Quality improvement in neurology: Amyotrophic Lateral Sclerosis Quality Measures

Full Manuscript with additional information on methodology and an expanded discussion section

Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology

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Disclosures:
1. Dr. Miller has received research support from the Muscular Dystrophy, and is a consultant for Cytokinetics, Neuraltus, and Asubio pharmaceuticals.
2. Dr. Brooks has received funding and/or research grants from AB Science, Acorda, ALS Therapy Alliance, Asubio, Avanir., Biogen Idec, Bristol-Myers Squibb, Cytokinetics, GlaxoSmithKline, Knopp Bioscience, Muscular Dystrophy Association, Neuraltus, NINDS Clinical Research Consortium, QuestCor, and Teva.
3. Ms. Swain-Eng is a full-time employee of the American Academy of Neurology.
4. Dr. Basner is Principal Investigator of a Muscular Dystrophy Association grant, Opto-Electronic Plethysmography (OEP): A novel non-invasive quantitative assessment of lower rib cage paradox and use of accessory muscles in patients with amyotrophic lateral sclerosis; Site Investigator and Sleep Protocol Subcommittee member of an NHLBI/NIH grant, Sleep-Disordered Breathing During Pregnancy and Risks to Cardiovascular Health; and co-investigator of the following: R01HL103676-01A1 NIH/NHLBI; Subclinical Interstitial Lung Disease in MESA; R01HL093081 NIH/NHLBI; Pulmonary Vascular Changes in Early COPD; and InterMune PIPF-016: a randomized, double-blind, placebo-controlled, phase 3 study of the efficacy and safety of Pirfenidone in patients with Idiopathic Pulmonary Fibrosis (IPF).
5. Dr. Carter reports no disclosures.
6. Ms. Casey is a full-time employee of Northwestern Medical Faculty Foundation, Department of Neurology.
7. Dr. Cohen reports no disclosures.
8. Dr. Dubinsky reports disclosures for relationships with Allergan Pharmaceuticals, NIH, and AHRQ.
9. Ms. Forshew is a consultant for Questcor and Asubio Pharmaceuticals.
10. Dr. Jackson has received research support from Knopp Pharmaceuticals, Biogen Idec, and Cytokinetics.
11. Dr. Kasarskis is a consultant for Asubio Pharmaceuticals and ATSDR.
12. Dr. Procaccini reports no disclosures.
13. Dr. Sanjak reports no disclosures.
14. Dr. Tolin reports no disclosures.

Amyotrophic Lateral Sclerosis measurement set approved by the AAN Board of Directors on July 31, 2012

ABSTRACT

Objective: To describe new quality measures for amyotrophic lateral sclerosis (ALS) management derived through a standardized, rigorous, evidence-based consensus process, and their suitability for quality improvement activities, pay-for-reporting initiatives and maintenance of certification requirements.

Methods: ALS measures were developed using the established American Academy of Neurology (AAN) process. Guidelines and consensus papers from 2006 to 2011 from the National Guidelines Clearinghouse, the National Quality Measures Clearinghouse PubMed, and the Cochrane Library were evaluated to determine the acceptability of the guidelines and other evidence-based reviews. Candidate recommendations from acceptable evidence sources were documented, reviewed, and prioritized by the work group based on the link to desired outcomes, the level of evidence and strength of recommendation, face validity, feasibility to collect data, and gaps or variations in care. The prioritized recommendation statements were then developed into candidate measures. A period of public comment was followed by review and approval from the American Academy of Neurology and supporting organizations.

Results: The literature search identified 378 relevant recommendation statements from 20 clinical practice guidelines and consensus papers, and 57 evidence papers. Systematic assessment resulted in the development of 11 quality measures for ALS. The measures are focused on evaluating the use of effective therapeutic options in patients, and increasing patient awareness of advanced planning and patient safety.

Conclusions: The AAN ALS quality measurement set consists of clinical process measures to be performed at the level of the individual practitioner and/or adapted by multi-disciplinary practice teams or collaborative care physician models. The AAN ALS quality measures, when implemented by providers, have the potential to significantly improve care for individuals with ALS.

