

REVIEW ARTICLE

Improving quality measurement for dementia care

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Impact Statement: We certify that this work is novel. This work enriches the literature on existing gaps in dementia quality measurement and offers recommendations for a set of national dementia quality measures as a way to improve diagnostic evaluation and longitudinal care, and advance equity in dementia care.

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Abstract

Nearly 7 million Americans are living with Alzheimer's disease or a related dementia (ADRD). Timely detection, quality of care, and access to services for people with ADRD remain poor. Broad acceptance and implementation of quality standards may help improve care processes, outcomes, and inequities in ADRD care. We review existing quality measures for ADRD and identify care domains that lack well-developed measures or for which uptake of existing measures is low. Increasing the use of existing evidence-based ADRD quality measures for health system performance improvement, pragmatic research, and Alternative Payment Models like the Centers for Medicare & Medicaid Services Guiding an Improved Dementia Experience (GUIDE) Model, launched in 2023, may promote changes in care delivery and help address disparities in dementia care.

KEYWORDS

Alzheimer's disease, caregiving, dementia, measurement, quality, value-based care

Highlights

- US dementia care needs better measurement tools to assess quality and inequities.
- Increased use of current Alzheimer's disease and related dementias quality measures is urgently needed to improve care.
- Consensus on high-quality dementia care is vital for health system expectations.

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- The Centers for Medicare & Medicaid Services Guiding an Improved Dementia Experience (GUIDE) Model tests a new payment strategy to enhance dementia care quality.
- Other payers can boost measurement to drive quality care like the GUIDE Model.

1 | INTRODUCTION

In the United States, Alzheimer's disease and related dementias (ADRD) affect an estimated 6.7 million people.¹ Identifying, treating, and caring for people with ADRD requires both medical and social services to provide high-quality care that is person centered and prevents avoidable complications, including hospitalizations. This care also comes at an enormous cost, estimated between \$157 billion and \$345 billion per year in 2023, most of which is borne by persons with the disease and their families.¹⁻³ As the proportion of the population aged ≥ 65 years expands, the number of people at risk of developing and living with dementia is expected to grow and to make greater demands on families, health-care and social systems, and private and public budgets.⁴

Despite the growing prevalence of ADRD, widespread dissemination of high-quality, evidence-based care management models^{5,6} for people with dementia remains limited compared to other chronic and life-limiting diseases that affect older persons. There are proposed domains of "comprehensive dementia care," including elements such as establishing a care plan, providing caregiver education and support, and addressing behavioral and psychological symptoms of dementia.⁷ A key step in improving health outcomes for persons with dementia and their family caregivers is measuring ADRD care quality within established domains of comprehensive dementia care. Quality indicators measure practice performance to assess the quality of care provided and can include processes of care, care or health outcomes, and measures of organizational resources or structure. Developing a quality measure is a multi-step process, which involves defining the construct to be measured, generating and selecting items, determining how the items will be scored, piloting and field testing the measure, adapting the measure based on the field testing results, and evaluating the measure properties.^{7,8} While several quality measure sets or endorsed measure lists for best practices in dementia care have been developed in an effort to define, assess, and drive high-quality dementia care,⁹⁻²¹ few measures have seen widespread use and there are domains of dementia care which lack well-developed, validated quality measures.²²⁻²⁴

In this article, we recommend payers and providers move quickly to put already-available quality measures into wider use. We also identify four priority areas for new quality measurement development including early detection and diagnosis of ADRD, person-centered care planning and elicitation of individualized health goals, formal identification of and support for family or friend caregivers, and measures to guide the definition and development of dementia-capable health

systems.²⁵ Moreover, there are well-documented disparities in dementia care among socially vulnerable older adults, those living in rural areas, and racial and ethnic minority groups.^{26,27} Quality measurement in these sub-populations of people with ADRD is particularly important to identify and raise awareness of disparities in dementia care to guide system and policy change. Both new research and prompt establishment of widespread quality measure reporting are needed.

