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A spatial analysis of amyotrophic lateral sclerosis (ALS) cases in the United States and their proximity to multidisciplinary ALS clinics, 2013

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Abstract

Background—Amyotrophic lateral sclerosis (ALS) is a fatal motor neuron disease that typically results in death within 2–5 years of initial symptom onset. Multidisciplinary ALS clinics (MDCs) have been established to provide specialty care to people living with the disease.

Objective—To estimate the proximity of ALS prevalence cases to the nearest MDC in the US to help evaluate one aspect of access to care.

Methods—Using 2013 prevalence data from the National ALS Registry, cases were geocoded by city using geographic information system (GIS) software, along with the locations of all MDCs in operation during 2013. Case-to-MDC proximity was calculated and analyzed by sex, race, and age group.

Results—During 2013, there were 72 MDCs in operation in 30 different states. A total of 15,633 ALS cases were geocoded and were distributed throughout all 50 states. Of these, 62.6% were male, 77.9% were white, and 76.2% were 50–79 years old. For overall case-to-MDC proximity, nearly half (44.9%) of all geocoded cases in the US lived >50 miles from an MDC, including

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approximately a quarter who lived >100 miles from an MDC. There was a statistically significant difference between distance to MDC by race and age group.

Conclusions—The high percentage of those living more than 50 miles from the nearest specialized clinic underscores one of the many challenges of ALS. Having better access to care, whether at MDCs or through other modalities, is likely key to increasing survivability and obtaining appropriate end-of-life treatment and support for people with ALS.

Keywords

Amyotrophic lateral sclerosis; motor neuron disease; multidisciplinary ALS clinics; access to care

Introduction

Amyotrophic lateral sclerosis (ALS), also known as motor neuron disease or Lou Gehrig's disease, is a progressive, fatal neurodegenerative disorder that causes the loss of motor neurons, typically resulting in paralysis, respiratory failure, and death within 2–5 years of symptom onset (1). Despite ALS being initially identified in 1869, the actual pathogenesis and cause(s) remain unknown for the approximate 90% of sporadic cases and there is currently no cure. Additionally, because ALS, like most non-communicable diseases, is not a notifiable disease in the United States (US), the epidemiology of ALS has been difficult to accurately access, particularly on a national level.

To help address the epidemiology of ALS in the US, the federal Agency for Toxic Substances and Disease Registry (ATSDR) launched the congressionally-mandated population-based National ALS Registry (Registry) in 2010. Briefly, the main goals of the Registry are to quantify the incidence and prevalence of ALS in the US, describe the demographics of persons with ALS, and examine potential risk factors for the disease (2). Recent findings estimate that almost 16,000 Americans, or 5/100,000, lived with the disease in 2013 (3) and approximately 5000, or 1.5/100,000, are diagnosed annually (4).

Because ALS is a terminal disease with limited care options, multidisciplinary ALS clinics (MDCs) have been established over the past few decades as a means to provide symptomatic and palliative care specifically to patients with ALS (5). MDCs, considered by many as the gold standard of ALS care, are located in large metropolitan areas and contain various ALS experts and services that can help meet the needs of people living with the disease (e.g. neurologists, occupational/physical therapists, dietitians, gastroenterologists, respiratory therapists, speech-language pathologists, and social workers). Typically, ALS patients who use MDCs travel to, and spend at least one full day a quarter at, these facilities to obtain comprehensive care.

While the effects on survival from MDCs have largely been positive (6–11), there have been other studies yielding mixed results (12,13). The purpose of this paper is not to debate the effectiveness of MDCs, nor to minimize the treatment ALS patients receive at non-MDCs (e.g. via their local primary care physician or neurologist), but to provide a spatial representation of ALS prevalence cases and MDCs in the US to help determine one aspect of access to care.