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a lethal, progressive, neurodegenerative disease characterized by loss of motor neurons in the spinal cord, brainstem, and motor cortex.[1] Patients become paralyzed as the disease advances and lose function in the limbs, speech, swallowing and breathing muscles. The cause of the disease is still not known for most patients. Approximately 25,000 people in the US have ALS, and 5,000 people are diagnosed with ALS annually in the US.[1] The lifetime risk of developing ALS is 1 in 350 in men, and 1 in 420 for women.[2] Most patients die from respiratory failure 2 to 5 years after onset of symtoms.[3] Cognitive dysfunction is seen in 20-50% of patients.[4] The disease burden for patients and caregivers is enormous, steadily increasing with advancing disease. The average cost of care has been estimated at $50,000 per patient per year, but this does not include lost productivity for the caregiving family.[5]

ALS is not curable, but a number of important therapies are now available. In 1999, the American Academy of Neurology (AAN) published an evidence-based practice parameter for managing patients with ALS, including recommendations for the only disease- modifying drug, riluzole, which modestly lengthens survival.[6] That publication was updated in 2009, including some important advances demonstrating the value of new treatment options such as multidisciplinary clinics, riluzole, noninvasive ventilation, enteral feeding, and symptomatic treatments for pseudobulbar affect and sialorrhea.[7,8]

The value of multidisciplinary clinics for persons with ALS has been demonstrated in several studies, showing longer survival, better quality of life, and greater access to therapies for patients with this disease.[8-14] Moreover, the online outcomes project, ALSConnection, documented that patients attending multidisciplinary clinics, compared with community care, were more satisfied with their medical care, and the telling of the diagnosis, and had more beneficial use of different therapies.[15] Enhanced survival and increased quality of life have been documented with utilization of noninvasive ventilation,[8,9]and enteral feeding is probably effective in prolonging survival.[8.16,17]

To identify gaps in care, specific aspects of ALS patient management have been evaluated serially using a national Amyotrophic Lateral Sclerosis Clinical Assessment, Research, and Education (ALS CARE) database to encourage compliance with evidence-based

recommendations and to measure continuing quality improvement.[18] The most recent analysis of 5,600 patients with ALS shows that proper management of many ALS symptoms has increased substantially since the first publication of the AAN ALS guidelines in 1999, and awareness of therapeutic opportunities has increased. However, many evidence-based treatment recommendations are still underutilized.[18] This was notable in community-based care, but also documented in multidisciplinary clinics. For example, only 9% of appropriate patients received enteral feeding with percutaneous endoscopic gastrostomy (PEG), and noninvasive ventilation (NIV) was used by only 21% of appropriate patients, despite being associated with improved quality of life and survival.[18]

These gaps in care led to an American Academy of Neurology (AAN) initiative to develop a new measurement set for examining the quality of ALS care. The AAN ALS quality measurement set was developed by an interdisciplinary expert panel work group representing physician organizations, patient advocacy groups, and other relevant stakeholder groups concerned about the care of patients with ALS. The AAN ALS quality measurement set may also be used in quality initiatives, public reporting (eg the Centers for Medicare &Medicaid Services Physician Quality Reporting System), maintenance of certification performance in practice programs, and accountability programs. In addition, the quality measures may provide a matrix for achieving disease-specific care certification through The Joint Commission process for ALS-specific care certification.[19]

The AAN ALS quality measure set has value in improving care beyond that of traditional quality assessment methods. The AAN is an established measure developer. The AAN has produced quality measures for stroke and stroke rehabilitation[20], Parkinson disease[21], and epilepsy[22] and plans to develop subsequent measurement sets for other neurologic conditions. This report describes the development of the AAN ALS quality measurement set for the care of patients with ALS through the established AAN measure development process.[23]

METHODS

The AAN ALS quality measure development process followed the AAN procedures for measure development.[23] The steps in the measure development process require submitting the topic for selection, completing an evidence-based literature search, constructing draft

measures and technical specifications, convening a multidisciplinary work group to review candidate measures, soliciting public comments during a 30 day period, refining the final measures and corresponding technical specifications, and obtaining approvals from the AAN ALS quality measure expert panel work group, AAN committees and the AAN Board of Directors. In addition, the measurement set was reviewed by the American Medical Association's Performance Measurement Advisory Group to assign Current Procedural terminology (CPT)-II codes.

