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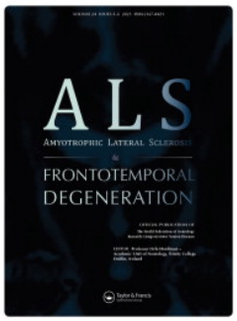

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RESEARCH ARTICLE

An electronic health record cohort of Veterans with amyotrophic lateral sclerosis

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Abstract

Objective: To assemble and characterize an electronic health record (EHR) dataset for a large cohort of US military Veterans diagnosed with ALS (Amyotrophic Lateral Sclerosis). *Methods:* An EHR dataset for 19,662 Veterans diagnosed with ALS between January 1, 2000 to December 31, 2020 was compiled from the Veterans Health Administration (VHA) EHR database by a query for ICD9 diagnosis (335.20) or ICD10 diagnosis (G12.21) for Amyotrophic Lateral Sclerosis. *Results:* The cohort is predominantly male (98.94%) and white (72.37%) with a median age at disease onset of 68 years and median survival from the date of diagnosis of 590 days. With the designation of ALS as a compensable illness in 2009, there was a subsequent increase in the number of Veterans diagnosed per year in the VHA, but no change in median survival. The cohort included a greater-than-expected proportion of individuals whose branch of service at the time of separation was the Army. *Conclusions:* The composition of the cohort reflects the VHA population who are at greatest risk for ALS. The greater than expected proportion of individuals whose branch of service at the time of separation was the Army suggests the possibility of a branch-specific risk factor for ALS.

Keywords: *Amyotrophic lateral sclerosis, electronic health records, veteran health*

Introduction

Amyotrophic lateral sclerosis (ALS) is a devastating neurodegenerative disease that affects motor neurons in the brain and spinal cord. Disease onset usually occurs between 60 and 80 years of age and life expectancy from the time of diagnosis typically ranges from three to five years, with respiratory failure as the typical cause of death (1). Unfortunately, treatment options remain limited with only four medications approved by the United States Food and Drug Administration (FDA) for slowing the progression of ALS – riluzole (2), edaravone (3), phenylbutyrate-taurursodiol (4) and tofersen (5) that have only modest impacts on survival. Because of the difficulty in conducting trials in this heterogenous and rapidly

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progressive disease with relatively low rates of patient participation in clinical trials (6), there is growing interest in using point-of-care data from electronic health records to advance the understanding and treatment of ALS (7,8).

For unknown reasons, among military Veterans, the risk for ALS is one and a half times the rate of the general population (9). Because of this increased risk, in 2009 ALS was designated a service-connected illness by the VA (10), allowing Veterans diagnosed with ALS access to comprehensive medical care from the VHA throughout their lives. It is estimated that more than three-fourths of Veterans with ALS receive care from VHA (10). As the largest integrated healthcare system in the United States of America with an extensive longitudinal EHR database, the VHA EHR dataset provides an opportunity to identify and assess relationships of various EHR factors related to ALS onset and progression and to potentially identify novel treatments.

We sought to characterize the population of Veterans receiving care for ALS through VHA and to identify trends in the EHR dataset that correlate with the designation of ALS as a service-connected illness. From the VHA EHR dataset, we identified over 19,000 Veterans diagnosed with ALS between January 1, 2000 and December 31, 2020 for analysis. The population was predominantly male with a median age at diagnosis of 68 years and median survival of 590 days. Designation of ALS as a compensable illness in 2008, was followed by an increase in the number of veterans diagnosed per year in the VHA, but no change in median survival.

Materials and methods

This study utilized the VHA Corporate Data Warehouse (CDW), a central repository that aggregates VHA EHR data. Individuals diagnosed with ALS from January 1, 2000 to December 31, 2020 were identified by a query for ICD9 diagnosis (335.20) or ICD10 diagnosis (G12.21) for Amyotrophic Lateral Sclerosis. Codes for other motor neuron diseases such as primary lateral sclerosis and progressive bulbar palsy were not included as they are more prone to inaccuracies (9). Information extracted from the EHR included demographics, other ICD-9 and ICD-10 diagnoses, vital signs, lab values, prescriptions, and procedures. Individuals with unique and readily identifiable demographic characteristics (year of birth; year of death; race; ethnicity; and marital status) were removed from the dataset because of the potential risk for re-identification (11). Survival was defined as the time from diagnosis to death reported in the VA Vital Status File which utilizes data from the Centers for Medicare and Medicaid, the Social Security Administration, VHA patient treatment files, and the National Cemetery Association (12). Follow-up survival time was censored on December 31, 2020, for those alive on this date. The study protocol involving the analysis of fully de-identified data was reviewed and approved with a Full Waiver of informed consent granted (Expedited, Category #5 research) by the respective Institutional Review Boards of Stanford University and Lawrence Livermore National Laboratory. The study was performed in compliance with all regulations and guidelines from the United State Department of Health and Human Services. All statistical analyses were performed with Python library stats models (13).

