

Identifying Providers of Care After a Diagnosis of ALS: A Retrospective Review of the Medicare Claims Database

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INTRODUCTION

- Without a cure, the management of patients with amyotrophic lateral sclerosis (ALS) is largely supportive; the range of clinical symptomatology requires the expertise of multiple health care providers.
- Recent guidelines for the care of patients with ALS recommend the involvement of a multidisciplinary team.^{1,2}
- Studies have demonstrated prolonged survival for patients seen in an ALS clinic compared with those patients receiving care outside of these centers.^{3,4}

OBJECTIVE

- This analysis of the US Centers for Medicare & Medicaid Services (CMS) longitudinal claims dataset was conducted to identify sites of care used by patients with ALS.

METHODS

- Retrospective review of quarterly claims data from the US CMS longitudinal claims dataset (2005-2009).
 - Data included 100% of adjudicated inpatient and outpatient CMS Medicare claims and physician office setting claims from a 5% sample of Medicare patients.
 - Medicare randomly selected patients for inclusion in the 5% physician office sample using the last 2 digits of the patient's Medicare number.
- Inclusion criteria:
 - Aged ≥ 65 years;
 - ≥ 2 ALS medical claims with a first ALS claim (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] code 335.20) occurring between the first quarter of 2006 and the second quarter of 2008;
 - In the CMS dataset ≥ 1 year prior to the first ALS medical claim; and
 - In the 5% physician office sample.
- Institutions providing care were identified as either ALS centers or non-ALS centers.
 - ALS centers included sites of care designated as ALS-specific treatment centers by the Muscular Dystrophy Association (MDA) and/or the ALS Association (ALSA).
 - Non-ALS outpatient centers were hospital-associated outpatient treatment sites identified by matching institution name and center zip code.
- Non-ALS outpatient centers were then classified by the volume of patients with ALS treated in 2009.
 - High-volume non-ALS outpatient centers treated ≥ 15 patients with ALS.
 - Moderate-volume non-ALS outpatient centers treated 10 to 14 patients with ALS.
 - Low-volume non-ALS outpatient centers treated < 10 patients with ALS.

- The setting(s) associated with the first quarter where an ALS medical claim (ICD-9-CM code 335.20) appeared was evaluated to determine the initial site of care. This was interpreted as the quarter of ALS diagnosis.
 - To determine sites of care, patients were counted in each setting where a medical claim for ALS was recorded during the defined quarter of diagnosis.
- Postdiagnosis sites of ALS-related care were identified by the presence of an ALS medical claim (ICD-9-CM code 335.20) or an ALS-related medical claim.
- ALS-related medical claims were based on symptoms likely to be related to a patient's disease.
 - A multistep process was used to develop a classification of likelihood (high or moderate) that reported symptoms were ALS-related.
 - Following an initial review of the available literature, a patient record analysis was done on the complete claims history of 50 Medicare patients with a diagnosis of ALS to review the frequency of reported symptoms prior to diagnosis.
 - Based on this analysis, an initial list of possible ALS-related symptoms was generated and reviewed by one of the authors (DAK) who has significant clinical experience in the diagnosis and treatment of ALS (Table 1).

TABLE 1: Codes Identified as High or Moderate Likelihood of Being ALS Symptoms

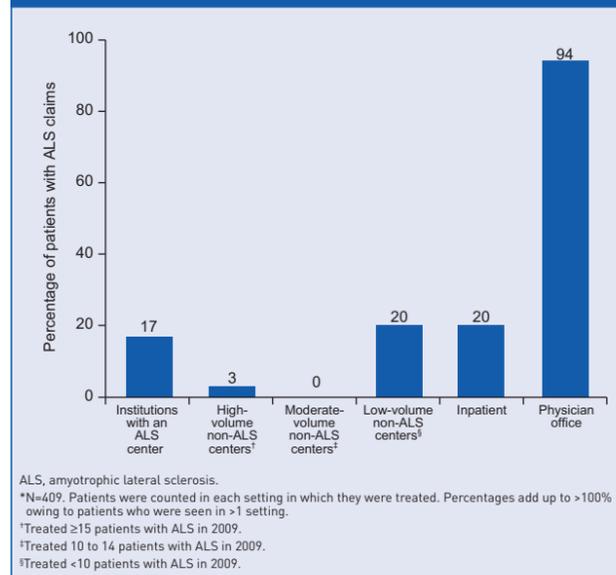
Type of onset	Subgroup	Diagnosis of interest	ALS-related ICD-9-CM codes		
Bulbar	Speech	Developmental speech, language disorder	315.39		
		Speech and language deficits (including aphasia, dysphasia, voice resonance disorder, speech disturbance, dysarthria)	438.1X 784.3 784.4X 784.5X		
		Swallowing	Dysphagia	787.2 438.82	
			Disturbance, salivary secretion Salivary gland disorder	527.7 527.8	
	Pain	Pain, throat	784.1		
		Atrophy, muscular disease Muscle weakness (generalized)	728.2 728.87		
	Limb	Muscle strength	Difficulty walking Gait abnormality Lack of coordination	719.7 781.2 781.3	
			Involuntary muscle movement	Cramping Spasm Twitching/Fasciculation	729.82 728.85 781.0
				Myopathy (including myopathy with weakness)	359.X
		Other	Disorder of muscle and/or ligament	728.X	
Pain			Pain in joint Pain in limb	719.4 729.5	

- No hypothesis testing was conducted.

