Racial/Ethnic Differences in Healthcare Resource Utilization Among Patients with Amyotrophic Lateral Sclerosis in Texas

Tiffany Kuo, PharmD[a,b], Tim Reynolds, PharmD, MS[a], Linda Chen, PharmD, MS[a], Karen Rascati, Ph.D.[b], Chanhyun Park, Ph.D., M.Pharm., M.Ed., R.Ph.[b], Paul Godley, PharmD, FASHP[a]

Baylor Scott & White Health[a], University of Texas at Austin College of Pharmacy[b]

Background and Study Rationale

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease marked by the gradual deterioration of upper and lower motor neurons.[1] It is a relatively rare disorder, with an estimated annual prevalence of 4.42 per 100,000 population worldwide.[2] Average life expectancy from the onset is 3 to 5 years. While a definitive cure remains elusive, ongoing endeavors are evident through the emergence of novel treatments in the market. Existing literature reveals inconsistent findings regarding differences in healthcare resource utilization (HCRU) among patients of different races/ethnicities. Given that Texas is a racially diverse state, this study sought to enhance our understanding of the associations between HCRU among patients of different racial/ethnic groups in our patient population.

Objective

To examine differences in HCRU among patients with ALS across different races/ethnicities.

Methods

Study Design: Retrospective, observational cohort study
**Data Source:** Baylor Scott & White Health electronic health records (EHR)
Inclusion Criteria:
- Had a diagnosis of ALS between January 1, 2013 and June 30, 2023 as defined by the International Classification of Diseases (ICD)-9-CM code 335.20 and ICD-10-CM code G12.21 and confirmed through chart review;
- Had at least one outpatient visit at a BSWH facility between and including on the date of diagnosis and the end of overall observation period.

Exclusion Criteria:
- Had other motor neuron diseases that were not ALS.

Primary Outcome: Association of patient race/ethnicity with HCRU
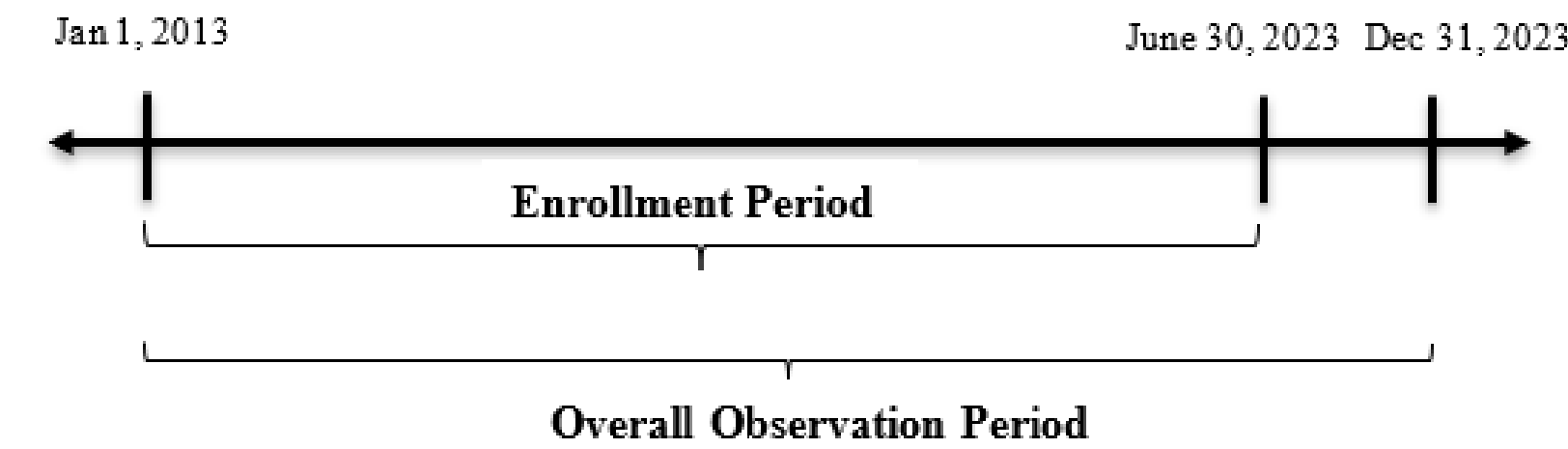
Discussion

Significant differences were found in HCRU. **Non-Hispanic Black** patients were more than 6 times as likely to receive **tracheostomy**. All racial/ethnic groups had lower odds of receiving **riluzole** compared to Non-Hispanic White patients, with the **Hispanic** group showing significantly lower odds. **Hispanic** patients had higher incidence rates of **ED visits** and **inpatient admissions** compared to Non-Hispanic White patients.

Exploring factors that influence the decision-making process of tracheostomy use and medication prescribing among patients may offer insights into the disparities observed in clinical decisions across different racial/ethnic groups. Further study is needed to address barriers hindering Hispanic patients' access to primary care and reduce ED visits.