Results

Population

The number of Veterans diagnosed with ALS during the assessment period was determined to be 21,599. From this cohort, 1,937 (8.97%) had unique demographic profiles as determined by an expert data analyst and were removed from further analysis prior to sharing the comprehensive deidentified and anonymized data set of 19,662 individuals diagnosed with ALS. The median age at the entered ALS diagnosis date was 68 years and the Kaplan–Meier estimator demonstrated a median overall survival from the time of diagnosis of 590 d with 21.57% remaining alive at the end of the observation period (Table 1). In this identified population, 98.94% were identified as male, and 72.37% were identified as White (Table 1).

Military experience

Within the cohort, just under half (49.37%) identified the Army as the branch in which they last served. Others listed the Navy (22.10%), Air Force (17.66%), and Marine Corp (8.96%) as their branch at the time of their separation from the military (Table 2). Agent Orange exposure during military service was listed for 11.99% of the population and only 0.26% were listed as having been exposed to radiation during their military service. The length of service was not consistently included in the VA demographic data and therefore not included in the tabulation.

Trends associated with designation of ALS as a service connected illness

In 2006, the Institute of Medicine released a study on ALS in Veterans and determined that there was suggestive evidence of an association between military service and later development of ALS (14). Based on this conclusion, the VA designated ALS as a compensable illness in 2009 (15). As a result, Veterans diagnosed with ALS were given access to

Table 1. Demographic characteristics of veterans with ALS included in cohort.

Age (years) at diagnosis, median (range)	68.0 (24.0–90.0[a])
Year of diagnosis, median (range)	2012 (2000–2020)
Male sex – no. (%)	19,336 (98.94%)
Race and Ethnicity	
White race – no. (%)	14,231 (72.37%)
Black race – no. (%)	1006 (5.12%)
Other race – no. (%)[b]	112 (0.01%)
None indicated – no. (%)	4313 (21.94%)
Hispanic ethnicity – no. (%)	380 (1.93%)
Median survival in days	590
Alive at end of observation – no. (%)	4242 (21.57%)

[a]Any age greater than 90 years is listed as 90 years to minimize risk for re-identification.
[b]American Indian or Native Alaskan (7) Asian (19), Hawaiian Pacific Islander (15), Other (71).

Table 2. Military experience of veterans with ALS included in cohort.

Military branch at separation	Number (%)
Army	9709 (49.37%)
Navy	4346 (22.10%)
Air force	3473 (17.66%)
Marine corp	1762 (8.96%)
Coast guard	200 (1.02%)
Other[a]	179 (0.91%)
Agent orange exposure	2357 (11.99%)
Radiation exposure	52 (0.26%)

[a]None listed (158); USPHS (7); Merchant Marines (7); Other (5); NOAA (2).

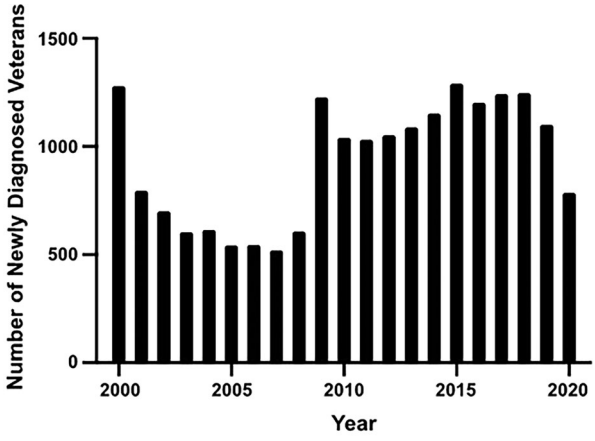

Figure 1. Number of newly diagnosed ALS cases in VHA EHR by year.

a full spectrum of clinically appropriate services from VHA throughout their lives.