The recently established Centers for Medicare & Medicaid Services (CMS) Guiding an Improved Dementia Experience (GUIDE) Model is a major step forward. In addition to being an Alternative Payment Model (APM), it is serving as an example of systematic use of quality measures, aiming to align health system services with performance measures included in the CMS Merit-based Incentive Payment System (MIPS) Value Pathway for Supportive Care for Neurodegenerative Conditions to the extent possible.²⁸ GUIDE requires data reporting and sharing on five key performance measures: use of high-risk medications for older adults, quality of life (i.e., Patient-Reported Outcomes Measurement Information System Global Health 10), caregiver burden, total Medicare cost of care, and long-term nursing home stays.²⁹ With this national CMS model underway, now is the time for a standardized approach to assessing dementia care quality.³⁰

In addition to initiatives such as the GUIDE Model, legislative actions have the potential to incentivize both the use of existing quality measures and the development of new measures to assess the quality of dementia care. For example, the 2014 Improving Medicare Post-Acute Care Transformation (IMPACT) Act legislated the development and implementation of new quality measure reporting with standardized tools for use in skilled nursing facilities, home health care, and other sites that provide post-acute and long-term care to persons with ADRD. The IMPACT Act required quality measures to address safety, care transitions, exchange of health information and patient care preferences, and dementia-relevant metrics, including measures of cognitive and functional status.³¹

The Medicare Access and CHIP (Children's Health Insurance Program) Reauthorization Act of 2015 (MACRA) created the Quality Payment Program (QPP), an incentive-based payment model for Medicare to pay providers for delivering better care, as measured by outcomes, rather than the amount of care.³² QPP mandates participation in either the MIPS or an APM. Under MACRA requirements, MIPS measures must address care coordination, patient and caregiver experience, population health and prevention, patient-reported outcomes, and functional status measures that include an emphasis on patients with multiple chronic conditions. Although no specific dementia-related quality measures are currently required as part of

MIPS reporting,³³ six dementia-specific measures have been incorporated into MIPS and can be reported voluntarily. In 2023, the MIPS Value Pathway (MVP) reporting option was introduced, including a Supportive Care for Neurodegenerative Conditions MVP that focuses on promoting high-quality care for patients with cognition-based neurological disorders, including but not limited to AD/DRD.

While the GUIDE Model and other federal initiatives may incentivize the use of existing measures, they are unlikely to bridge existing gaps in dementia quality measurement, especially for longitudinal care management for people with dementia. In this context, the goal of this paper is to suggest specific action steps to improve the quality measurement of dementia care now.

2 | METHODS

To prepare this paper, we reviewed literature on quality measure sets specific to dementia as well as previous reviews and reports regarding definitions of comprehensive dementia care.³⁴ We chose a theoretical framework published in the 2016 RTI International report “Examining Models of Dementia Care.”⁷ We chose this framework because the report had been commissioned by US Health and Human Services’ Office of the Assistant Secretary for Planning and Evaluation (ASPE) specifically to describe the domains of comprehensive dementia care. The RTI report’s framework was then used as a template to map individual quality measures from the identified measure sets. This mapping helped to determine alignment across measure sets as well as gaps where dementia care domains had few or no individual measures.

The following sections review existing dementia care quality measures (Section I); current gaps in measurement where quality measures need to be further validated or developed (Section II); and future directions, including specific action steps that could be enacted to support dementia care measurement (Section III).

3 | SECTION I: REVIEW OF EXISTING DEMENTIA CARE MEASURES

Several frameworks for assessing the quality of dementia care have been put forward with similar components. The Administration for Community Living (ACL) developed a framework in 2014 that includes measuring the detection of dementia, functional and cognitive ability, decision-making capacity, educational and emotional support for persons with dementia and their caregivers, and coordination of care among different providers and services. In 2014, the National Quality Forum (NQF) published “Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer’s Disease,”²⁰ which identified a need for measure development for comprehensive dementia diagnostic evaluation and needs assessment, caregiver assessment and support, and dementia-capable health-care and community care systems. A framework developed by the Alzheimer’s Association in 2018 includes nine components of quality dementia care and places an emphasis on person-centered assessment for the person living with dementia.³⁵