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Materials and methods

The National ALS Registry

In 2008, the US Congress passed the ALS Registry Act (US Public Health Service Act) (14). This Act allowed for the creation of the National ALS Registry to collect and analyze data regarding persons living with ALS in the US. Because ALS is non-notifiable in the US (meaning physicians are not required to report newly diagnosed or existing cases to local and state government agencies, which in turn notify federal agencies), ATSDR's Registry uses a novel two-pronged approach for case ascertainment, which has previously been described (15). Briefly, the first approach applies a pilot tested algorithm to large national databases (e.g. Medicare, Veterans Health Administration) to identify cases, while the second approach uses a secure web-portal to allow people with ALS to self-identify to capture cases not identified in the first approach. Cases from both approaches are then merged and de-duplicated to ensure that cases are not counted twice. All activities involving the National ALS Registry have been reviewed and approved by the Institutional Review Board (IRB) of the Centers for Disease Control and Prevention (CDC)/ATSDR.

Study population

For this analysis, the 15,908 prevalent cases identified through ATSDR's 2013 ALS surveillance report were used (3). These cases, covering the entire US, reflect the most recent year for which national data are available. The 2013 US Census estimates were used as the denominator to match the case data (16). Information about patient demographic characteristics, specifically sex, race, and age group was used where available. Race was classified as white, black, or other, while age was categorized as 18–49, 50–79, and ≥80 years old. For all cases, the patient's city of residence at enrollment or city identified in the national data was abstracted. Because of the Registry's case ascertainment methods and data structure, city was the smallest geographic resolution available.

Multidisciplinary ALS clinics (MDC)

Three ALS organizations currently fund and operate MDCs throughout the US to provide specialty care to people with the disease: the ALS Association (ALSA), the Muscular Dystrophy Association (MDA), and the Les Turner ALS Foundation (LTAF). These organizations provided ATSDR a list of their respective MDCs that were in operation during 2013 to match the case data time-period. Collectively, there were 72 different MDCs in operation during 2013. Of these, most were maintained and operated individually by MDA (n = 39, 54.2%) and ALSA (n = 27, 37.5%), five (6.9%) were joint ALSA/MDA were joint ALSA/MDA MDCs, and the remaining one belongs to LTAF (Supplemental table).

While each organization has its own specific criteria of what constitutes an MDC, they all largely operate using uniform care, adhere to the practice parameters set out by the American Academy of Neurology (17), participate in ALS-related research, and undergo a certification process. The MDCs used in this analysis include ALSA's Certified Treatment Centers of Excellence, MDA's designated ALS Care Centers, and LTAF's Lois Insolia ALS Clinic. Although ALSA and MDA operate other centers (e.g. ALSA's Recognized Treatment Centers and MDA's Care Centers), the focus of this paper is on centers that are staffed by

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multidisciplinary teams of health professionals skilled in the diagnosis and medical management of ALS, including symptom control, medical interventions and therapies to help maintain the highest possible quality of life.

Data geocoding and analysis

For each ALS case, the patient's city was geocoded using the Google Maps Geocoding API (18). Of the total 15,908 cases, 15,633 (98.3%) were successfully geocoded to the city of residence. Google's geocoder uses multiple components to geocode to either a neighborhood, locality, or administrative area when a street address is not provided. Cases not geocoded were due to incorrectly added city or missing data. All 72 (100%) MDC clinics were geocoded successfully. ArcGIS 10.3 geographic information system (GIS) software (19) was then used to (1) map the geocoded cases and MDCs; and (2) calculate the proximity of cases to the nearest MDC, categorized by four distance categories (0–25, >25–50, >50–100, and >100 miles). For regional analysis, the US was grouped into four regions as specified by the US Census Bureau: Northeast, South, Midwest, and West (20).

Data were largely descriptive and analyzed using SAS software, version 9.3 (21). Additionally, a Chi-square statistical test was used to compare (1) the demographics of the geocoded cases (i.e. sex, race, and age group) by MDC distance categories; and (2) the demographics of the non-geocodable cases with those of the geocoded cases. Unknown and missing cases for sex, race, and age groups were excluded from the Chi-square analysis comparing the demographics of the geocoded cases by MDC distance categories.

