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Research Article

HOSPITALIZATION INPATIENT COSTS AND DEMOGRAPHICS FOR AMYOTROPHIC LATERAL SCLEROSIS IN THE U.S. FROM 2010-2014

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ABSTRACT

Introduction: Amyotrophic lateral sclerosis is a progressive and fatal neuromuscular disease affecting nerve cells controlling voluntary muscles in all parts of the body.

Methods: An analysis of the U.S. NIS of HCUPnet was performed over a 5-year period from 2010-2014 using the ICD-9 principal diagnosis code: 335.20 amyotrophic lateral sclerosis, to determine the costs and demographics of hospitalized ALS patients in the U.S.

Results: There were 11,605 hospital discharges for ALS in the U.S. between 2010 and 2014. The mean cost per hospitalization over this period was \$15,885. Cost per geographic region per hospitalization varied with the West costing \$22,366, the Northeast \$17,712, the South \$13,946, and the Midwest \$12,408.

Discussion: ALS is a devastating and costly disease. With no cure in site, this disease will continue to contribute to health care costs nationally. Further research is needed to gain a better understanding of the financial impact in the U.S.

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INTRODUCTION

Amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease, is a progressive and fatal neuromuscular disease that affects nerve cells controlling voluntary muscles in all parts of the body. During 2010-2011, prevalence of ALS in the United States (U.S.) was estimated to be 3.9 cases per 100,000 persons (1). The Agency for Toxic Substances and Disease Registry suggests that 12,000 to 15,000 people in the U.S. have ALS. ALS is found slightly more commonly in males and diagnosed between 55 and 75 years old. On average, patients live from two to five years after symptoms develop. Older age at the time of diagnosis has a negative impact on life expectancy (2). Caucasians and non-Hispanics are more likely to develop the disease compared to other races (3). About five to ten percent of ALS cases are considered familial ALS, which means that at least two people in a family suffer from ALS (2). Mutation in a gene known as "chromosome 9 open reading frame 72" or C9ORF72 was seen in about 25-40 percent of all familial cases (2). Some studies suggest military veterans are one and a half to two times more likely to develop ALS, possibly due to unknown risk factors such as lead, pesticides, and other environmental toxins (3, 4). Several studies have also linked athletes who play contact sports such as football and soccer to have an increased risk for ALS (5-7). However,

the majority of ALS cases are considered sporadic and random with no clear associated risk factors. In ALS, symptoms tend to first present in the limb or bulbar muscles, then spread out to the rest of the body (8). As motor neurons degenerate or die, they stop sending messages to the muscles. Since the muscles are unable to perform, they gradually weaken, fasciculate, and atrophy. Early symptoms of ALS include muscle weakness or stiffness; then, ultimately patients lose their strength, ability to speak, eat, and move (3). No cure has yet been found for ALS, however, there are treatments that can help control symptoms and prevent unnecessary complications. Currently, supportive care is provided by multidisciplinary teams including physical, speech, nutritional, and breathing therapy as well as medication to reduce motor neuron damage, (9-11). With more ongoing research looking into potential treatments or cures for ALS, the cost of the disease state needs to be analyzed. This study looked to analyze hospital inpatient costs and demographics in the United States over a five-year span from 2010 to 2014.

MATERIALS AND METHODS

An analysis of the U.S. National Inpatient Sample (NIS) of the Healthcare Cost and Utilization Project (HCUPnet) was performed over a five-year period for the years 2010 through 2014 using the International Classification of Diseases, 9th

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Revision, Clinical Modification (ICD-9-CM) principal diagnosis code: 335.20 amyotrophic lateral sclerosis (12). HCUPnet is part of the Agency for Healthcare Research and Quality (AHRQ) and is the largest publicly available online query system of all-payer healthcare databases. All costs were adjusted to 2014 U.S. dollars based on the Gross Domestic Product (GDP) price index (13). The patient demographics analyzed were patient age, gender, third party payer, and geographic region. Patient age was broken up into: ages 1-44 years old, 45-64 years old, 65-84 years old, and 85 years and older. Gender was divided into: males and females. Third party payer was categorized into: Medicare, Medicaid, Private Insurance, and Other. Geographical location was categorized into the four regions as defined by the U.S. Census Bureau: Northeast, Midwest, South, and West. The objective was to determine the costs and patient demographics of hospitalized patients with ALS in the U.S.