References

1. Rowland LP, Shneider NA. Amyotrophic lateral sclerosis. N Engl J Med. 2001;344(22):1688-1700. doi:10.1056/NEJM200105313442207
2. Xu L, Liu T, Liu L, et al. Global variation in prevalence and incidence of amyotrophic lateral sclerosis: a systematic review and meta-analysis. J Neurol. 2020;267(4):944-953. doi:10.1007/s00415-019-09652-y

Results

Table 1. Baseline Characteristics by Racial/Ethnic Group

	Non-Hispanic White (n=474)	Non-Hispanic Black (n=34)	Hispanic (n=47)	Other/Unknown (n=81)	p-value
Age of onset median [Q1-Q3]	65 [57-72]	63 [53-71]	58 [53-64]	64 [57-72]	p=0.005[a]
Age category of symptom onset, n (%)					p=0.001[a]
<45	24 (5.2%)	3 (9.1%)	7 (15.6%)	6 (7.8%)	
45-65	205 (44.3%)	15 (45.5%)	29 (64.4%)	37 (48.1%)	
66-80	206 (44.5%)	13 (39.4%)	8 (17.8%)	30 (39.0%)	
>80	28 (6.1%)	2 (6.1%)	1 (2.2%)	4 (5.2%)	
Age of diagnosis median [Q1-Q3]	67 [59-74]	64 [55-72]	59 [54-67]	65 [58-73]	p=0.002[a]
Age category of diagnosis, n (%)					p=0.002[a]
<45	14 (3.0%)	3 (8.8%)	6 (12.8%)	6 (7.4%)	
45-65	192 (40.5%)	15 (44.1%)	26 (55.3%)	33 (40.7%)	
66-80	227 (47.9%)	13 (38.2%)	14 (29.8%)	36 (44.4%)	
>80	41 (8.7%)	3 (8.8%)	1 (2.1%)	6 (7.4%)	
Male, n(%)	240 (50.6%)	15 (44.1%)	27 (57.5%)	46 (56.8%)	p=0.483[b]
Site of onset, n(%)					p=0.298[b]
Bulbar	138 (29.2%)	6 (17.7%)	15 (32.6%)	28 (35.0%)	
Spinal	334 (70.8%)	25 (82.4%)	31 (67.4%)	52 (65.0%)	
Primary insurance type, n(%)					p<0.001[b]
Commercial	109 (23.0%)	8 (23.5%)	13 (27.7%)	23 (28.4%)	
Medicare	340 (71.7%)	22 (64.7%)	24 (51.1%)	54 (66.7%)	
Medicaid	2 (0.4%)	2 (5.9%)	1 (2.1%)	0 (0.0%)	
Other	23 (4.9%)	2 (5.9%)	9 (19.2%)	4 (4.9%)	
Annual household income, n(%)					p=0.003[a]
≤$49,999	26 (5.5%)	8 (23.5%)	4 (8.7%)	7 (8.7%)	
$50,000-$74,999	118 (25.2%)	12 (35.3%)	20 (43.5%)	21 (26.6%)	
$75,000-$99,999	158 (33.7%)	7 (20.6%)	7 (15.2%)	27 (34.2%)	
≥$100,000	167 (35.6%)	7 (20.6%)	15 (32.6%)	24 (30.4%)	
Smoking status, n (%)					p=0.735[b]
Never smoker	280 (60.5%)	18 (52.9%)	26 (55.3%)	46 (60.5%)	
Smoker	32 (6.9%)	5 (14.7%)	4 (8.5%)	7 (9.2%)	
Former smoker	151 (32.6%)	11 (32.4%)	17 (36.2%)	23 (30.3%)	
Marital status, n (%)					p=0.001[b]
Married/Partnered	350 (75.3%)	14 (41.2%)	34 (73.9%)	45 (71.4%)	
Single/Divorced	76 (16.3%)	15 (44.1%)	11 (23.9%)	12 (19.1%)	
Widowed	39 (8.4%)	5 (14.7%)	1 (2.2%)	6 (9.5%)	
BMI at diagnosis, n (%)					p=0.002[a]
BMI<18.5	12 (2.5%)	6 (17.7%)	3 (6.4%)	2 (2.5%)	
BMI 18.5-24.9	139 (29.3%)	9 (26.5%)	10 (21.3%)	17 (21.0%)	
BMI 25.0-29.9	111 (23.4%)	9 (26.5%)	13 (27.7%)	15 (18.5%)	
BMI≥30.0	87 (18.4%)	5 (14.7%)	7 (14.9%)	8 (9.9%)	
Unknown	125 (26.4%)	5 (14.7%)	14 (29.8%)	39 (48.2%)	

a. Kruskal-Wallis test; b. Chi-square test; BMI=body mass index.