Results

MDC locations

The 72 MDCs were distributed in 30 different states, with some states and large metropolitan areas having multiple MDCs. More than half of the MDCs (*n*=42, 58.3%) are east of the Mississippi River. Of the four Census regions (Map), the largest number of MDCs are located in the South (*n*=20, 27.8%), followed by the Northeast (*n*=19, 26.4%), Midwest (*n*=17, 23.6%), and the West (*n*=16, 22.2%). When analyzing MDCs by population, the Northeast has the highest proportion of MDCs per 1,000,000 population (0.34), followed by the Midwest (0.25), West (0.22), and the South (0.16). The individual states with the greatest numbers of MDCs are California and New York (*n*=7, 9.7%), followed by Michigan and Texas (*n*=5, 7.0%). The three most populated cities with MDCs are New York City (*n*=8,305,061 population with 3 MDCs), Los Angeles (*n*=3,843,507 population with 1 MDC), and Chicago (*n*=1,194,337 population with 2 MDCs).

ALS case demographics and distribution

Of the 15,633 geocoded cases, most were male, white, and in the 50–79 year age range (Table 1). The mean age of cases at diagnosis was 63.5 years. Cases were distributed in all 50 states and DC and Puerto Rico (Map). More than half of the cases (*n* = 9515, 60.9%) are east of the Mississippi River. Of the four Census regions, most cases are in the South (*n* = 5724, 36.7%), followed by the Midwest (*n* = 3824, 24.5%), West (*n* = 3171, 20.2%), and the Northeast (*n* = 2888, 18.5%). The Midwest has the highest rate of cases per region with a

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rate of 5.7 per 100,000 population, followed by the Northeast (5.2), South (4.7), and the West (4.3). The individual states with the greatest numbers of cases were California (n=1450, 9.3%), Florida (n=1010, 6.5%), and Texas (n = 976, 6.2%). Geocoded cases were younger compared with non-geocodable cases (p< 0.0001), but there was no statistically significant difference for sex or race.

Proximity of cases to MDCs

For overall case-to-MDC proximity, about 45% of all geocoded persons with ALS in the US lived>50 miles from an MDC, and this includes approximately a quarter (24.6%) who lived>100 miles from an MDC (Table 2). In the continental US, the West had the furthest case-to-MDC proximity average. Similarly, when examining state level continental US cases, ALS cases in Montana resided the greatest distance from an MDC as the furthest case-to-MDC distance was approximately 600 miles.

When case-to-MDC proximity was evaluated by sex, there was no statistically significant difference among males vs. females at any distance category (0–25, >25–50, >50 100, >100 miles). Regarding race, a higher percentage of Blacks and Other lived closer to MDCs at the 0-25 mile range compared with Whites (Table 2). There was a statistically significant difference for distance categories among Whites vs. Blacks and Whites vs. Other (p<0.001), in addition to Blacks vs. Other (p<0.05). For age, a higher percentage of those ≥80 years lived within 0–50 miles of an MDC compared with the other two age groups. There were statistically significant differences for distance groupings among those 18–49 years vs. those ≥80 years, and those 50–79 vs. ≥80 years (p<50.05). However, there was no statistically significant difference between those 18–49 years compared with those 50–79 years.

Discussion

This spatial analysis is the first to map population-based ALS prevalence cases for the entire US and examine their proximity to the closest multidisciplinary ALS clinic (MDC). Knowing case counts, demographic information, and proximity to specialty care clinics can help inform healthcare professionals and ALS organizations on how to better allocate clinical resources to meet the needs of those living with the disease, especially ones who do not have convenient access to MDCs or other relevant treatment facilities.

Data from this analysis show that those living with ALS tend to be white, male and in older age groups, which is consistent with other findings (4,22,23). While cases were distributed in all 50 states, overall they tended mostly to cluster in large metropolitan areas. Although the prevalence rates were fairly consistent across the four Census regions, three states (California, Florida, and Texas) contained almost a quarter of all ALS cases. This is not necessarily unexpected given that these are among the top five most populated states, have about 26% of the overall US population and, furthermore, these states have a high percentage of people who fit the ALS age demographic (e.g. age ≥50 years) (24). Comparing demographics among the geocoded cases versus those that were non-geocodable, revealed that age was significantly different among the two groups. However, this difference is unlikely to change the overall interpretation because the number of non-geocodable cases was small (<2%).