Topic selection. ALS was selected for measure development because it is a clinical priority for neurology, has a high burden of illness, has demonstrated gaps in care with room for improvement, and has unexplained variations in care. This measure development project also supports the move toward quality improvement by medical professional societies and patient advocacy groups, including the American Association of Neuromuscular and Electrodiagnostic Medicine, American Academy of Physical Medicine and Rehabilitation, Muscular Dystrophy Association, Amyotrophic Lateral Sclerosis Association and the Amyotrophic Lateral Sclerosis Research Group (ALSRG)

Work group formation. The AAN convened a cross-specialty and multi-disciplinary AAN ALS quality measure work group that had broad representation of key stakeholders by inviting nominations for work group members from physician and non-physician associations, patient and caregiver advocacy organizations, health plans, and large group employers. The final work group (see end of manuscript for list of work group members and contributing organizations) included ten neuromuscular clinicians (9 neurologists, 1 physiatrist), a pulmonologist, gastroenterologist, two nurses, two occupational therapists, one physical therapist, one speech pathologist, one patient, a methodologist, and AAN staff, facilitators, and members of the AAN's Quality Measurement and Reporting subcommittee. All AAN ALS quality measure work group members completed a profile and material interest disclosure statement (COI form). The work group was convened according to the AAN's conflict of interest policy.[24]

Evidence-based literature search strategy. A comprehensive literature search strategy to identify published guidelines, consensus papers, relevant existing quality measures, and researching regarding gaps in care, unexplained variations in care and costs of care from

2006 to 2011 was conducted by a medical librarian using the National Guideline Clearinghouse, the National Measures Clearinghouse, PubMed, Ovid MEDLINE, Ovid EMBASE, Scopus and the Cochrane Library. Internet searches were carried out on relevant neuromuscular websites. The main searches were supplemented by material identified by individual members of the work group. Search terms included ALS, amyotrophic lateral sclerosis, Lou Gehrig's disease, motor neuron disease, any of these conditions and nutrition issues, and safety issues related to these diseases. All available guidelines, measures and consensus papers were evaluated using the American Medical Association convened Physician Consortium for Performance Improvement® (PCPI)'s Framework for Determining Acceptability of Guidelines and other Evidence Review Documents.[25]

Evidence-based evaluation supporting development and writing of measures. The AAN ALS quality measure working group leadership screened each relevant full-text guideline or consensus paper against the PCPI framework for determining the acceptability of guidelines and other evidence review documents.[25] If the inclusion of an article based on eligibility criteria was unclear, the expert work group co-chairs and facilitators were consulted. The recommendation statements and their corresponding level of evidence (as defined by the guideline developers' rating scheme methodology) were then extracted from eligible guidelines and consensus papers. Candidate recommendations were documented, reviewed, and ranked by the co-chairs and facilitators based on face validity, feasibility to collect data, and gaps or variations in care. Measure specifications were carefully drafted with an experienced methodologist to include a full measure description, a numerator, a denominator, and applicable exceptions to the measures.

RESULTS

The literature review and evidence search identified 378 recommendations from twenty guidelines and consensus papers[6-8,15,26-42] and many supporting evidence papers. Review of the recommendations statements by the AAN ALS quality measure work group leadership resulted in 13 recommendation statements that were rated highest on clinical importance, link to desired outcomes, evidence base, the level of evidence, gaps in care associated with the recommendation, and validity and feasibility to implement the recommendation in practice as a quality measure. The 13 candidate measures were reviewed by the work group and 2 measures were dropped, due to feasibility issues, at the face-to-face meeting on

November 11, 2011. The set of 11 measures were posted for a 30-day public comment period. A total of 222 comments were received from physicians, patients, insurers, and other interested individuals from the United States and Canada which further refined the draft measures. The final 11 measures were approved by the AAN ALS quality measure work group, the AMA Performance Measurement Advisory Group for CPT II codes, appropriate AAN committees, and lastly the AAN Board of Directors on July 31, 2012. This AAN ALS quality measurement set will be revised periodically with an extensive review every 3 years.

Brief measure titles and measure statements for each of the 11 ALS Performance Measures are listed in Table 1. The measurement set includes measures addressing accurate and appropriate evaluation/monitoring of disease status and associated symptoms to guide treatment options (measures 1, 3, 4, 5, 7, 8, and 9), measures addressing effective therapeutic options in eligible patients (measures 2, 4, 6 and 8), a measure addressing increasing patient awareness of advanced planning (measure 10), and a measure addressing patient safety (measure 11). For the full measure specifications, and exceptions, see appendix e-1 on the *Neurology*® website at www.neurology.org . Each measure statement contains the denominator and numerator for each measure.

