Measure #1: ALS Multidisciplinary Care Plan Developed or Updated

Amyotrophic Lateral Sclerosis

Measure Description

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.

*Multi-disciplinary care plan should include a neurologist and at least four of the following specialists: pulmonologist, gastroenterologist, physiatrist, psychiatrist, social worker, occupational therapist, physical therapist, speech language pathologist, psychologist, respiratory therapist, genetic counselor, palliative care specialist, specialized nurse, dietician, or dentist.

Measure Components

<table>
<thead>
<tr>
<th>Numerator Statement</th>
<th>Patients for whom a multi-disciplinary care plan* was developed, if not done previously, and the plan was updated at least once annually.</th>
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<th>Denominator Statement</th>
<th>All patients with a diagnosis of amyotrophic lateral sclerosis.</th>
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Denominator Exclusions

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

- Documentation of a system reason for not developing and updating annually a multi-disciplinary care plan (eg patient has no insurance to cover a multidisciplinary plan)

Supporting Guideline & Other References

- Specialized multidisciplinary clinical referral should be considered for management of patients with ALS to optimize health care delivery (Level B) and prolong survival (Level B) and may be considered to enhance quality of life (Level C).¹

- Multidisciplinary care should be available for people affected by ALS as attendance at a multidisciplinary clinic improves care, and may extend survival.² (GPP)

- The following specialties should be part of or be readily available to the multidisciplinary team: a consultant in neurology, pulmonologist, gastroenterologist, rehabilitation medicine physician, social counselor, occupational therapist, speech language pathologist, specialized nurse, physical therapist, dietician, psychologist, dentist.²(GPP)

- Initiate discussions about all treatment options such as non-invasive, invasive ventilation and terminal phase treatment as soon as symptoms or signs of respiratory problems develop. Discussions should be as early as possible to enable advance planning or directives (Level II; note this is a systematic review).³

- A palliative care approach should be incorporated into the care plan for patients and carers from the time of diagnosis (Class III recommendation; note this is a systematic review).⁴


Measure Importance

Relationship to desired outcome

In specialized multidisciplinary clinics, patients with ALS receive comprehensive care from a neurologist, pulmonologist, gastroenterologist, physiatrist, social worker, occupational therapist, speech language pathologist, respiratory therapist, specialized nurse case manager, physical therapist, dietitian, psychologist, dentist, and/or palliative care expert. Moreover, the level of satisfaction with the rendering of the diagnosis and overall satisfaction with care is significantly higher for patients attending a multidisciplinary clinic.

Specialized clinics coordinate care and interface with a primary care physician, local neurologist and community-based services. Patients who attend specialized ALS clinics are younger and have longer symptom duration than neurology clinic patients, indicating possible referral bias. Patient care and survival were examined for 97 patients attending specialized ALS clinics in Italy compared with 124 patients in neurology clinics. There was increased utilization of riluzole, percutaneous endoscopic gastrostomy (PEG), and noninvasive ventilation (NIV) in the ALS clinics, and fewer hospital admissions. Mean survival was longer in specialized ALS clinics (1,080 days vs. 775 days, p=0.008). Using COX multivariate analysis, attending an ALS specialized clinic independently predicted longer survival for patients.

Prolonged survival (7.5 months, p<0.0001) was found for patients in Ireland attending multidisciplinary ALS clinics. Patients at ALS clinics were younger and more likely to receive riluzole (99% vs. 61%). Multidisciplinary care was an independent predictor of survival (p=0.02) and reduced the risk of death by 47% in a 5-year study. Dutch patients in multidisciplinary ALS clinics (n=133) were compared with 75 patients receiving general care. Patients were well-matched and data were collected by a blinded nurse. Patients in multidisciplinary clinic received more aids and appliances (93% vs. 81%, p =0.008) and had higher quality of life (SF-36® Health Survey, p <0.01). Beneficial effects derived from a single visit to a multidisciplinary clinic, suggesting better coordination of care. Importantly, patients attending multidisciplinary clinics had fewer hospital admissions and shorter inpatient stays than those cared for in the community.