A 2016 report by RTI International entitled “Examining Models of Dementia Care” (hereafter referred to as the RTI framework) was commissioned by the US Department of Health and Human Services (HHS), Office of the ASPE. The RTI list of Dementia Care Framework Components was developed in 2016 to identify important components of clinical practice to be incorporated in programs intended to help people living with dementia and their family caregivers. The measures in the RTI framework are based on a review of clinical guidelines, practice recommendations, and quality measures that were available in English and had been published in the years from 2006 to 2015. The RTI team searched for documents to review in the Agency for Healthcare Research and Quality (AHRQ) National Guidelines Clearinghouse, the clinical practice literature, discipline-specific professional literature, and Alzheimer’s Association recommendations for health-care professionals. Among the 37 sources reviewed for the RTI framework, 25 sources were from the US organizations, clinicians, and researchers. The remaining 12 sources were from non-US organizations, clinicians, and researchers. The RTI framework identified 14 components of comprehensive dementia care that cover aspects of care for people in all stages of dementia and their families. For this review, we compared dementia care measures from existing national and international quality measurement sets and endorsed lists to the 14 distinct care components in the RTI framework (Table 1).

As shown in Table 2, no existing measure set or endorsed list includes all 14 RTI framework domains, with the number of domains encompassed ranging from four to eight. However, measures for all domains, except therapeutic environment, do exist across sets. Additional details on the specific measures included for each domain across measure sets and endorsed lists can be found in Appendix S1 in supporting information.

The first domain in the RTI framework, the detection of possible dementia, appears in only three of the reviewed measure sets or endorsed lists. Assessing Care of Vulnerable Elders-3 (ACOVE-3) includes cognitive and functional screening of vulnerable elders on an annual basis. While not a quality measure, the Medicare Annual Wellness Visit, a component of the CMS QPP, includes detection of cognitive impairment, and the CMS Nursing Home Compare measure set includes cognitive assessment as part of the Minimum Data Set for nursing homes. Whereas measures related to diagnosis are included in four lists (ACOVE-3, American Academy of Neurology/American Psychiatric Association, NQF, National Institute for Health and Care Excellence [NICE]), nine lists include measures of assessment and reassessment. While medical management is mentioned in most measure lists, its meaning in the context of dementia is unspecified. Only three measure lists cover care planning, and of these, only the NICE measures reference person-centered assessment and care planning. Other RTI framework domains that are largely absent from existing quality measure lists include acknowledgment and emotional support for the person with dementia and assistance for the person with dementia with daily functioning and activities. One exception is the Consumer Assessment for Healthcare Providers and Systems (CAHPS), which includes a measure of emotional and spiritual support but only for those in hospice. Although five measure lists include a

TABLE 1 Existing quality of care measurement sets for dementia.

| Category | Measure set or endorsed list | Developed by |
|--|---|------------------|
| US research based | Assessing Care of Vulnerable Elders-3 (ACOVE-3) ^{8,9} | RAND Corporation |
| Professional societies | Dementia Management Measurement set ¹⁰ | AAN/APA |
| Centers for Medicare & Medicaid Services (CMS) | CMS Quality Payment Program (QPP) ¹¹ | CMS |
| | CMS Nursing Home Compare (NHC) and Home Health Compare (HHC) ^{12,13} | CMS |
| | Consumer Assessment of Healthcare Providers and Systems (CAHPS) ¹⁴ | AHRQ |
| Policy | National Quality Forum (NQF) ²⁰ | NQF |
| | National Committee Quality Assurance (NCQA) HEDIS measures ^{36,37} | NCQA |
| International | The United Kingdom National Institute for Health and Care Excellence (NICE) Measurement Set ¹⁵ | NICE |
| | International Consortium of Health Outcomes Measurement (ICHOM) set ¹⁷ | ICHOM |

Abbreviations: AAN, American Academy of Neurology; AHRQ, Agency for Healthcare Research and Quality; APA, American Psychiatric Association; HEDIS, Healthcare Effectiveness Data and Information Set.