Discussion

Measure #1: ALS Multidisciplinary Care Plan

A multi-disciplinary care plan is needed for each patient, to optimize health care delivery,[10,13,,43] prolong survival,[10-12] and enhance quality of life.[12] Recent clinical studies have shown that patients in multidisciplinary clinics specializing in ALS care have increased use of riluzole, increased number of gastrostomy procedures, increased use of NIV, increased use of adaptive equipment, improved quality of life, and lengthened survival[10-12] with fewer hospital admissions and shorter inpatient stays than those in community care.[18, 42] Those same studies have shown that there is underuse of riluzole, gastrostomy, and noninvasive ventilation in some multi-disciplinary clinics.[18,43] Low utilization of palliative care, case management, gastrostomy, NIV and riluzole may contribute to any lack of survival benefit.[8]

Specialized multidisciplinary ALS clinical referral should be considered for management of patients if ALS Clinics are located within travel distance of the patient. They coordinate care and interface with primary care physicians, local neurologists and community-based services.

Neurologists and genetic counselors offer diagnostic evaluation; pulmonologists and respiratory therapists monitor respiratory function and manage NIV, gastroenterologists and speech therapists monitor swallowing and other indicators for gastrostomy placement, dentists and dietitians monitor eating ability, nutritional status and weight; physiatrists, occupational and physical therapists assist with mobility and activities of daily living; specialized nurse case managers, social workers, and palliative care experts help with coordination of care and quality of life.[9,18]

Measure #2 Disease modifying pharmacotherapy for ALS discussed

Riluzole is the only drug approved by the Food and Drug Administration (FDA) for slowing disease progress in ALS. An AAN practice guideline[45] recommended riluzole to prolong survival for patients with ALS by an average of 3 months.[26] More recently, studies using large databases have suggested that treatment with riluzole might be associated with a prolonged survival of 6 to 21 months.[46-50] Recent surveys show that only 60% of patients with ALS in the US are taking riluzole, compared with over 75% in European countries.[26,51] This utilization is improved compared to 45% in 1997, a rise that reflects increased awareness and experience of treating physicians.[44,51] The cost is still a major factor for many patients. These data reflect the utilization of riluzole in large multidisciplinary clinics, and it is much lower in community-treated patients. Considerable misunderstanding exists around safety and efficacy, both for patients and physicians. More education is needed. The most influential factor in whether patients take riluzole is the means whereby the patient is informed of the treatment effect by the treating physician.[26,51] ALS experts in a multidisciplinary clinic are most likely to adequately inform patients about this neuroprotective medication. Also, the more recent registry studies suggesting a much greater survival benefit have been impressive.[26] This measure may be used with other approved disease-modifying pharmacotherapy for ALS, if approved by the FDA after the finalization of this measure.

Measure #3: ALS cognitive and behavioral impairment screening

Considerable evidence for cognitive and behavioral impairment in ALS has important implications for the individual and their caregivers.[52]Cognitive impairment in ALS is best identified through neuropsychological assessment using standardized measures and normative data.[53] Although there has not been a systematic study of how many clinics do

screening, there is good evidence that there is a gap. Patients commonly reported being told by their doctor about physical symptoms such as problems walking (85%) or stiffness/cramps (74%) but not psychological issues like emotional liability (46%) or cognitive change (11%). Patients and caregivers have indicated that they do want to know about whether they are so affected. These data suggest that screening is not being done widely enough.[54] Recent studies have demonstrated the feasibility of screening patients in a busy specialized ALS clinic.[55-57] Routine integration of cognitive and behavior screening in the ALS clinic will likely enhance treatment compliance and improve ALS patient outcomes.[58]

Measure #4: ALS symptomatic therapy treatment offered

Quality of life is diminished by pseudobulbar affect, sialorrhea, and ALS related symptoms. This measure was developed because effective symptomatic management is one of the primary goals of ALS patient care. Most of these symptoms are treatable, at least to some degree, and have been shown to improve the patient's quality of life. Treatment for both refractory sialorrhea and pseudobulbar affect are effective, though underutilized in ALS.[8,59-61] Many practitioners are unaware of pseudobulbar affect and recently approved effective treatments.[61] The expected patient outcome linked to this measure is improving patient quality of life which is evidence-based.