By contrast, another study, in Southern Italy, documented no increase in survival from attendance at a multidisciplinary clinic. Riluzole use was higher in patients attending a multidisciplinary clinic (61% vs. 43%, p = 0.02) but very few patients received PEG (6% vs. 2% in each group). There was a non-significant 10% increase in survival in those attending a multidisciplinary clinic after 12 months. Low utilization of palliative care, case management, PEG, NIV, and riluzole, compared with the 3 positive studies above, may account for the lack of survival benefit in this study.

Thus, three studies show that multidisciplinary clinics specializing in ALS care are probably effective in several ways: increased use of adaptive equipment; increased utilization of riluzole, PEG, and NIV; improved quality of life; and lengthened survival. However, one study with
low use of these treatments found no survival benefit.

References

Opportunity for Improvement

Treatments for ALS are underutilized even in specialized clinics. Studies suggest that even in tertiary care centers, there are varying degrees of adherence to the evidence-based AAN Practice parameters.

Recent studies show that there is a much higher utilization rate of evidence-based treatments in multidisciplinary clinics than in community-based care. Data are especially indicative of underuse of riluzole (60% of patients), PEG (9%), and noninvasive ventilation (22%), with greatest gains in utilization occurring in the specialized ALS clinics. These important treatments lengthen life and improve quality of life, but they are neglected by many patients and health care professionals.

Access to the limited number of ALS specialized clinics may involve long distance travel which may be a barrier for patients who are unable to travel to an ALS clinic. Telemedicine might be a solution to this challenge.

References
**Measure Designation**

| Measure purpose       | • Quality improvement  
|                       | • Accountability  
| Type of measure       | • Process  
| Level of Measurement  | • Individual practitioner  
| Care setting          | • Ambulatory care setting  
| Data source           | • Electronic health record (EHR) data  
|                       | • Administrative Data/Claims (inpatient or outpatient claims)  
|                       | • Administrative Data/Claims Expanded (multiple-source)  
|                       | • Paper medical record  

**Technical Specifications: Administrative/Claims Data**

Administrative claims data collection requires users to identify the eligible population (denominator) and numerator using codes recorded on claims or billing forms (electronic or paper). Users report a rate based on all patients in a given practice for whom data are available and who meet the eligible population/denominator criteria.

The specifications listed below are those needed for performance calculation. Additional CPT II codes may be required depending on how measures are implemented. (Reporting vs. Performance)

**Denominator** (Eligible Population)

- ICD-9 -CM Diagnosis Codes: 335.20 (amyotrophic lateral sclerosis)
  - AND
  - CPT E/M Service Code: 99201, 99202, 99203, 99204, 99205 (office-new patient), 99211, 99212, 99213, 99214, 99215 (office-established patient), 99241, 99242, 99243, 99244, 99245 (outpatient consult), 99304, 99305, 99306, 99307, 99308, 99309, 99310 (nursing facility), 99324, 99325, 99326, 99327, 99328, 99334, 99335, 99336, 99337 (domiciliary), 99341, 99342, 99343, 99344, 99345, 99347, 99348, 99349, 99350 (home visit)

**Numerator**

Patients for whom a multi-disciplinary care plan* was developed, if not done previously, and the plan was updated at least once annually.

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**Reporting Instructions:**

- For all patients meeting the denominator criteria, report the CPT Category II, 0580F, ALS multidisciplinary care plan developed or updated

0580F ALS multidisciplinary care plan developed or updated

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Denominator
All patients with a diagnosis of amyotrophic lateral sclerosis.

Exclusions

Reporting Instructions:

- Documentation of a system reason for not developing and updating annually a multi-disciplinary care plan (e.g., patient has no insurance to cover rehabilitation or treatment plan)

Reporting Instructions:

  - For patient with appropriate exclusion criteria, report 0580F-3P