RESULTS

Patient demographics

The NIS analysis indicated that from 2010 through 2014, there were 11,605 hospital discharges with the primary diagnosis of amyotrophic lateral sclerosis [table 1].

Table 1 Yearly patient demographics per hospitalization with primary diagnosis of ALS from 2010 to 2014

Patient Demographics		Patient Demographics per Year 2010-2014					Total
		2010	2011	2012	2013	2014	
National Statistics		2,278	2,467	2,335	2,200	2,325	11,605 (100%)
Gender	Male	1,140	1,146	1,195	1,190	1,220	5,891 (50.8%)
	Female	1,138	1,321	1,140	1,010	1,105	5,714 (49.2%)
Age	1-44	172	164	155	135	175	801 (6.9%)
	45-64	903	1,073	1,055	940	950	4,921 (42.4%)
	65-84	1,157	1,138	1,020	1,055	1,105	5,475 (47.2%)
	85+	46	92	105	70	95	408 (3.5%)
Payer	Medicare	1,369	1,415	1,275	1,350	1,295	6,704 (57.8%)
	Medicaid	248	206	240	150	225	1,069 (9.2%)
	Private Insurance	439	605	645	545	620	2,854 (24.6%)
	Other	222	241	175	155	185	978 (8.4%)
Region	Northeast	403	510	520	490	460	2,383 (20.5%)
	Midwest	528	486	505	570	545	2,634 (22.7%)
	South	905	1,023	925	740	910	4,503 (38.8%)
	West	442	449	385	400	410	2,086 (18.0%)
Emergency Room Discharges		610	553	542	513	716	2,934

Table 2 Yearly discharge status for patients with primary diagnosis of ALS from 2010 to 2014

Demographics	Patient Discharge Status in Number of Patients (% of Patients)					Total
	2010	2011	2012	2013	2014	
in patient deaths	280 (12.3%)	287 (11.7%)	295 (12.6%)	235 (10.7%)	210 (9%)	1,307 (11.3%)
Routine Discharge	633 (27.8%)	670 (27.2%)	685 (29.3%)	600 (27.3%)	635 (27.3%)	3,223 (27.8%)
Another Hospital	59 (2.6%)	75 (3%)	55 (2.4%)	70 (3.2%)	80 (3.4%)	339 (2.9%)
Another institution (nursing home, rehab)	609 (26.7%)	700 (28.4%)	690 (29.6%)	695 (31.6%)	680 (29.3%)	3,374 (29.1%)
Home Health Case	686 (30.1%)	725 (29.4%)	590 (25.3%)	580 (26.4%)	665 (28.6%)	3,246 (28.0%)

The hospital discharges varied between 2,200 and 2,467 per year with a mean of 2,321 hospital discharges per year. The incidence between males and females was similar with 50.8% of discharges of males and 49.2% of female. The most prevalent age group was the 65-84 years old, making up 47.2% of the patient population followed by patients aged 45-64 making up 42.4% of the patient population. The geographic makeup of the patient population was varied. The South had the highest percentage of hospitalization discharges with 38.8%, followed by the Midwest with 22.7%, then the Northeast with 20.5%, and lastly the West with 18.0%. Most

patients were on federal insurance with 57.8% of patients on Medicare and 9.2% on Medicaid, while only 24.6% of patients had private insurance. Over the five-year span from 2010 to 2014, 60.0 % of patients were discharged into another healthcare setting (2.9% to another hospital, 29.1% to a rehabilitation center or nursing home, and 28.0% to home health care) [table 2]. There were 1,307 deaths during hospital stays during this time frame which represents 11.3% of all hospitalizations for ALS.

Hospitalization costs

There was insufficient data to adequately analyze the cost per hospitalization according to patient's age; therefore, age was excluded from the cost analysis. Only Medicare and Private Insurance had sufficient data available to analyze cost per hospitalization; therefore only these two categories were included as third party payers. The mean cost per hospitalization during this time frame was \$15,885 (adjusted to 2014 US dollars) [table 3]. The mean cost per hospital stay was higher in males (\$17,341) compared to females (\$14,384). This was the case every year during this time frame except for the year 2013 which females had a higher mean cost of \$16,126 compared to males which was \$14,703.

Males also had a longer mean length of stay of 7.7 days compared to females of 6.6 days. Although there were years that the average cost per hospitalization varied, the cumulative mean cost per stay over the five-year span for a Medicare patient was very similar to that of a patient with private insurance.

