percentage of patients with dementia or their surrogate decision maker who 2) received comprehensive counseling regarding ongoing palliation & symptom management, and end of life decisions within two years of initial diagnosis or assumption of care.
Pain Assessment and Follow-Up for Patients with Dementia[a]	Percentage of patients with dementia who underwent documented screening for pain symptoms at every visit and if screening positive also had a documentation of a follow-up plan.
Pharmacological Treatment of Dementia[a]	Percentage of patients with dementia or their caregivers with whom available guideline-appropriate pharmacological treatment options and nonpharmacological behavior and lifestyle modifications were discussed at least once in the last12-month period.

[a] New measure added in 2015.

Work Group encourages providers and practices to utilize the existing Elder Maltreatment Screen and Follow-Up measure for these concerns.(22) The Work Group also chose not to develop a measure addressing falls, gait or mobility because of likely duplication of existing measures. Multiple falls measures are available for individuals interested in monitoring falls performance, including measures endorsed by NQF.(23)

Several potential outcome measures were discussed for possible development and inclusion in the final measure set. The Work Group considered several intermediate outcome measures (proportion of patients identified as at-risk drivers who had ceased driving, proportion of patients for whom advance care plans were developed, proportion of patients not on anticholinergic drugs). Ultimately, it was concluded that the inexorably neurodegenerative and terminal nature of dementia and its constituent diseases makes specification of rigorous outcome measures with appropriate risk adjustment difficult at this time. Several of the measures construed herein as process measures (i.e. functional status, BPSD assessment) are included in similar form in the Dementia Outcomes Set using Patient Reported Outcome measurement tools recently published by the International Consortium for Health Outcomes Measurement (ICHOM)(24)

As noted above, this update focuses on the management of dementia and what are termed "Major Neurocognitive Disorders" in DSM-5. As a result, the measurement set *does not* apply to individuals diagnosed with MCI, delirium, amnestic disorders, alcohol-induced persisting amnestic disorders, postconcussion syndrome, encephalopathy, memory loss, alteration of consciousness, and other unspecified persistent mental disorders. The full set of dementing disorders to which the update *does* apply is found in Appendix e-1 of the measurement set document.

CONCLUSIONS

The goal of quality measures is to guide their users to evidence-based improvements in care and, eventually, health care outcomes. The measures described herein offer a broad scope of processes necessary to improve the good care of patients with dementia. It is the hope of the Work Group that implementation of the measures will lead to measurable

TABLE 2. Measures Reviewed by the Dementia Management Update Quality Measurement Set Work Group

2009 Dementia Management Quality Measures
Measure #1: Staging of Dementia *(Retired 2015)*
Measure #2: Cognitive Assessment *(PCPI maintains stewardship of this measure)*
Measure #3: Functional Status Assessment
Measure #4: Neuropsychiatric Symptom Assessment
Measure #5: Management of Neuropsychiatric Symptoms *(Retired 2015)*
Measure #6: Screening for Depressive Symptoms *(Retired 2015)*
Measures addressing safety
Measure #7: Counseling regarding Safety Concerns
Measure #8: Counseling regarding Risks of Driving
Measures addressing underuse of patient-centered care strategies
Measure #9: Palliative Care Counseling and Advance Care Planning
Measure #10: Caregiver Education and Support

improvements in the care of this most vulnerable population. At present there are no disease-modifying medications for any of the diseases that cause the dementia syndrome, so many of the principles underlying good care in patients with dementia focus on nonpharmacologic aspects. The measures are unusual for the degree of emphasis they accord to the caregivers, indeed often conceptualizing the patient/caregiver dyad as the 'unit' of treatment. This focus is novel and still relatively uncommon in quality measures. The focus on communication represents another important shift toward more holistic care concepts than is currently common in most quality measures, yet is essential to good care for patients with dementia.

Clinicians should also be cognizant of reasonable performance expectations: there is no expectation that any provider will achieve instant 100% satisfaction of any, let alone all, of the measures. Such expectations miss the point that quality measurement is but the first step in quality improvement. Taking the time to assess and report one's performance is a crucial first step; providers should not fear 'being dinged' if they do not achieve 100% immediate fulfillment of the measurement set. Only by measuring one's performance can one become aware of areas in need of improvement and then initiate the changes necessary to achieve better care. Clinicians should implement these measures in advance of payment mandates, such as MIPS, to ensure readiness and to ensure that the highest quality of care is being provided.

Several limitations associated with the current Update provide direction for future Work Groups. First, given anticipated changes in the dementia care landscape, increased participation from social workers, emergency clinicians, and disease-specific advocacy groups will be important considerations for future Work Groups. Second, the development of outcome measures, with the necessary attendant schemata for risk adjustment, will certainly be a future focus. Third, measures to address coordination of care – especially as it relates to transitions between care levels – warrant future attention if cross-cutting measures in this area prove insufficient. Finally, future updates will review previously-proposed measures for emergent relevance within a shifting care landscape.

This update represents the current state of evidence. Given increased funding and research, it is hoped that care for patients with dementia will evolve rapidly in coming years. The Work Group recognizes that quality care for patients with dementia is often still conducted in a precarious environment of inadequate home-based care and high-risk transitions between levels of care, amid numerous other challenges not limited to care models favoring procedures over so-called cognitive care, inadequate social support systems, and the long-term viability of Medicare. The AAN and APA will continue to revise the measurement set as needed to address areas in which improvement can and should occur. Clinicians must remain vigilant to ensure care being provided is of the highest quality.

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