

Quality Improvement in Dementia Care: Dementia Management Quality Measurement Set 2018 Implementation Update

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The Dementia Management Quality Measurement Set was first developed and released in 2013 by the PCPI Foundation (1) (formerly the American Medical Association [AMA]–convened Physician Consortium for Performance Improvement [PCPI]). Developed by an appointed multistakeholder technical expert panel (TEP), the 2013 Measurement Set was supported by staff from AMA, American Academy of Neurology Institute (AANI), American Psychiatric Association (APA), American Medical Directors Association, and American Geriatric Society. Several of the original measures were included into the Centers for Medicare and Medicaid Services (CMS) Physician Quality Reporting System after being finalized through the federal rulemaking process (Table 1).

PCPI, now an independent-membership foundation separate from AMA, continues to prioritize measurement science, quality improvement programs, and clinical data registries, while charging yearly membership dues. Under its new business model, PCPI updates and develops new quality measures. Because of this shift, PCPI transitioned its originally developed measures to subject matter–appropriate organizations whose expertise could successfully support the measures' stewardship and maintenance needs. As such, AANI and APA agreed to jointly steward and maintain the Dementia Management Measurement Set. The first planned maintenance update began in early 2015 (2, 3). It should be noted that PCPI continues to maintain the Dementia Cognitive Assessment, one of the original quality measures included in the Dementia Management Measurement Set (Table 2).

While the Measurement Set's 2015 maintenance was underway, Congress passed the Medicare Access and CHIP Reauthorization Act (MACRA) of 2015. Among many of its provisions, MACRA updated physician payment rules (e.g. fee-for-service) and mandated that physician payment must reflect positive health outcomes resulting from high-quality and efficient care. This cleared the path for value-based payment models, like the CMS Quality Payment Program

(QPP). The 2 arms of QPP include Advanced Alternative Payment Models, in which practices assume a percentage of risk associated with care outcomes and cost efficiency, and the Merit-Based Incentive Payment System (MIPS), which collapsed several existing CMS-administered programs under a single quality payment system. For instance, in 2017, CMS's inaugural year of MIPS, the Quality Performance Category included some of the original AMA/PCPI-developed dementia quality measures, and in more recent program years, including 2019, CMS adopted the AANI/APA 2015 updated dementia measures (4).

Several advances in health care have occurred since the release of the 2013 Measurement Set. These advancements include prioritization of meaningful outcome measures that demonstrate cost efficiency, novel care delivery models (e.g. integrated care), and new data management methods (e.g. clinical data registries, certified electronic health technology, improvements to interoperability). Together these advancements have presented new perspectives on the provision of high-quality care for patients with dementia and the operationalization of quality measurement. As such, many opportunities remain to improve the provision of high-quality dementia management, including quality measurement.

This report describes the results of the AANI/APA-led 2018 triennial systematic review of updates related to the Measurement Set. This iterative process demonstrates AANI's and APA's dedication to ensuring that the Measurement Set optimally reflects ongoing advances in the clinical practice of dementia.

For this update, the AANI/APA TEP comprised psychiatrists and neurologists with expertise in dementia management or quality measurement implementation. Panelists examined evidence released between 2015 and 2018, including current clinical practice guidelines, systematic literature reviews, 2018 CMS benchmarking quality measure performance data, implementation experiences, and other relevant evidence. Like the TEP responsible for the 2015 update, 2018 panelists

TABLE 1. 2009 Dementia Management Quality Measures^a

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

^a PCPI=Physician Consortium for Performance Improvement

defined dementia as a syndrome, rather than a disease. Therefore, throughout this Measurement Set, the term dementia describes numerous diseases and disorders that lead to the symptoms of cognitive and functional decline constituting the syndrome. This update specifically applies to individuals for whom dementia and its underlying dementing disorder have been rigorously evaluated and diagnosed. Though quality measures for the diagnosis of dementia or mild cognitive impairment (MCI) are important, they are outside the scope of this Measurement Set. Based on the evidence review, the 2018 TEP ultimately recommended reaffirmation of the Measurement Set to both organizations' oversight groups. Reaffirmation included implementing technical updates that ensure the Measurement Set's intent is achieved during the clinical encounter. Updates also addressed feasibility to capture specific data elements required by clinical data registries, such as AANI's Axon Registry and APA's PsychPRO.

OPPORTUNITIES FOR IMPROVEMENT

AANI and APA experts noted that new evidence available in published literature, including clinical practice guidelines, systematic literature reviews, or meta-analyses, continue to support the intent of the 2015 Dementia Management Quality Measurement Set. As with previous reports on the dementia quality data set, it should be noted that no single measurement set can capture all aspects of providing care for patients with dementia and their caregivers. Like the 2015 update, the 2018 Measurement Set Update focuses on key thematic elements in caring for patients with dementia, irrespective of the underlying dementing disease. As stated previously, quality measures related to the diagnostic assessment of dementia and cognitive assessments are outside the purview of this update, as the PCPI retained stewardship of the Dementia Cognitive Assessment measures, which were included in the original PCPI Measurement Set. However, cognitive assessments are a crucial component of high-quality dementia care.