Table 3 Mean cost and length of stay per hospitalization for patients with a primary diagnosis of ALS. Length of stay is in days and cost is adjusted to 2014 U.S. dollars.

Patient Demographics		2010	2011	2012	2013	2014	Total						
Demographics	Mean Cost per Demographic	Mean Length of Stay	Mean Cost per Demographic	Mean Length of Stay	Mean Cost per Demographic	Mean Length of Stay	Cumulative Mean Cost per Demographic	Mean Length of Stay					
Gender	National	15,128	7.9	16,218	6.5	16,761	7.3	15,356	6.6	15,894	7.2	15,885	7.1
	Male	16,729	8.9	20,092	7.6	17,402	7.5	14,703	6.0	17,867	8.3	17,341	7.7
	Female	13,530	6.9	12,857	5.6	16,089	7.1	16,126	7.4	13,716	6.0	14,384	6.6
Payer	Medicare	15,052	7.8	15,424	6.5	17,374	7.2	14,734	6.4	13,971	6.2	15,295	6.8
	Private Insurance	10,919	5.9	14,127	5.7	14,810	6.0	16,932	6.9	17,908	7.2	15,268	6.4
Region	Northeast	8,846	5.4	28,175	8.8	16,420	6.7	16,462	7.8	16,672	7.2	17,712	7.3
	Midwest	15,100	8.0	10,170	5.4	11,885	5.6	12,916	4.8	11,680	5.7	12,408	5.9
	South	14,246	7.4	12,239	6.2	13,866	7.2	15,430	8.3	14,442	6.6	13,946	7.1
	West	22,696	11.1	18,210	5.9	30,570	10.7	17,343	4.7	23,220	10.4	22,366	8.5
National Aggregate Cost		34,462,572		40,008,873		39,136,479		33,784,261		36,954,238		184,346,423	

The mean cost per hospital stay for a Medicare patient was \$15,295 while for a private insurance patient was \$15,268. Medicare patients had an average length of stay of 6.8 days while private insurance patients had 6.4 days. The region with the highest mean cost per stay during this five-year span was the West with a mean cost of \$22,366 per hospitalization. Next was the Northeast at \$17,712 per stay, South at \$13,946 per stay, and the Midwest at \$12,408 per stay. The regions followed the same order for the largest mean length of stay with the West at 8.5 days, the Northeast at 7.3 days, the South at 7.1 days, and the Midwest at 5.9 days. The aggregate U.S. hospital costs each year \$34,462,572 in 2010, \$40,009,873 in 2011, \$39,136,479 in 2012, \$33,784,261 in 2013, and \$36,954,238 in 2014. The mean aggregate U.S. hospital cost per year was \$36,869,285.

DISCUSSION

This study provides epidemiologic and cost data regarding ALS inpatient hospitalizations in the U.S. over a five-year span from 2010 to 2014. The South had a higher percentage of patient discharges compared to all other regions. This is consistent with recent research that showed in the U.S., most ALS patients are located in the South and the Midwest (14). This contradicts previous research which showed higher mortality from ALS in northern states (15). This may be due to a potential shift in geographical demographics for ALS patients over recent years. The cost per hospitalization is higher and the length of stay per hospitalization is longer than the average hospitalization across all disease states in 2012 (\$10,400; 4.5 days per hospitalization) (16). Depending on the geographic region, costs per hospitalization and length of stay may vary for ALS patients. In 2012, the cost per hospitalization across all diseases in the U.S. was \$10,800 in the Northeast, \$10,200 in the Midwest, \$9,300 in the South, and \$12,300 in the West (16). The reason why costs vary per geographic region for ALS patients is currently unknown and should be researched further going forward. ALS patients that had longer length of stays typically had higher mean costs per hospitalization. This is not necessarily accurate for every demographic for every year and is the results of the cumulative data for each demographic at the end of the five-year period. One trend was that the mean cost per hospitalization rose every year during this five-year span for patients with private insurance, however the mean cost decreased each of the last two years for Medicare patients.

With 60% of patients being discharged into another healthcare setting, ALS adds to the cost of healthcare in the outpatient setting as well. It is important to acknowledge that this study only recognizes patient populations for hospitalizations in the United States and is not a complete representation of ALS as a whole. Some patients may be hospitalized multiple times within a year and some patients may not be hospitalized at all so it is possible that patient demographics for ALS patients may vary.

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