RESULTS

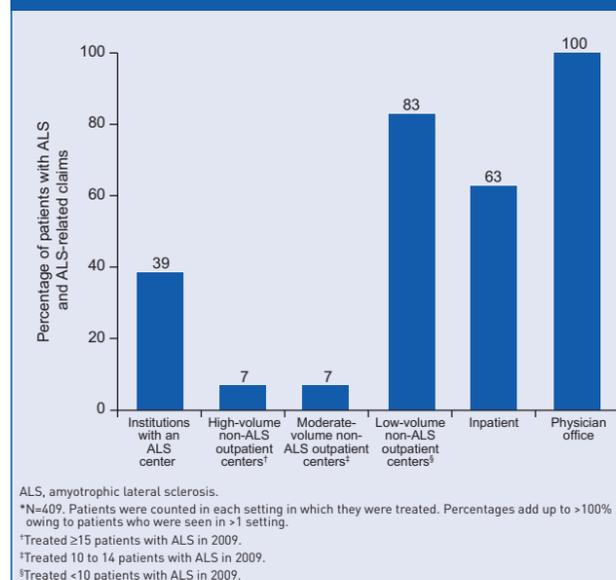
- A total of 409 patients met the inclusion criteria.
- Only 17% of patients had an ALS medical claim in the quarter of diagnosis at a designated ALS center (Figure 1). Additionally, $< 25\%$ of patients had an ALS medical claim in the quarter of diagnosis at high-, moderate-, or low-volume non-ALS centers.

Figure 1: Setting Types Visited in the Quarter of Diagnosis*



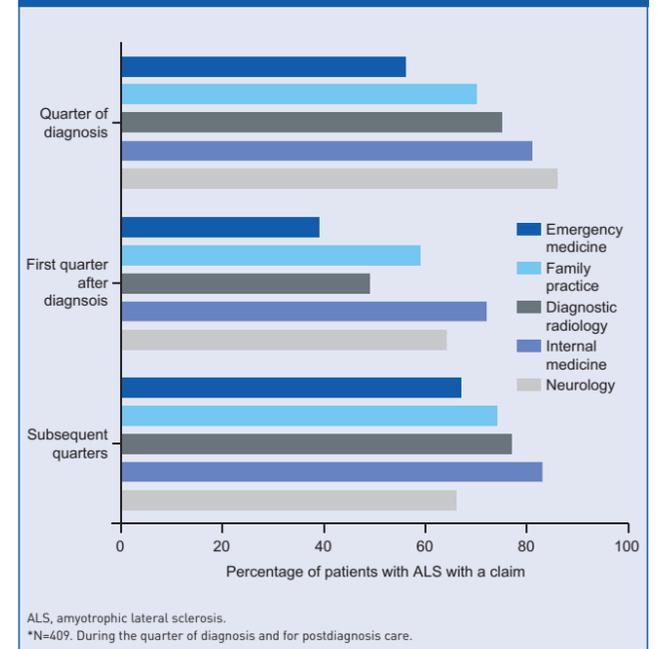
- Only 39% of patients had ≥ 1 ALS or ALS-related medical claim in a facility associated with a designated ALS center post ALS diagnosis (Figure 2).
- For the majority (61%) of patients, an ALS or ALS-related claim occurred exclusively outside a designated ALS center.

Figure 2: Care Settings for Postdiagnosis ALS-Related Medical Claims by Institution Type*



- In the quarter of diagnosis, the most frequently visited physician specialty was neurology (Figure 3).
- The involvement of a neurologist peaked during the quarter of ALS diagnosis.
 - 86% of patients saw a neurologist during the quarter of their diagnosis and 66% of patients saw a neurologist ≥ 2 quarters after diagnosis.
- In the quarters following diagnosis, internal medicine was the most commonly visited specialty.

Figure 3: Specialty Interaction With Patients With ALS*



LIMITATIONS

- The Medicare database does not include patients covered under commercial insurance.
- The small sample size limited the strength of the analyses.
- This analysis did not include specialization within an area (eg, specialty neurologist vs general neurologist).

CONCLUSIONS

- A large number of Medicare patients never visited an MDA- and/or an ALSA-designated ALS treatment center in the quarter of diagnosis or in subsequent quarters.
- For patients with ALS in this sample, neurologist involvement in patient care decreased after diagnosis.
- Patients with ALS in this sample saw a variety of providers after diagnosis; internal medicine was the most commonly visited physician type.
- Future research should confirm the findings of this analysis, explore reasons why patients may not be accessing ALS centers, and further characterize the care provided (including multidisciplinary involvement) at alternative sites of care.

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DISCLOSURES

J.R. Williams and D. Kerr are employees of Biogen Idec. D. Fitzhenry, L. Grant, and D. Martyn are employees of Trinity Partners LLC.

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