TABLE 2 Review of existing measure sets by RTI framework domains.

| HHS-ASPE/RTI1 framework for models of dementia care | Quality measure sets or endorsed lists specific to dementia | | | | | | | | International measure sets | |
|---|---|-----------|---------|---------|---------|-------|-----|------|----------------------------|-------|
| | ACOVE-3 | AAN & APA | CMS-QPP | CMS-NHC | CMS-HHC | CAHPS | NQF | NCQA | NICE | ICHOM |
| 1. Detection of possible dementia | o | | o | o | | | | | | |
| 2. Diagnosis | o | o | | | | | o | | o | |
| 3. Assessment/ongoing reassessment | o | o | o | o | o | o | o | | o | o |
| 4. Care planning | | | o | o | | | | | o | |
| 5. Medical management | o | o | o | o | o | o | o | o | o | |
| 6. Information, education, informed and supported decision making | o | o | o | | | o | o | o | o | |
| 7. Acknowledgment and emotional support for person with dementia | | | | | | o | | | | |
| 8. Assistance for person with dementia for daily functioning and activities | | | o | o | | | | | | |
| 9. Involvement, emotional support, and assistance for family caregivers | o | o | o | | | o | | | o | o |
| 10. Prevention and mitigation of behavioral & psychological symptoms | o | o | o | o | o | o | o | | o | |
| 11. Safety for person with dementia | o | o | o | o | o | | | | | o |
| 12. Therapeutic environment | | | | | | | | | | |
| 13. Care transitions | | o | o | o | o | o | o | o | o | o |
| 14. Referral and coordination of care and services | | | | | | o | | | | |

Abbreviations: AAN, American Academy of Neurology; ACOVE-3, Assessing Care of Vulnerable Elders-3; APA, American Psychiatric Association; ASPE, Office of the Assistant Secretary for Planning and Evaluation; CAHPS, Consumer Assessment for Healthcare Providers and Systems; CMS, Centers for Medicare & Medicaid Services; HHC, Home Health Compare; HHS, US Department of Health and Human Services; ICHOM, International Consortium of Health Outcomes Measurement; NCQA, National Committee for Quality Assurance; NHC, Nursing Home Compare; NICE, National Institute for Health and Care Excellence; NQF, National Quality Forum; QPP, Quality Payment Program; RTI, RTI International.

measure related to support for family caregivers, only two (NICE and International Consortium of Health Outcomes Measurement) include an assessment of caregiver emotional and social needs and quality of life.

The RTI framework includes a “therapeutic environment” component that refers to the creation of a comfortable and familiar physical and social environment for the person living with dementia to support all aspects of functioning and quality of life. None of the measure lists we reviewed addressed this concept. Only the CAHPS included a measure related to referral and coordination of care and services for the person living with dementia and caregivers. However, the CAHPS measure is limited to access to specialists without addressing coordination of care or collaboration among providers or between the health system and community-based dementia services.

4 | SECTION II: GAPS IN MEASURING DEMENTIA CARE

Our review of existing quality measures for dementia, using the RTI framework as the guide, identified important variations across measure sets and critical gaps, including: early detection and diagnosis of dementia; person-centered care planning and elicitation of individualized health goals; formal identification of and support for family caregivers; emotional support and assistance with daily activities for people living with dementia; creation of therapeutic environments to support function and quality of life; and referral and coordination of care and services. Additionally, measures are needed to guide the definition and development of dementia-capable health systems.³⁸⁻⁴⁰ Four of these gaps in measurement are described in detail below.

4.1 | Early detection and diagnosis

The majority of people with ADRD never receive a medical diagnosis.⁴¹⁻⁴⁴ Among those who do and their family caregivers, fewer than half report knowledge of the diagnosis.⁴⁵⁻⁴⁷ When a diagnosis is made, it is often at mid- and later stages of dementia^{48,49} when psychological and behavioral symptoms may be more difficult to manage, poor care coordination has resulted in avoidable crises, and opportunities for proactive and preventive care planning have been lost—including advance care planning when the individual with dementia can participate and voice their own care preferences.

There are no guidelines or performance measures that recommend routine population-based screening for cognitive impairment in clinical practice,^{50,51} and the most recent US Preventive Services Task Force recommendations cite insufficient evidence to support routine cognitive impairment screening of asymptomatic individuals in primary care.^{52,53} However, multiple national expert panels representing a broad range of stakeholders have proposed early detection of cognitive symptoms and dementia diagnosis as a national priority. Specifically, the National Academy of Medicine, the National Plan to Address Alzheimer's Disease, and the Medicare Annual Wellness Visit (AWV)

all identify earlier detection of cognitive symptoms as a core aim for improving the quality of health care for people with dementia or at risk of dementia,⁵⁴⁻⁵⁶ and early detection is a central focus for action under the Centers for Disease Control and Prevention Building Our Largest Dementia Infrastructure (BOLD) programs. The US Department of Veterans Affairs Dementia Steering Committee also does not endorse routine population-based cognitive screening but highly recommends full evaluation if dementia warning signs are present.⁵⁷

