

# Quality improvement in neurology: Amyotrophic lateral sclerosis quality measures

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

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Amyotrophic lateral sclerosis (ALS) is a lethal, progressive neurodegenerative disease characterized by loss of motor neurons.<sup>1</sup> Patients with ALS 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 United States have ALS, and 5,000 people are diagnosed with ALS annually in the United States.<sup>1</sup> Most patients die from respiratory failure 2 to 5 years after onset of symptoms. Cognitive dysfunction is seen in 20% to 50% of patients.<sup>2</sup> The disease burden for patients and caregivers is enormous. The average cost of care has been estimated at \$50,000 per patient per year.<sup>3</sup>

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.<sup>4</sup> That publication was updated in 2009 to include 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.<sup>5,6</sup>

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.<sup>7–15</sup> Moreover, the online outcomes project ALS-Connection documented that patients attending multidisciplinary clinics were more satisfied with their medical care and the telling of the diagnosis and had more beneficial use of different therapies compared to those receiving community care.<sup>13</sup> Enhanced survival and increased quality of life have been documented

with utilization of noninvasive ventilation,<sup>5,7,16–18</sup> and enteral feeding is probably effective in prolonging survival.<sup>5</sup>

To identify gaps in care, specific aspects of management of patients with ALS 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.<sup>14,19</sup> 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.<sup>14</sup>

These gaps in care led the AAN to develop a new ALS quality measurement set to improve the quality of care for patients with ALS. 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 includes measures that may be used in quality initiatives, public reporting (e.g., 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.<sup>20</sup>

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

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measures for stroke and stroke rehabilitation,<sup>21</sup> Parkinson disease,<sup>22</sup> and epilepsy.<sup>23</sup> The details of the overall AAN measure development process are available,<sup>24</sup> and additional details on the ALS measure development are available in the full manuscript and the full measurement set (appendices e-1 and e-2 on the *Neurology*<sup>®</sup> Web site at [www.neurology.org](http://www.neurology.org)).

**METHODS** The AAN ALS quality measure development process followed the AAN process for measure development.<sup>24</sup> 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 draft 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.

**RESULTS** The literature review and evidence search identified 378 recommendation statements from 20 guidelines and consensus papers<sup>5-7,16,18,25,26</sup> and many supporting evidence papers (references in appendix e-1). Review of the recommendation 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, level of evidence, gaps in care associated with the recommendation, and validity and feasibility to implement the recommendation in practice in a quality measure. Thirteen candidate measures were reviewed by the work group, and 2 measures were dropped at the face-to-face meeting on November 11, 2011 due to feasibility issues. The set of 11 measures was posted for a 30-day public comment period. A total of 222 comments were received from physicians, patients, insurers, and other interested stakeholders 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 the table. The measurement set addresses accurate and appropriate evaluation/monitoring of disease status and associated symptoms to guide treatment options (measures 1, 3, 4, 5, 7, 8, and 9), effective therapeutic options in eligible patients (measures 2, 4, 6, and 8), increasing patient awareness of advanced planning (measure 10), and patient safety (measure 11). For

the full measure specifications and exceptions, see appendix e-2. The measure statement contains the denominator and numerator for each measure. The appropriate exceptions for each measure can be found in the full measure specifications (appendix e-2).

**DISCUSSION** AAN ALS quality measures, derived from the best available evidence, may act as indicators of high-quality clinical care across the spectrum of neurologic, 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)<sup>27</sup> through the demands for setting standards<sup>28</sup> to addressing the gaps for quality standard-based clinical care.<sup>29</sup> Attempts to evaluate the quality of care for patients with ALS have already commenced in France<sup>30</sup> and the United Kingdom.<sup>31</sup> 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.<sup>24</sup> Widespread adoption of the AAN ALS quality measures has the potential to substantially improve the quality of care for patients with ALS at all levels of health care 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 patients with ALS, 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 his or her family. In a recent analysis, too few patients received evidence-based

**Table** Amyotrophic lateral sclerosis (ALS) quality measures approved by the American Academy of Neurology

Measure title and description
<b>1. ALS multidisciplinary care plan developed or updated</b>
Percentage of patients diagnosed with ALS for whom a multidisciplinary care plan was developed, if not done previously, and the plan was updated at least once annually.
<b>2. Disease-modifying pharmacotherapy for ALS discussed</b>
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.
<b>3. ALS cognitive and behavioral impairment screening</b>
Percentage of patients diagnosed with ALS who are screened at least once annually for cognitive impairment (e.g., frontotemporal dementia screening or ALS Cognitive Behavioral Screen [CBS]) and behavioral impairment (e.g., ALS CBS).
<b>4. ALS symptomatic therapy treatment offered</b>
Percentage of visits for patients with a diagnosis of ALS with patient offered treatment for pseudobulbar affect, sialorrhea, and ALS-related symptoms.
<b>5. ALS respiratory insufficiency querying and referral for pulmonary function testing</b>
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 (e.g., vital capacity, maximum inspiratory pressure, sniff nasal pressure, or peak cough expiratory flow), at least every 3 months.
<b>6. ALS noninvasive ventilation treatment for respiratory insufficiency discussed</b>
Percentage of patients diagnosed with ALS and respiratory insufficiency with whom the clinician discussed at least once annually treatment options for noninvasive respiratory support (e.g., noninvasive ventilation, assisted cough).
<b>7. ALS screening for dysphagia, weight loss, and impaired nutrition</b>
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.
<b>8. ALS nutritional support offered</b>
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 percutaneous endoscopic gastrostomy or radiographic inserted gastrostomy.
<b>9. ALS communication support referral</b>
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.
<b>10. ALS end of life planning assistance</b>
Percentage of patients diagnosed with ALS who were offered at least once annually assistance in planning for end of life issues (e.g., advance directives, invasive ventilation, hospice).
<b>11. ALS falls querying</b>
Percentage of visits for patients with a diagnosis of amyotrophic lateral sclerosis with patient queried about falls within the past 12 months.

treatment that can ease the disease burden. Although incurable at this time, advances in contemporary care options available to the patient with ALS have been shown to prolong life and also to improve the quality of that 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 patients with ALS. The 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 for the care of patients with ALS may raise the standard of care and lead to the desired outcome, an increased life expectancy with an enhanced quality of life.

#### AUTHOR CONTRIBUTIONS

Robert G. Miller: drafting/revising the manuscript, study concept or design, analysis or interpretation of data, accepts responsibility for conduct of research and will give final approval, study supervision, obtaining funding. Benjamin Rix Brooks: drafting/revising the manuscript, study concept or design, analysis or interpretation of data, accepts responsibility for conduct of research and will give final approval, acquisition of data, statistical analysis, study supervision. Rebecca J. Swain-Eng: drafting/revising the manuscript, study concept or design, accepts responsibility for conduct of research and will give final approval, acquisition of data, study supervision. Robert C. Basner: drafting/revising the manuscript, study concept or design, accepts responsibility for conduct of research and will give final approval. Gregory T. Carter: drafting/revising the manuscript, study concept or design, analysis or interpretation of data, accepts responsibility for conduct of research and will give final approval, study supervision. Patricia Casey: drafting/revising the manuscript, accepts

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