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Almost half of all geocoded persons with ALS in the US lived>50 miles from an MDC. While this finding is largely dependent on what part of the country the case lives in and whether or not the area was considered rural, there are several factors that appear to correlate with case-to-MDC proximity, such as race and age. For race, a statistically significantly higher percentage of Blacks and those classified as Other lived closer to MDCs at the 0–25 mile range compared with Whites. This, perhaps, is due to a generally higher percentage of ethnic and racial minorities living in urban areas (25), which are where MDCs are located. Conversely, Whites historically have moved further out of urban areas and more into the suburbs (26), away from MDCs. For age, those in the highest age category (≥80 years) lived closer to MDCs at the 0–25 and >25–50 mile range compared with those in the younger age categories. While recent findings show that the percentage of older adults is higher in rural areas than in the rest of the US (27), it is possible that some ALS patients, once diagnosed, move closer to areas that provide better care (e.g. an urban area with an MDC). In addition, it is also possible that those living in rural areas are underdiagnosed because of the lack of specialty medical services, and are therefore not captured by our case ascertainment methods leading to the higher prevalence of older adults living closer to MDCs.

Large ALS organizations in the US (i.e. ALSA, MDA, and LTAF) have spent decades establishing MDCs to provide high quality care to people living with the disease. This analysis shows that the collective MDC network provides broad geographic coverage across a vast swathe of states. However, the data also show that there are areas of the country where MDC coverage is lacking, such as the upper states in the West and Midwest (e.g. Montana, North Dakota). While the lack of MDCs in these areas is likely due to healthcare supply and demand (e.g. low case counts, sparse population density, absence of neurologists), ALS organizations are continuing to establish more MDCs around the country to expand access to care.

In localities that are underserved by MDCs, these ALS organizations are also using alternative outreach models that allow for continued expansion of services to those in need. Examples include providing transportation services for patients to MDCs and offering expertise to patients from clinicians through email, telephone, and FaceTime visits. Such services are important to help provide a full continuum of care, especially since the burden of travel increases as the disease progresses. Other potential options for expanding access to care may include issuing wearable devices (e.g. smart watches) to patients for monitoring vital statistics (28), establishing satellite or mobile health clinics that focus specifically on persons with ALS and other debilitating diseases (29), and offering continuing medical education (CME) online to rural neurologists on how to diagnose and treat persons with ALS, especially if their clinics see very few ALS patients (30).

Another promising model currently being used by some MDCs that has widespread potential to increase further access to care is telemedicine. Telemedicine allows MDC clinicians and others to connect with ALS patients anywhere via a web-cam and a secure internet connection. A national movement in this direction would be facilitated by the creation of payor ‘telemedicine-in-the- home’ billing codes and changes in licensure laws that currently restrict crossing state lines with this technology. Studies suggest that persons with ALS who use telemedicine have decreased emergency room visits and hospital admissions, save on

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travel-related expenses, and are generally satisfied with their care, among other benefits (31–33). However, even telemedicine has its limitations (e.g. lack of internet and/or computer access in rural areas) and may not be able to address all the medical needs of an ALS patient, especially where a physical examination is needed.

Limitations

The findings in this analysis are subject to some limitations. First, because ALS is not a notifiable disease in the US ensuring that all cases are captured in the Registry is challenging. Therefore, the possibility of under-ascertainment exists, especially for harder to reach minority and/or rural populations with ALS. Secondly, not all people with ALS go to MDCs. For example, some people may elect to be treated by their local health care provider, while others may go to non-MDCs operated by ALSA or MDA (e.g. ALSA's Recognized Treatment Centers and MDA's Care Centers), and yet others may seek no treatment at all. Similarly, veterans with ALS may seek treatment at VA hospitals; however, these facilities were excluded from this analysis because it is unclear which ones have specialists available for persons with the disease, and non-veterans cannot use these facilities. Furthermore, case location is not necessarily an exact address because the National ALS Registry does not collect street addresses of patients, only city of residence at enrollment or city listed in the national databases. Thus, this analysis used distance categories to decrease the misclassification of not having exact street addresses. Similarly, case distance was plotted via a straight line to the nearest MDC. Therefore, it is likely the distances are longer when actually driving street routes.