Measure #5: ALS respiratory insufficiency, querying and referral for pulmonary function testing

Patients should be queried about symptoms of respiratory insufficiency, screened with pulmonary function testing on a regular basis, and referred for pulmonary consultation when appropriate. Unreported respiratory insufficiency symptoms may expose the patient to poor respiratory outcomes including aspiration, atelectasis, pulmonary infection, pulmonary embolism, and asphyxia due to airway obstruction. Treatment of respiratory insufficiency improves survival, quality of life and respiratory symptoms.[35,62,63] The diagnosis and management of respiratory insufficiency are critical because most deaths from ALS are due to respiratory failure.

Measure #6: ALS noninvasive ventilation treatment for respiratory insufficiency,

discussed

There is evidence that implementation of noninvasive ventilation (NIV) will result in substantially improved survival and quality of life.[8,62,63] In a randomized controlled trial of delayed onset of treatment, patients using NIV experienced a median survival benefit of 205 days,[62] which exceeds the benefit of any other single intervention in ALS care. Even though published guidelines have made a positive impact in doubling utilization rates, underutilization of this important treatment is still evident. Moreover, recent studies document frequent nocturnal patient-ventilator asynchrony in patients with ALS, even when using NIV prescribed as per current AAN practice parameters.[64] More attention to monitoring the quality of patient sleep and oxygenation with NIV, and reducing asynchrony, is likely to further improve the efficacy of this treatment.[64] While the number of studies is limited, the use of devices to mobilize upper airway secretions, such as mechanical insufflation/exsufflation and assisted cough, can minimize the risk of pulmonary infections and mucous plugging which may lead to acute respiratory failure.

Measure #7: ALS Screening for dysphagia, weight loss or impaired nutrition

Poor nutritional status is a significant risk factor for worse outcomes in ALS. Patient's with a BMI less than 20 have a 7.7 higher risk of death compared with well-nourished patients.[65] Dysphagia due to bulbar weakness and hypermetabolism are two major causes. A nutrition specialist can monitor caloric intake, body mass and dysphagia. The prevalence of malnutrition varies between 16 - 55% in ALS patients.[65-67] Nutritional status should be checked at 3 month intervals by measuring weight, assessing frequency/severity of choking, duration of meals and caloric intake.[65-72] Treatment to stabilize weight and lengthen survival is underutilized. Only 19% of patients utilized nutritional supplements and only 16% of patients utilized enteral feeding in one large study.[18]

Early nutritional interventions for patients with dysphagia include the use of foods that are soft, moist and thickened. Nutritional supplements such as protein shakes can be a useful adjunct. Counseling patients on maintaining proper posture and eating upright may be of additional benefit.

Measure #8: ALS nutritional support offered via Enteral Feeding.

Patients who are losing weight should be counseled on options for maintaining appropriate nutrition through enteral feeding by placement of a percutaneous endoscopic gastrostomy (PEG) tube or a radiologically inserted gastrostomy (RIG). Placement of a PEG or RIG stabilizes body weight and allows for adequate nutrition, hydration and a route for taking medications.[7,9,16,17] Patients can still continue to take oral nutrition to the extent they are able but the gastrostomy tube will often improve their quality of life.[73]

Many patients who should have enteral feeding do not receive this treatment with only 43% of ALS patients who met guideline indications for gastrostomy tube placement undergoing the procedure.[16-18,72-74] Traditionally, forced vital capacity (FVC) below 50% was a concern for worse outcomes in PEG placement.[74] A recent report showed high rates of success and low morbidity in patients with FVC less than 50% when skilled anesthesia support was used.[75]

Measure #9: ALS communication support referral

Speech assessment in ALS patients identifies dysarthria, which limits communication. Communication is vital to quality of life and 95% of patients with ALS lose the ability to communicate.[76-77] Patients who accept gastrostomy, non-invasive ventilation or tracheostomy-ventilation have a greater need for augmentative alternative communication as the disease progresses.[76-79] Both high tech and low tech options are available through a speech language pathologist to enhance continued communication.[79] Dysarthria is present in nearly all ALS patients with bulbar onset and in nearly 70% of ALS patients with spinal onset. Nearly 88% of ALS patients are evaluated by this criterion, but fewer than half implement appropriate interventions.[80-83]