Concerns about standard measures for early identification of dementia are based on the lack of trials measuring the long-term harms and benefits of screening, the modest benefit of pharmacotherapies, and potential stigma of a dementia diagnosis.⁵⁸⁻⁶² These concerns may dissuade both patients and providers from discussing symptoms or completing an evaluation.⁶³ However, the growing body of evidence and US Food and Drug Administration approval for drugs such as lecanemab and donanemab that may slow progression in some individuals with early-stage Alzheimer's disease (AD) may result in increased demand for screening.⁶⁴⁻⁶⁶ The national interest in early detection and diagnosis⁶⁷ is also based on growing evidence that non-pharmacological interventions, including lifestyle changes especially around risk factor reduction (e.g., exercise, hearing amplification) and comorbidity management, collaborative care, and caregiver education and training can improve patient and caregiver outcomes.⁶⁸⁻⁷⁰ Moreover, diagnosing dementia allows patients and caregivers to receive guidance about pharmacotherapies, as well as progression and expected complications; to support medical decision making along the disease course;⁶⁰ to plan for future health states and long-term care needs;⁷¹ and potentially to prevent injury from unsafe driving, wandering, home hazards, falls, or medication errors. Dementia also impacts the ability to self-manage other chronic conditions, like diabetes or heart disease. Early detection of cognitive impairment may prevent complications of other conditions and may alert clinicians to the need to engage family members or other care partners in care management.⁷²

4.2 | Person-centered care planning and elicitation of health goals

Addressing individual patient preferences from a culturally competent perspective is a core component of person-centered care⁷³ and a requirement under Section 2402(a) of The Patient Protection and Affordable Care Act (ACA). Understanding what matters most to individuals is a central tenet of the Institute for Healthcare Improvement's Age-Friendly Care movement.⁷⁴ The CMS GUIDE Model also requires the development of a comprehensive person-centered care plan that is led by the beneficiary and their care partner.

Person-centered care planning for dementia requires ongoing, comprehensive assessment that prioritizes helping the person with dementia to live fully⁷⁵ and aligns care recommendations with the individual's health priorities. This often requires input from a family member or caregiver to fully determine the values and goals of the person with dementia.⁷⁶ However, persons with dementia should not

be excluded from care plan development because of impairments that limit participation; rather, identification of a person with impaired capacity should prompt additional assessment that adapts conversations to the individual's capacity to understand and provide input, and identifies and incorporates a family member or other representative who has knowledge of the patient's preferences.

Documentation and sharing of person-centered care plans between all care providers is an essential component of high-quality care.⁷⁵ One strategy for implementing person-centered care is the use of a structured care plan that explicitly addresses all of the core components and identifies the intent of each component. The Office of the National Coordinator for Health Information Technology helps design electronic health record formatting so care plans can be communicated between health-care providers and patients.⁷⁷

Another model for addressing individual patients' preferences has been developed by the National Committee for Quality Assurance (NCQA).⁷⁸ NCQA's approach is to assess what is most important to persons living with complex care needs, including those with dementia, and use individualized goal setting and attainment tracking to determine the degree to which high-quality care is being delivered. Goal setting is done through a four-step process of eliciting values and care preferences, negotiating a specific goal, developing an action plan, and monitoring progress toward goal attainment. The individual, caregiver, and clinician collaborate in the goal-setting process, both to ensure that goals are realistic and to facilitate re-evaluation and revision of goals as the disease progresses and needs change. This approach could be the foundation of personalized care, as cultural norms and individual-specific values and preferences are incorporated into the goal-setting process.