Conclusion

ALS is a rapidly fatal disease that can impact anyone, but particularly those who are white, male, and in older age groups. Multidisciplinary ALS clinics (MDCs) have been established by large ALS organizations in the US over the past few decades to provide specialty care to people living with the disease. Collectively, these MDCs provide broad geographic coverage, especially in urban areas. However, roughly half of the almost 16,000 individuals in the US with ALS live>50 miles from an MDC. While steps are currently being taken by these ALS organizations to increase access to care for people with ALS, more options, such as tele-medicine, may benefit those in rural, non-urban settings. Having better access to care, whether at MDCs or through other modalities, is likely key to increasing survivability and obtaining appropriate end-of-life treatment and support for persons living with this deadly disease.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Mitsumoto, HC., Pioro, E. Amyotrophic lateral sclerosis. Philadelphia, PA: FA Davis Company; 1998.
2. Antao V, Horton DK. The national amyotrophic lateral sclerosis (ALS) registry. J Environ Health. 2012; 75:28–30.
3. Mehta P, Kaye W, Bryan L, Larson T, Copeland T, Wu J, et al. Prevalence of Amyotrophic Lateral Sclerosis — United States, 2012–2013. MMWR Surveill Summ. 2016; 65(No. SS-8):1–12.
4. Wagner L, Rechtman L, Jordan H, Ritsick M, Sanchez M, Sorenson E, et al. State and metropolitan area-based amyotrophic lateral sclerosis (ALS) surveillance. Amyotroph Lateral Scler Frontotemporal Degener. 2015; 23:1–7.
5. Galvin M, Madden C, Maguire S, Heverin M, Vajda A, Staines A, et al. Patient journey to a specialist amyotrophic lateral sclerosis multidisciplinary clinic: an exploratory study. BMC Health Serv Res. 2015; 15:571. [PubMed: 26700026]
6. Traynor B, Alexander M, Corr B, Frost E, Hardiman O. Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study, 1996–2000. J Neurol Neurosurg Psychiatry. 2003; 74:1258–61. [PubMed: 12933930]
7. Rooney J, Byrne S, Heverin M, Tobin K, Dick A, Donaghy C, et al. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. J Neurol Neurosurg Psychiatry. 2015; 86:496–501. [PubMed: 25550416]
8. Van den Berg J, Kalmijn S, Lindeman E, Veldink J, de Visser M, Van der Graaff M, et al. Multidisciplinary ALS care improves quality of life in patients with ALS. Neurology. 2005; 65:1264–7. [PubMed: 16247055]
9. Miller R, Jackson C, Kasarskis E, England J, Forshew D, Johnston W, et al. Practice Parameter update: the care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review). Neurology. 2009; 73:1227–33. [PubMed: 19822873]
10. Chiò A, Bottacchi E, Buffa C, Mutani R, Mora G. Positive effects of tertiary centres for amyotrophic lateral sclerosis on outcome and use of hospital facilities. J Neurol Neurosurg Psychiatry. 2006; 77:948–50. [PubMed: 16614011]
11. Sorenson E, Mandrekar J, Crum B, Stevens J. Effect of referral bias on assessing survival in ALS. Neurology. 2007; 68:600–2. [PubMed: 17310031]
12. Stephens H, Felgoise S, Young J, Simmons Z. Multidisciplinary ALS clinics in the USA: a comparison of those who attend and those who do not. Amyotroph Lateral Scler Frontotemporal Degener. 2015; 16:196–201. [PubMed: 25602166]
13. Zoccolella S, Beghi E, Palagano G, Fraddosio A, Guerra V, Lepore V, et al. ALS multidisciplinary clinic and survival. Results from a population-based study in Southern Italy. J Neurol. 2007; 254:1107–12. [PubMed: 17431705]
14. US. Public Health Service. ALS Registry Act. Washington, DC: 110th Congress. Public Law. 2008; 122 Stat 4047:110–373. Available at https://wwwn.cdc.gov/als/ALSRegistryActPublicLaw.aspx.
15. Horton K, Mehta P, Antao VC. Quantifying a nonnotifiable disease in the United States: the National Amyotrophic Lateral Sclerosis Registry model. Jama. 2014; 312:1097–8. [PubMed: 25057819]
16. U.S. Census Bureau. American Community Survey 5-year estimates. 2013. Available at https://www.census.gov/pro-grams-surveys/acs/data.html
17. Miller RG, Brooks BR, Swain-Eng RJ, Basner RC, Carter GT, Casey P, et al. Quality improvement in neurology: amyotrophic lateral sclerosis quality measures: report of the Quality Measurement