Logistic regression was performed for the use of **non-invasive ventilator (NIV), tracheostomy, gastrostomy tube, mobility equipment, prescribing of riluzole, edaravone, phenylbutyrate/taurursodiol, and dextromethorphan/quinidine. Negative binomial regression** was used for **number of emergency department (ED) visits per patient per month (PPPM), outpatient visits PPPM, and inpatient admissions PPPM.** The initial intention was to utilize a zero-inflated negative binomial (ZINB) model for the analysis. However, due to convergence challenges encountered with the ZINB model owing to small sample sizes within certain covariates, the decision was made to utilize a negative binomial model instead. **Multivariate generalized linear regression with gamma distribution with log link** was used for **inpatient hospital length of stay (LOS)** due to its non-negative, right-skewed distribution. All models have been adjusted for age of diagnosis, sex, site of onset, primary insurance, annual household income, smoking status, marital status, and BMI at diagnosis.

Table 2. Healthcare Resource Utilization by Baseline Characteristics

	NIV use		Tracheostomy use		Gastrostomy tube placement		Mobility equipment use	
	OR, 95% CI	p-value	OR, 95% CI	p-value	OR, 95% CI	p-value	OR, 95% CI	p-value
Race/Ethnicity								
Non-Hispanic White	1 [Reference]		1 [Reference]		1 [Reference]		1 [Reference]	
Non-Hispanic Black	1.23 [0.57-2.69]	p=0.598	6.20 [2.43-15.84]	p<0.001	1.62 [0.73-3.59]	p=0.231	6.76 [0.86-53.29]	p=0.070
Hispanic	1.08 [0.55-2.12]	p=0.828	0.78 [0.26-2.29]	p=0.647	0.88 [0.44-1.76]	p=0.720	0.70 [0.32-1.55]	p=0.385
Other/Unknown	0.87 [0.49-1.56]	p=0.642	0.80 [0.30-2.15]	p=0.664	0.54 [0.29-0.99]	p=0.048	1.41 [0.65-3.05]	p=0.378

	Prescribing of riluzole		Prescribing of edaravone		Prescribing of sodium phenylbutyrate and taurursodiol		Prescribing of dextromethorphan and quinidine	
	OR, 95% CI	p-value	OR, 95% CI	p-value	OR, 95% CI	p-value	OR, 95% CI	p-value
Race/Ethnicity								
Non-Hispanic White	1 [Reference]		1 [Reference]		1 [Reference]		1 [Reference]	
Non-Hispanic Black	0.70 [0.33-1.51]	p=0.368	3.58 [1.31-9.74]	p=0.013	1.44 [0.35-5.87]	p=0.612	0.48 [0.13-1.77]	p=0.271
Hispanic	0.36 [0.18-0.71]	p=0.003	0.55 [0.18-1.72]	p=0.307	1.00 [0.31-3.28]	p=0.997	0.49 [0.19-1.29]	p=0.148
Other/Unknown	0.71 [0.40-1.27]	p=0.251	1.15 [0.49-2.68]	p=0.754	0.75 [0.21-2.70]	p=0.665	0.76 [0.36-1.62]	p=0.482

	Number of ED visits PPPM		Number of outpatient visits PPPM		Number of inpatient hospital admissions PPPM		Inpatient hospital LOS (days)		
	IRR, 95% CI	Std error	IRR, 95% CI	Std error	IRR, 95% CI	Std error	Coefficient, 95% CI	p-value	
Race/Ethnicity									
Non-Hispanic White	1 [Reference]		1 [Reference]		1 [Reference]		1 [Reference]		
Non-Hispanic Black	1.60 [0.79-3.24]	0.576	0.96 [0.70-1.32]	0.155	0.99 [0.45-2.18]	0.398	0.29 [-0.36-0.95]	p=0.382	
Hispanic	2.00 [1.09-3.65]	0.614	1.20 [0.89-1.62]	0.182	2.57 [1.37-4.81]	0.822	0.10 [-0.34-0.53]	p=0.669	
Other/Unknown	0.64 [0.34-1.20]	0.206	0.89 [0.69-1.16]	0.119	0.32 [0.13-0.82]	0.153	-0.07 [-0.88-0.74]	p=0.859	

NIV Use

Tracheostomy Use

Gastrostomy Tube Placement

Mobility Equipment Use

Riluzole

Edaravone

Sodium phenylbutyrate/taurursodiol

Dextromethorphan/quinidine

Number of ED Visits PPPM

Number of Outpatient Visits PPPM

Number of Inpatient Admissions PPPM

Inpatient Hospital LOS (days)

BMI=body mass index; CI=confidence interval; ED=emergency department; IRR=incidence risk ratio; NIV=non-invasive ventilator; LOS=length of stay; OR=odds ratio; PPPM=per patient per month; std error=standard error; *=statistically significant at α<0.05.