The Axon Registry, described in more detail in Methods, is intended to permit clinical providers an opportunity to maximize their quality of care by examining data from their

own clinical documentation in way that quantifies how often the quality metrics are met for their patient populations. The overarching goal of the data collection and assessment is to identify a benchmark performance rate and trends among different conditions or patient types that may alert clinicians where some measures may warrant improvement. For example, within a given practice there may be subsets of patients with certain conditions that have barriers to adequate documentation of advanced care planning. Identification of these factors that may vary among clinical providers offers an opportunity to put resources in place that can enhance successful implementation of the quality metrics.

METHOD

In the summer of 2018, AANI and APA convened an expert panel to review evidence released since the 2015 Measurement Set update. Details of the full measure development process are available online (2). A medical librarian identified 4,428 abstracts for review from peer-reviewed publications published after the 2015 Measurement Set since the 2015 Dementia Management Measurement Set was published. PubMed/National Library of Medicine, PubMed, MEDLINE, EMBASE, and the Cochrane Library Databases were searched using the following keywords/search terms, including all articles citing the Dementia Update 2015 measure publication.

- Treatment gaps in care/failure to assess/practice gap
- Dementia
- Patient care preferences dementia
- Guidelines/quality measures/performance measures/ quality indicators

The literature search strategy sought publications that addressed the implementation and utilization of the dementia management quality measures in the field. In addition to these publications, feedback was obtained regarding performance of the measures from CMS and from users of the Axon Registry. The Axon Registry is a quality improvement registry that offers real-world data for American Academy of Neurology members across a variety of practices and patients. The Axon Registry works by extracting information directly from the electronic health records of a participating clinical provider. This information is directly transmitted to the registry and used in a secure manner to allow for the provider to track his or her own performance in meeting quality measures. The measures analyzed by the Axon Registry comprise metrics that have been shown to be associated with better outcomes in conditions such as amyotrophic lateral sclerosis, child neurology, dementia, distal symmetric polyneuropathy, epilepsy, essential tremor, headache, multiple sclerosis, and Parkinson disease (PD). There are also cross-cutting measures available to improve care for patients who experience depression, falls, and sleep disorders. From the dashboard portal, participating clinicians and administrators can access the data, run queries on their own patient population, benchmark practice performance, and uncover

TABLE 2. 2015 Dementia Management Measurement Set update

Measure Title	Measure Description
Disclosure of Dementia Diagnosis	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 ^a	Percentage of patients with dementia whose caregivers 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 ^a	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 ^a	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 ^a	Percentage of patients with dementia or their caregivers for whom there was a documented safety screening in 2 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 decision-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 and symptom management and end of life decisions within 2 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 encounter and if screening positive also had a documentation of a follow-up plan
Pharmacologic Treatment of Dementia	Percentage of patients with dementia or their caregivers with whom available guideline-appropriate pharmacologic treatment options and nonpharmacologic behavior and lifestyle modifications were discussed at least once in the last 12-month period

^a Technical updates made to allow for performance in a registry

potential areas for quality improvement. The Axon Registry is designed to minimally affect practices and physician workflows. The Axon Registry enables quality improvement through the collection of data across a variety of practice settings, patients, and presentations. Data from published research articles, CMS, and the Axon Registry were aggregated and reviewed by the expert panel to determine necessary 2018 Measurement Set updates.

RESULTS

The TEP selected 63 articles for review that were generally found to support the 2015 Measurement Set content. Most articles did not directly test measure performance, but rather provided results/data from a wide range of dementia studies that addressed outcomes in clinical care. Therefore, it was necessary to extrapolate the literature results in reference to the Measurement Set. The TEP determined that the denominators (i.e. the total population of patients appropriate for use of the quality measures, identified by dementia-related International Classification of Diseases [ICD] codes) were not affected by new data. There were 2 exceptions. The TEP noted that ICD codes for PD (ICD-9 332.0 and ICD-10 G20) and HIV disease (ICD-9 042 and ICD-10 B20) were included in the eligible population for the 2015 update of the Measurement Set to capture patients with those conditions

who also have dementia within the measures' denominators. However, they inadvertently included patients with these conditions without dementia. As a result, the 2018 Measurement Set was updated so that the measures' denominators accurately include codes that describe patients with PD or HIV who also have dementia. The codes that included patients with HIV or PD alone (i.e. without dementia) were removed from the denominator. This update enhances the precision of the quality measures.