4.3 | Identification and support of caregivers

Current care delivery systems generally do not formally identify, include, and address the educational needs, health, and well-being of dementia caregivers.^{79–81} Informal, non-paid caregivers who are often family members comprise the foundational care system for individuals living with dementia, providing substantial and unreimbursed care. Although current quality measures such as MIPS assess the provision of caregiver counseling and referral to additional resources for support,⁵¹ they do not adequately reflect the integral role of caregivers in health-care delivery. To do so requires identification of family or friend care partners, formal inclusion in the care planning process, and attention to their experience of strain and well-being. Other important components are assessing the need for coaching for specific caregiving roles and tasks; degree of engagement with clinicians and community resources; ensuring that resources are tailored to the patient's and caregiver's needs; and addressing access to and affordability of dementia-related health care, long-term care, and home and community-based services.

In *Families Caring for an Aging America* (2016), produced by the National Academies of Sciences, Engineering, and Medicine, recommendation 1a is to “develop, test, and implement effective mechanisms

within Medicare, Medicaid, and the US Department of Veterans Affairs to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports.”⁸² The 2018 RAISE Family Caregivers Act mandated the development of a national caregiving strategy. While not specific to dementia, the 2022 National Strategy to Support Family Caregivers identifies five priority areas, including increased awareness of family caregiving, emphasis on caregiver integration into processes and systems, access to services and supports, financial and workplace protections, and better research and data collection. The CMS GUIDE Model, introduced in 2024, is the first of its kind to reimburse direct support for caregivers of Medicare beneficiaries with dementia. GUIDE requires that all participating health-care providers must make a reasonable effort to identify a caregiver for the beneficiary with dementia, and assess that caregiver knowledge, needs, well-being, stress level, and other challenges. Health system participants are also required to coordinate in-home respite care for beneficiaries with moderate or severe-stage dementia. As previously noted, a measure of caregiver burden will be included in the GUIDE performance measurement set. The GUIDE Model represents a significant step forward in recognizing the importance of assessing and supporting the well-being of family caregivers.

4.4 | Dementia capable health systems

There are many elements essential to creating dementia-capable health-care systems.^{30,83} Dementia capability domains include early detection, home and community-based services to aid in maintaining function, safety education, a built environment geared toward support of the individual with dementia, support for families and caregivers, advance care planning, adequate choices regarding supervision and residential care, and end-of-life care.⁸⁴ The concept of “dementia capability” can apply to a clinical team, a particular health-care system, or community-based services, which includes several health and social care systems plus regional government and long-term services and supports.³⁸ NQF identified a need for better defining metrics to assess dementia capability; one such measure, developed by the ACL for its grantees, evaluates whether an organization provides a range of service options: primary care and specialty medical services for people living with dementia, support services for their caregivers, and staff training in dementia. The dementia capability assessment also evaluates whether organizations have standard procedures for identifying cognitive impairment, referring people for evaluation or services, identifying primary caregivers, and determining if a person with possible dementia lives alone, as the absence of a caregiver is a source of added vulnerability and social need.

A health system that is dementia capable should include measures in each domain of the RTI framework, and a standardized comprehensive measure set defining dementia capability is a necessary first step for promoting adoption among health systems. The Medicare AWV may become an entry point for assessing the dementia capability of a health system. For example, for persons who report early cognitive

symptoms or have an abnormal cognitive assessment as part of an AWW, measuring the rate of subsequent cognitive evaluation, diagnosis, and implementation of successive measures within the RTI framework—including identification of a family caregiver or other care partner and incorporation of an individual's goal into a person-centered care plan—can be used to evaluate the degree of a system's dementia capability and identify gaps calling for program development.

5 | SECTION III: FUTURE DIRECTIONS AND RECOMMENDATIONS

5.1 | Use of existing measures

Implementation of existing measures will support assessment of dementia care quality. CMS could emphasize or require measure reporting in pay-for-performance models and incentivize the use of elective measures.⁸⁵ Table 3 lists available CMS MIPS measures that could be used to assess quality of care within most domains of the RTI framework, including measures within the MIPS Value Pathway for Supportive Care for Neurodegenerative Conditions recommended by the CMS Innovation Center for the GUIDE model. To drive improvement in current care, measures that are available now can be selected by health systems participating in GUIDE, implementing a comprehensive dementia care program, or seeking to improve dementia care. Payers who cover dementia-related services could mandate these related MIPS measures for populations with high dementia prevalence and provide incentives for better performance. The items in Table 3 represent a core set of currently available measures that could be used to assess minimum quality standards for comprehensive dementia care.