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and Reporting Subcommittee of the American Academy of Neurology. Neurology. 2013; 81:2136–40. [PubMed: 24271651]

18. Google Maps Geocoding API. [Accessed on 3/30/2017] Google Maps, Mountain View, California. 2017. Available at https://developers.google.com/maps/documen-tation/geocoding/intro
19. ESRI. ArcGIS Desktop: Release 10.3. Redlands, CA: Environmental Systems Research Institute. ESRI, Redlands, California; 2016.
20. US. Census Bureau. [Accessed on 3/30/2017] Geographic Terms and Concepts - Census Divisions and Census Regions. 2017. Available at https://www.census.gov/geo/reference/gtc/gtc_census_divreg.html
21. SAS Institute Inc. Base SAS® 9.3 Procedures Guide. Cary, NC: SAS Institute Inc; 2011.
22. Miller R, Anderson F, Brooks B, Mitsumoto H, Bradley W, Ringel S. and ALS CARE Study Group, Outcomes research in amyotrophic lateral sclerosis: lessons learned from the amyotrophic lateral sclerosis clinical assessment, research, and education database. Ann Neurol. 2009; 65:S24–S8. [PubMed: 19191307]
23. Rechtman L, Jordan H, Wagner L, Horton K, Kaye W. Racial and ethnic differences among Amyotrophic Lateral Sclerosis (ALS) cases in the United States. Amyotroph Lateral Scler Frontotemporal Degener. 2014; 16:65–71. [PubMed: 25482100]
24. US. Census Bureau. [Accessed on 3/30/2017] Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2016. 2016. Available at https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2016_PEPANNRES&src=pt
25. US. Census Bureau. [Accessed on 3/30/2017] The Black Population: 2010. 2011. Available at https://www.census.gov/prod/cen2010/briefs/c2010br-06.pdf
26. US. Census Bureau. [Accessed on 3/30/2017] The White Population: 2010. 2011. Available at https://www.census.gov/prod/cen2010/briefs/c2010br-05.pdf
27. Institute of Medicine (IOM) Rebuilding the Unity of Health and the Environment in Rural America. Washington, DC: The National Academies Press; 2006.
28. Rodgers MM, Pai VM, Conroy RS. Recent Advances in Wearable Sensors for Health Monitoring. IEEE Sensors J. 2015; 15:3119–26.
29. Carmack H, Bouchelle Z, Rawlins Y, Bennet J, Hill C, Oriol N. Mobilizing a Narrative of Generosity: Patient Experiences on an Urban Mobile Health Clinic, Communication Quarterly. 2017
30. Agency for Toxic Substances and Disease Registry (ATSDR). [Accessed on 3/30/2017] Amyotrophic Lateral Sclerosis (ALS) Continuing Education Module. 2016. Available at https://www.atsdr.cdc.gov/emes/ALS/
31. Bashiri M, Greenfield L, Oliveto A. Telemedicine Interest for Routine Follow-Up Care Among Neurology Patients in Arkansas. Telemed e-Health. 2016; 22:514–18.
32. McClellan F, Washington M, Ruff R, Selkirk S. Early and innovative symptomatic care to improve quality of life of ALS patients at Cleveland VA ALS center. J Rehabil Res Dev. 2013; 50:vii–xvi.
33. Pinto A, Almeida JP, Pinto S, Pereira J, Oliveira AG, de Carvalho M. Home telemonitoring of non-invasive ventilation decreases healthcare utilization in a prospective controlled trial of patients with amyotrophic lateral sclerosis. J Neurol Neurosurg Psychiatry. 2010; 81:1238–42. [PubMed: 20826878]