Measure #10: ALS end of life planning assistance

Palliative care should be adopted from the time of diagnosis. Many patients are not adequately informed about advance directives and end of life decision making and many hospice workers are not familiar with ALS.[84-86] Over 58% of seriously ill ALS patients do not have hospice care.[87] Approaches to end of life care vary widely and are not standardized either in timing or content.[88,89] End of life discussions will improve patient decision making with respect to disease management.[88, 89-95] Offering assistance in formulating an advanced care directive can initiate this discussion of the patient's preferences for life-sustaining treatments, with re-discussion every 6 months.[91-93] Clinicians and patients, families, and

caregivers face several dilemmas in coordinating care near the end of life in ALS. It is key to establish when the patient is ready to transition toward comfort care, rather than aggressively prolonging life. Patient autonomy should be fostered, with the understanding that a patient's needs, expectations, and perceptions of care may not match up well with those of the members of the health care team.[96-97]

Measure #11: ALS Falls, Querying

This measure is only for quality improvement initiatives, as the evidence base is very limited. Falls surveillance will lead to interventions to prevent falls and decrease fall-related deaths in patients with ALS.[98] Falls are an independent predictor of adverse health outcomes.[99] Fall-related deaths occur in 1.7% of ALS patients.[100] In ALS clinical trials, falls are one of the most frequent adverse events in all patient groups.[99]

Patients with ALS should be asked about recent falls and further examined for the presence of known risk factors: gait and balance disorders; deficits of lower extremity strength and coordination; and cognitive impairment. If substantial risks of falls are identified, appropriate interventions that are described in other evidence-based guidelines should be considered.[99] Falls surveillance will allow implementation of appropriate treatment interventions and home safety evaluations to prevent recurrence and adverse outcomes.

DISCUSSION

AAN ALS quality measures, derived from best available evidence, may act as indicators of high quality clinical care across the spectrum of neurological , medical, and psychological domains inherent in the management of patients with ALS . The deployment of this AAN ALS quality measurement set culminates a progression from an individual formulation (Ten Commandments for Optimal Motor Neuron Disease Patient Care)[101] through the demands for setting standards,[102] to addressing the gaps for quality standard-based clinical care.[103] Attempts to evaluate the quality of care for patients with ALS has already commenced in France[104] and the United Kingdom.[105] The 11 AAN ALS quality measures described herein are intended to be implemented in clinical practice, including both individual and multidisciplinary practice environments, and are geared to facilitate quality improvement.

The AAN ALS quality measures were developed using the AAN's evidence-based measure development process utilized previously for stroke, Parkinsonism and epilepsy. Widespread adoption of the AAN ALS quality measures has potential to substantially improve the quality of care for persons with ALS at all levels of healthcare delivery. Many patients receive some of their ALS care from primary care doctors who are likely to find many of the measures useful in improving the care they provide for patients with ALS. The AAN ALS quality measures may also identify the need for specialty care referrals for patients and improve overall care coordination. General neurologists, who may not regularly see many ALS patients, may also improve the quality of care they deliver by following the ALS measures. Even ALS experts at multidisciplinary clinics, who see the majority of persons with ALS and should be well-versed with ALS quality improvement metrics and tactics, may improve the care they provide by uniformly applying all of these AAN ALS quality measures. In addition, by auditing patient medical records, clinicians will be able to demonstrate improvement in patient outcomes by following these AAN ALS quality measures. Data from clinicians in the field will provide additional support for implementing these measures in practice, public reporting programs and other quality initiatives.

CONCLUSION

The diagnosis of ALS has profound implications for the patient and their family. In a recent analysis, too few patients received evidence-based treatment that can ease the disease burden. Although incurable at this time, advances in contemporary care options available to the ALS patient have been shown to prolong life and also to improve quality of that prolonged life.

These AAN ALS quality measures have been developed to address gaps in patient care, and to overcome the underutilization of evidence-based therapeutics for individuals with ALS. These AAN ALS quality measures are concerned with supportive care, management of patient safety, and planning for complex care needs, using a patient-centered approach to proactive decision making. The AAN ALS quality measures encourage multidisciplinary care plans, treatments for respiratory and nutritional dysfunction, use of the single disease modifying agent available, and plans for a smooth transition to palliative care. Multidisciplinary clinics are available to some patients, and where available, referral is encouraged.

The addition of practical and meaningful quality measures to the care of patients with ALS will raise the standard of care and lead to the desired outcome, a life expectancy improvement with an enhanced quality of living.