5.2 | Expansion of measures

As demonstrated in our review of existing measures, there is a need for new quality measures in several domains within the RTI framework. These domains include: acknowledgment and emotional support for the person with dementia, therapeutic environment, and referral and coordination of care and services (see Table 2). For these domains without validated measures, new quality measurement development should align with the Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living With Alzheimer's and Dementia (LINC-AD) strategy,^{21,86} which states that measurement development should use a person-centered, strengths-based approach; capture multiple types of diversity; be suitable for use across dementia stages; and be practical to adopt.

Research efforts seeking to improve the measurement of dementia care quality should continue. Two research efforts address dementia care outcome measures. One is LINC-AD,⁸⁷ which sets a goal of critiquing existing outcome measures across all nine of the Alzheimer's Association's Dementia Care Practice Recommendation domains and facilitating their dissemination and implementation. A related effort by the National Institute on Aging (NIA) IMbedded Pragmatic Alzheimer's

disease (AD) and AD-Related Dementias (AD/ADRD) Clinical Trials (IMPACT) Collaboratory Patient and Caregiver Relevant Outcomes (PCRO) Core is creating a library of existing clinical outcome assessments that can be used in conducting embedded pragmatic clinical trials among people living with dementia and their caregivers. These research initiatives represent important steps toward increasing the use of existing outcome measures that can inform the field of dementia care quality measurement.

The measurement development process should also be integrated with the CMS measure development principles.⁸⁸ These include general principles such as what is meaningful to measure for patients and family members and can be aligned across payers; as well as technical principles which define specific outcomes, align the measure with ease of use, and iteratively test to confirm measure validity and reliability. Unlike NQF and others, which can provide consensus endorsement of measures previously developed and tested, CMS has infrastructure in areas such as the QPP's Measure Development Plan,⁸⁹ which can prioritize measures for development and then enact the work.

5.3 | Addressing equity

When implementing existing measures and when conducting measure development, the needs of populations disproportionately negatively affected by dementia must be addressed. Data suggest that Black Americans and Hispanics are more than 2 and 1.5 times, respectively, to have AD than non-Hispanic Whites.⁹⁰ Concern exists about assessment measures that may have a cultural bias or access to health-care barriers that skew population estimates.⁹¹ Furthermore, although undiagnosed dementia is common among all older adults, members of racial and ethnic minority groups are more likely than non-Hispanic Whites to be undiagnosed. Black and Hispanic individuals are also at risk of being diagnosed in later stages of disease, resulting in disparities in treatment and care.⁹²

Although research suggests that key problems in dementia care are heightened in racial and ethnic minority populations, significant gaps in knowledge exist. Standardized reporting of quality measures by race and ethnicity, with care to account for other, frequently associated sociodemographic risk indicators, would help to advance understanding and provide a firmer foundation for action.

The National Institutes of Health-funded Resource Centers for Minority Aging Research gather data to develop culturally sensitive tools that assess the cognitive decline of minority populations with better precision;⁹³ nevertheless, evidence from these centers⁹⁴ indicates that to improve surveillance and monitoring and to determine whether and how these disparities in prevalence, diagnosis, and treatment increase the vulnerability of minority ethno-racial groups, there must be standardized, culturally valid quality measurement for AD/ADRD detection and care processes. These areas of research require the broad participation of researchers, clinicians, and policy scholars to ensure that new measures are culturally and linguistically sensitive and are shown to be valid for the populations in which they are used.

TABLE 3 Recommendations for use of selected existing CMS quality measures.