Similarly, new data supported that the current measures appropriately identify the given numerator. However, some technical updates were made to improve measure specificity. The numerator reflects the number of patients who satisfy the quality metrics presented in the Measurement Set, which permits calculating the proportion meeting the quality metric out of the total (denominator) or patients in a clinical setting with a dementia ICD code. The TEP recommended greater specificity be added to 5 of the measure numerators (Table 2 and available online at aan.com) allowing for collection of data in an electronic medical record or qualified clinical data registry. The TEP reviewed current data collected in the Axon Registry, and refined and expanded on the existing list to include additional key phrases likely used in practice to meet the individual measure numerators. This information was incorporated into the 2018 technical update of the Measurement Set as described below. Appendix e-1

([links.ww.com/WNL/B17](https://www.ww.com/WNL/B17)) includes details regarding the technical updates of each measure's specifications, such as numerator, denominator, exceptions, and timeframe for the measure. Finally, according to current literature, the panel decided that the definition of caregiver should be expanded. The term caregiver now refers to any relative, partner, friend, neighbor, or other individual who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult with a chronic or disabling condition.

DISCUSSION

The Dementia Management Quality Measurement Set described below includes the 9 clinical areas or care processes updated in 2015, as well as additional comments from the 2018 TEP review. The majority of quality measures within the Measurement Set are applied to care provided within the preceding 12-month period. However, there are 3 exceptions to the 12-month criteria. They include the following: 1) disclosure of the diagnosis of dementia, 2) inclusion of advanced directives that do not fall within the 12-month period (as both of those actions should be documented within the first 2 years after diagnosis), and 3) the quality measure that assesses pain should occur at each encounter.

Disclosure of diagnosis

Added to the set in 2015, disclosure of the diagnosis of the dementia syndrome and its underlying diseases was determined by the 2018 TEP as an appropriate quality measure for continued inclusion in the Measurement Set. Disclosure is closely linked to education and caregiver support, offering an invaluable opportunity to provide essential information, resources, and emotional support to the patient-caregiver dyad. The numerator specification, patients and patient/caregiver dyads, is noteworthy, recognizing that there is evidence that practitioners may be more likely to discuss the diagnosis with caregivers only rather than discussing the diagnosis with both the patient and caregiver (5). This language is intended to optimize disclosure to the patient and including the patient in the patient/caregiver dyad in an effort to minimize excluding the patient from the clinical decision-making process whenever possible.

Education and support of caregivers

This quality measure assesses whether caregivers were provided with education on dementia disease management and health behavior changes as well as referred to additional resources. This quality measure is unchanged from 2015. Recent evidence shows that caregiver support may be greatly beneficial in reducing the care burden and distress that place caregivers at risk for adverse health outcomes and compromise their ability to provide optimal care (6). Health care providers are well positioned to offer caregivers education about dementia and information about resources. The presence of this measure is intended to enable caregivers to implement the knowledge gained from the education and

information and, as a result, experience reductions in caregiver burden.

Functional assessment

Recent literature underscores the importance of evaluating both activities of daily living (ADLs) and instrumental ADLs (IADLs). Measuring complex IADLs is reported to help detect deficits as early as the beginning stages of dementia, when cognitive interventions may be more efficacious (7). Longitudinal documentation of IADL changes also increase the accuracy of estimating disease progression (8). Current quality measures require a validated tool or evidence of direct assessment of specific domains of ADLs and IADLs. Lawton IADL, Barthel ADL index, Katz Index of IADL, and the Functional Activities Questionnaire remain the most commonly used survey instruments. While functional assessments are typically documented subjectively during the encounter, use of a validated instrument may increase objectivity, accuracy, and trends over time. Further, identifying key words in a clinical data registry will limit subjective documentation and promote standardization of these data elements (e.g. an assessment for grooming could be "can shower alone" or "does not need help to bathe").

Screening for behavioral and psychiatric symptoms of dementia (BPSD)

BPSD symptoms were unified into a single quality measure in the 2015 updated Measurement Set. This change incorporated the previous stand-alone screening of depression into the overall BPSD quality measure. The 2018 literature review reaffirms this update, as recent studies typically utilize a comprehensive assessment of the full range of behavioral symptoms. According to recommendations made by a multidisciplinary expert panel addressing care for aggression, agitation, depression, anxiety, delusions, hallucinations, apathy, and disinhibition in dementia (9), as well as other evidence examined by the TEP, current findings do not provide sufficient support for modification to the current quality measure regarding specific behavioral management practices. A number of recent studies examined both pharmacologic and nonpharmacologic approaches, as well as the effects of antipsychotic medication discontinuation, but there are insufficient findings to add new quality measures regarding BPSD (10, 11).