The authors would like to thank all the ALS Measure Development Work Group Members for their contributions and work that supported the development of this manuscript: Robert G. Miller, MD (*neurology)*; Benjamin Rix Brooks, MD (*neurology*); Steven Ringel, MD (*neurology*); Hiroshi Mitsumoto, MD(*neurology*); Carlayne Jackson, MD (*neurology*); Christen Shoesmith, MD, BSc (*neurology*); Edward Kasarskis, MD, PhD(*neurology*); Robert C. Basner, MD (*pulmonology);* Nicholas Procaccini, MD (*gastroenterology*); Gregory Carter, MD (*physical medicine and rehabilitation*); Dallas Forshew, RN, BSN (*nursing*); Mohammed Sanjak, PhD, PT, MBA (*physical therapy/occupational therapy*); Pat Casey, MS, CRCC (*physical therapy/occupational therapy*); Bob Osborne RN (*hospice/palliative care*); Valerie Cwik, MD (*Muscular Dystrophy Association*); Christine Jasch OTR/L)(*patient representative*); Fredrik Tolin, MD, MBA (*Humana*); Rebecca J. Swain-Eng, MS, CAE (*AAN staff*); Gina Gjorvad (*AAN staff*); Rebecca Kresowik (*methodologist*); Richard Dubinsky, MD (f*acilitator*); Joel Kaufman, MD (*facilitator*); Adam Cohen, MD (*facilitator*); Christopher Bever, MD (*AAN QMR*); Eric Cheng, MD, MS (*AAN QMR*)

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Table 1. Measure title and description of final 11 ALS quality measures approved by the American Academy of Neurology

Measure Title and Description
1. ALS Multidisciplinary Care Plan Developed or Updated
Percentage of patients diagnosed with ALS for whom a multi-disciplinary care plan* was developed, if not done previously, and the plan was updated at least once annually.
2. Disease Modifying Pharmacotherapy for ALS Discussed
Percentage of patients with a diagnosis of amyotrophic lateral sclerosis with whom the clinician discussed disease-modifying pharmacotherapy (riluzole) to slow ALS disease progression at least once annually.
3. ALS Cognitive and Behavioral Impairment Screening
Percentage of patients diagnosed with ALS who are screened at least once annually for cognitive impairment (eg frontotemporal dementia screening or ALS Cognitive Behavioral Screen (CBS)) and behavioral impairment (eg ALS CBS).
4. ALS Symptomatic Therapy Treatment Offered
Percentage of visits for patients with a diagnosis of ALS with patient offered treatment* for pseudobulbar affect, sialorrhea, and ALS related symptoms**.
5. ALS Respiratory Insufficiency Querying and Referral for Pulmonary Function Testing
Percentage of patients with a diagnosis of amyotrophic lateral sclerosis who were queried about symptoms of respiratory insufficiency (awake or associated with sleep) and referred for pulmonary function testing (eg vital capacity (VC), maximum inspiratory pressure (MIP), sniff nasal pressure (SNP), or peak cough expiratory flow (PCEF)), at least every three months.
6. ALS Noninvasive Ventilation Treatment for Respiratory Insufficiency Discussed
Percentage of patients diagnosed with ALS and respiratory insufficiency with whom the clinician discussed at least

once annually treatment options for noninvasive respiratory support (eg noninvasive ventilation (NIV), assisted cough).
7. ALS Screening for Dysphagia, Weight Loss and Impaired Nutrition
Percentage of patients diagnosed with ALS who were screened at least every 3 months for dysphagia, weight loss or impaired nutrition* and the result(s) of the screening(s) was documented in the medical record.
8. ALS Nutritional Support Offered
Percentage of patients diagnosed with ALS and dysphagia, weight loss, or impaired nutrition who were offered at least once annually dietary or enteral nutrition support via PEG or RIG*.
9. ALS Communication Support Referral
Percentage of patients diagnosed with amyotrophic lateral sclerosis who are dysarthric who were offered a referral at least once annually to a speech language pathologist for an augmentative/alternative communication evaluation.
10. ALS End of Life Planning Assistance
Percentage of patients diagnosed with ALS who were offered at least once annually assistance in planning for end of life issues (eg advance directives, invasive ventilation, hospice).
11. ALS Falls Querying
Percentage of visits for patients with a diagnosis of amyotrophic lateral sclerosis with patient queried about falls within the past 12 months.