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Table 1

Demographics of ALS prevalence cases, based on geocode, in the U.S., 2013[a]

	Total Cases		Geocoded Cases		Non-geocodable cases	
Characteristics	**No.**	**%**	**No.**	**%**	**No.**	**%**
Total	15,908	100.0	15,633	100.0	275	100.0
Sex						
Male	9941	62.5	9,788	62.6	153	55.6
Female	5947	37.4	5,842	37.4	105	38.2
Unknown	20	0.1	3	0.0	17	6.2
Race						
White	12,318	77.4	12,183	77.9	135	49.1
Black	940	5.9	931	6.0	9	3.3
Other	866	5.4	836	5.3	30	10.9
Unknown	1784	11.2	1683	10.8	101	36.7
Age group (yrs)						
18-49	2234	14.0	2,172	13.9	62	22.5
50-79	12,105	76.1	11,907	76.2	198	72.0
≥80	1513	9.5	1,504	9.6	9	3.3
Unknown	56	0.4	50	0.3	6	2.2

[a]Of the 15,908 total ALS cases in the latest National ALS Registry prevalence report (Mehta, 2016), 15,633 (98.3%) were geocoded (i.e., were able to be mapped).

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Table 2

Proximity of geocoded ALS prevalence cases in the U.S. to the nearest ALS Multidisciplinary Clinic, by sex, race, and age group, 2013[a]

Distance	Characteristic								
	Sex[c]								
	Male		Female		Total				Chi-square p-value[b]
Miles from Clinic	No.		No.	%	No.	%			
0 – 25	3689	37.7	2271	38.9	5960	38.1			Male vs Female: p=0.06
>25 – 50	1650	16.9	1015	17.4	2665	17.0			
>50 – 100	1977	20.2	1190	20.4	3167	20.3			
>100	2472	25.3	1366	23.4	3838	24.6			
Total	9788	62.6	5842	37.4	15633	100.0			
	Race[d]								
	White		Black		Otder		Total		
Miles from Clinic	No.	%	No.	%	No.	%	No.	%	
0 – 25	4398	36.1	498	53.5	413	49.4	5309	38.1	**White vs Black: p<0.001**
>25 – 50	2156	17.7	96	10.3	120	14.3	2372	17.0	**White vs Otder: p<0.001**
>50 – 100	2547	20.9	162	17.4	120	14.3	2829	20.3	**Black vs Otder: p<0.05**
>100	3082	25.3	175	18.8	183	21.9	3440	24.6	
Total	12183	87.3	931	6.7	836	6.0	13950	100.0	
	Age Group (years)[e]								
	18-49		50-79		≥80		Total		
Miles from Clinic	No.	%	No.	%	No.	%	No.	%	
0 – 25	797	36.7	4523	38.0	619	41.2	5939	38.1	18-49 vs 50-79: p= 0.69
>25 – 50	379	17.5	2014	16.9	268	17.8	2661	17.0	**18-49 vs ≥80:p = 0.014**
>50 – 100	444	20.4	2422	20.3	292	19.4	3158	20.3	**50-79 vs ≥80:p = 0.017**
>100	552	25.4	2948	24.8	325	21.6	3825	24.6	

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Distance	Characteristic								
	Sex[c]								
	Male		Female		Total				Chi-square p-value[b]
Miles from Clinic	No.		No.	%	No.	%			
Total	2172	13.9	11907	76.4	1504	9.6	15583	100.0	

[a] Of tde 15,908 total ALS cases in tde National ALS Registry prevalence report (Mehta, 2016), 15,633 (98.3%) were geocoded (i.e., were able to be mapped).

[b] p <0.05 significance level. **Bold** denotes statistical significance.

[c] 3 cases were missing sex, n = 15,630.

[d] Race was defined as eitder identifying witd one racial group or, if racial identification included more tdan one racial group, respondents were classified as Otder. Race was unknown or missing for 1683 (10.8%) of people, n= 13,950.

[e] 50 cases were missing age, n = 15,583.