Screening for safety concerns

This measure specifies that safety screening should occur under 2 risk domains: 1) dangerousness to self or others and 2) environmental risks; further, the measure requires evidence that risk-reduction resources have been offered when the screen is positive. Although the measure was reaffirmed, the panel suggests that screening for safety risk is an identified gap in dementia care that may be attributable to the many sources of safety concerns in the context of dementia (12). This measure is distinctive in that screening for dangerousness examines the level of risk attributable to both the patient and

the environment. That is, the risk may relate to patient factors (e.g. cognitive loss, gait instability, and impulsivity) as well as to environmental factors (e.g. access to weapons and the mismanagement of machinery and appliances). This quality measure also requires evidence for offering resources for safety enhancement such as community and online resources that facilitate home safety (13). Routine screening for safety issues allows for documentation of ongoing individual concerns that may facilitate early detection of increased risk for a given patient with dementia, enabling the provision of high-quality care.

Driving screening and follow-up

This measure specifies a documented screening for driving risks as well as documentation of a discussion of alternatives to driving for patients in whom a risk is identified. Despite the TEP's acknowledgment that providers may report discomfort when discussing the topic of driving cessation because of the perceived negative effect on independence, quality of life, and relationships, data supported the decision to reaffirm this measure (14). Multiple factors are influential in the risk for impaired driving; consequently a composite assessment may be particularly helpful. Such a measure may include a composite score of 1.0 on the Clinical Dementia Rating scale (which translates to mild dementia); the assessment may also include caregiver report of unsafe or marginal driving ability, or a history of accidents, among others. The screening may lead to a discussion of driving safety, finding alternate transportation methods, or referral to additional simulator or on-road testing. The discussion should ideally consist of education on the higher risk of driving accidents in persons with dementia and plans for driving cessation, emphasizing the shared objective of preventing injury.

Advance care planning

The Advance Care Planning and Palliative Care Counseling Measure has 2 components: 1) documentation of an advanced care plan or surrogate decision maker and 2) counseling patients and caregivers about palliative care, symptom management, and end-of-life decision-making. Current data reaffirm the quality measure as drafted in the 2015 Measurement Set. Recent studies have made considerable progress in defining the scope and definition of optimal palliative care in dementia (15). Furthermore, advances have occurred in developing guidelines for specific circumstances such as feeding and swallowing issues (16). These important studies facilitate progress in implementing the current measure and support its ongoing utility.

Screening for pain

This measure specifies a documented screening for pain symptoms at every clinical encounter and, when positive, additional documentation of pain reduction intervention. Pain management is challenging in patients with dementia due to a variety of factors, including difficulties with communication. Inadequate pain control can lead to poor

quality of life and precipitate behavioral disturbances in patients with dementia (17). Pain assessment tools developed for patients with dementia may be particularly helpful to assist in detecting pain in patients who are unable to verbalize their symptoms (18).

Pharmacologic treatment of dementia

This measure specifies that discussion with patients or their caregivers should occur regarding options for guideline-appropriate pharmacologic treatment and nonpharmacologic behavior and lifestyle modifications. Recent data in the 2018 review reaffirm this measure. The use of cholinesterase inhibitors in AD and in dementia with Lewy bodies/PD dementia continues to be supported (19). A recent consensus statement supported the use of memantine as well (20). Nonpharmacologic and lifestyle interventions continue to show supportive evidence in the management of dementia of all types, and particularly in the context of vascular-related dementia, where there is less evidence in support of pharmacologic interventions (21).

CONCLUSIONS

Quality measures are one tool to help practitioners improve their care for patients with neurodegenerative diseases. The Dementia Management Quality Measurement Set has been established and refined to help facilitate practitioners' awareness of quality metrics that are supported by current literature. The Measurement Set also provides practitioners with the means to calculate the proportion of their administered care that adheres to guideline recommendations in the 9 areas addressed by the quality measures. As stated previously, the Measurement Set does not address the diagnosis or treatment of patients with MCI. The AANI released a separate measurement for MCI in September 2019 (22).

AANI and APA have conducted this review of the Dementia Management Measurement Set and provided technical updates with the goal of providing more feasible, and less burdensome, quality measures. Together they will continue to revise the measures as needed to reflect developments in the field. This report summarizes the technical edits that include providing a broader definition of caregiver, removing ICD-10 codes for patients with PD and HIV disease, and enhancing specificity of instructions to satisfy numerator requirements for 5 of the measures (Table 2 and available online at aan.com). While this effort was confined to updating the current measures, it is recognized that over time new findings will emerge that are likely to support new metrics that have a meaningful effect on quality of care. For example, new drug development or further research on pharmacologic practices may identify specific prescribing methods that may confer benefit or avoid harm in older patients that may be added as new measures. These current technical updates will enhance feasibility of collection in practice, without adding additional burden in modifying current documentation.

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