| HHS-ASPE/RTI framework for models of dementia care | Quality measures | |
|---|------------------|--|
| | Quality ID | Name |
| 1. Detection of possible dementia ^b | | |
| 2. Diagnosis | | |
| 3. Assessment/ongoing reassessment | 281 | Dementia: Cognitive Assessment ^a |
| | 282 | Dementia: Functional Status Assessment ^a |
| 4. Care planning | 047 | Advance Care Plan ^a |
| 5. Medical management | 130 | Documentation of Current Medications in Medical Record |
| | 238 | Use of High-Risk Medications in Older Adults ^a |
| 6. Information, education, informed and supported decision making | 321 | CAHPS for MIPS Clinician/Group Survey |
| | 487 | Screening for Social Drivers of Health |
| 7. Acknowledgment and emotional support for person with dementia | AAN22 | Quality of life outcome for patients with neurologic conditions ^a |
| | 134 | Preventive Care and Screening: Screening for Depression and Follow-Up Plan |
| | 370 | Depression Remission at Twelve Months |
| 8. Assistance for person with dementia for daily functioning and activities | 182 | Functional Outcome Assessment and Care Plan |
| | 048, 050 | Assessment of Presence or Absence of Urinary Incontinence in Women 65+, Plan of care for urinary incontinence in women 65+ |
| 9. Involvement, emotional support, and assistance for family caregivers | 288 | Dementia: Education and Support of Caregivers for Patients with Dementia ^a |
| 10. Prevention and mitigation of behavioral and psychological symptoms | 283 | Dementia: Associated Behavioral and Psychiatric Symptoms Screening and Management ^a |
| 11. Safety for person with dementia | 286 | Dementia: Safety Concern Screening and Follow-Up for Patients with Dementia ^a |
| | 318, 155 | Falls screening, Falls plan of care |
| | 181 | Elder Maltreatment Screen and follow-up plan |
| 12. Therapeutic environment | | |
| 13. Care transitions ^c | | |
| 14. Referral and coordination of care and services | 374 | Closing the Referral Loop: Receipt of Specialist Report |
| | 321 | CAHPS for MIPS Clinician/Group Survey |

Abbreviations: AAN, American Academy of Neurology; ASPE, Office of the Assistant Secretary for Planning and Evaluation; CAHPS, Consumer Assessment for Healthcare Providers and Systems; CMS, Centers for Medicare & Medicaid Services; HHS, US Department of Health and Human Services; MIPS, Merit-based Incentive Payment System; RTI, RTI International.

^aIncluded in MIPS Value Pathway (MVP M0004): Supportive Care for Neurodegenerative Conditions.

^bWhile not a quality measure, the Medicare Annual Wellness Visit includes detection of cognitive symptoms.

^cCare transitions are also measured by CMS using utilization measures, such as ambulatory care sensitive hospital admissions, 30-day readmissions, and emergency department visits.

5.4 | Consensus on dementia quality measures

We recommend a consensus process to determine a national standard for dementia care quality measures. A modified Delphi process could be conducted, similar to the one that led to the core measure set for age-friendly health-care delivery.⁹⁵ A panel for this work should include experts in dementia care, measurement, equity, and successful implementation of widespread quality initiatives. A national organization could serve as the organizing entity, such as the NCQA, which hosted the age-friendly health-care measure development, or the HHS Office of the ASPE, which supported the development of the RTI framework. The consensus process could be informed by work done by

entities such as the Partnership for Quality Measurement,⁹⁶ which performs a criteria-based evaluation of individual measures, which could then be considered for inclusion in an endorsed list.

6 | CONCLUSION

Dementia care in the United States needs better quality measures and increased reporting to assess improvements and identify inequities in care. Increased use of currently available measure sets is needed now. In parallel, work can continue regarding new measure development, and all related efforts must address health equity. Finally, we

recommend that a national effort be undertaken to reach a consensus on what constitutes high-quality dementia care, and that this consensus could be the foundation of what everyone should expect the US health-care system to deliver. As one national example, the CMS GUIDE Model will provide evidence as to whether an alternative payment approach to comprehensive dementia care improves care quality in fee-for-service environments. In the meantime, while the GUIDE Model demonstration is underway, other payers have opportunities to promote increased measurement of dementia care quality to drive improvement and evaluate the impact of services for people living with dementia and their caregivers.^{36,37}

AUTHOR CONTRIBUTIONS

All authors met criteria for authorship as follows: study concept and design (L.A.J., G.E.L.), acquisition of data (L.A.J., G.E.L., E.T., Z.J.K.), analysis and interpretation of data (L.A.J., G.E.L., E.T., Z.J.K., M.R.H., R.N.J., N.R.F., S.B.), and preparation of manuscript (L.A.J., G.E.L., E.T., Z.J.K., M.R.H., R.N.J., N.R.F., S.B.). All authors approved the final manuscript. No unnamed contributor played a role in manuscript preparation.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the [supporting information](#).

CONSENT STATEMENT

No consent was necessary as this review was not considered human subjects research.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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