To determine whether characteristics of the population of Veterans with a diagnosis of ALS in the VHA changed after this designation, we examined demographic trends by year of diagnosis. The average number of Veterans with a new diagnosis of ALS in this VHA dataset per year from 2000 to 2020 was 936 (range 519–1279). A year-to-year comparison (Figure 1) indicates that there was a marked and sustained increase in the number of new diagnoses in 2009, the year the VA designated ALS as a compensable illness.

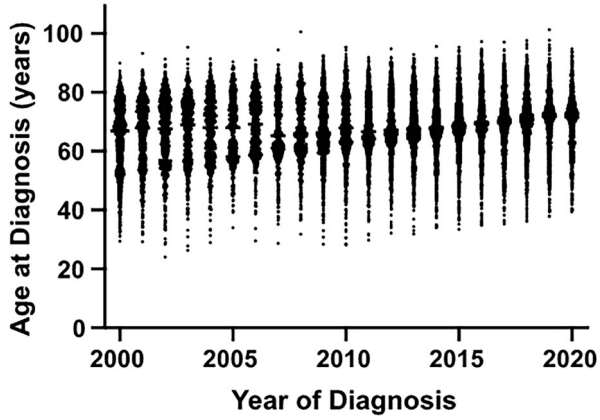

Figure 2. Age at time of ALS diagnosis by year of diagnosis.

We next sought to determine whether age at onset of ALS or prior use of the VHA healthcare system varied by year of diagnosis in a discernable pattern. There was a general increase in the median age of onset for newly diagnosed cases during the time period (Figure 2). There was little change in the percentage of individuals who were enrolled in VHA prior to their diagnosis of ALS (Table 3). Comparison of median survival by year of diagnosis indicates that diagnosis in 2000 was associated with longest survival but there was otherwise no identifiable pattern (Table 3). Self-identified race and ethnicity did exhibit variation by year of diagnosis – specifically, there was a marked decline in the percent of those in the Unknown category for race between 2000 and 2005 with a corresponding increase in specific race designations (Table 4).

Additional clinical data

The dataset includes other recordable aspects of clinical care, including medications, medical diagnoses, laboratory studies, vital signs, and clinical tests (Table 5). Among the individuals with ALS in this cohort, 15,007 (76%) were enrolled in VHA prior to the date of the ALS diagnosis; 5668 (28.82%) had electromyography-nerve conduction studies completed at a VHA facility; 9100 (46.28%) had pulmonary function tests completed at a VHA

Table 3. Prior enrollment in VHA at diagnosis and median survival by year of diagnosis.

Year	Enrollment in VHA prior to diagnosis (percent)	Median survival (days)
2000	69	784
2001	69	664
2002	74	651
2003	77	752
2004	73	629
2005	76	538
2006	80	536
2007	74	524
2008	76	538
2009	77	612
2010	79	571
2011	79	528
2012	79	590
2013	78	562
2014	75	587
2015	75	561
2016	77	605
2017	78	618
2018	80	599
2019	78	517
2020	80	n.d.
2000–2020	76	590

Table 4. Race and ethnicity trends by year of diagnosis.

Year	AI AN	Asian	Black Hisp	Black	HN PI	Other	Unk Hisp	Unk	White Hisp	White	Total
2000	0	0	0	23	0	1	5	915	14	321	1279
2001	0	0	0	17	0	0	0	568	9	202	796
2002	0	1	0	25	0	0	1	416	9	248	700
2003	0	0	0	23	0	2	0	219	11	349	604
2004	0	0	0	23	0	0	2	202	9	378	614
2005	0	0	0	23	0	1	3	131	8	376	542
2006	0	0	0	24	1	1	2	110	3	403	544
2007	0	0	0	19	0	1	4	93	8	394	519
2008	0	1	0	21	0	2	1	98	11	473	607
2009	1	2	0	54	1	4	3	187	16	959	1227
2010	1	0	0	42	0	4	4	171	5	813	1040
2011	1	1	0	61	0	5	5	152	14	792	1031
2012	0	0	0	59	2	2	2	134	15	838	1052
2013	1	2	0	46	0	7	9	121	15	887	887
2014	0	2	0	55	3	5	4	111	21	951	1152
2015	0	3	0	78	0	12	7	101	23	1066	1290
2016	1	2	1	81	1	2	9	98	20	987	1202
2017	1	0	0	88	1	5	6	101	20	1020	1242
2018	0	0	1	103	1	9	11	101	21	1000	1247
2019	0	3	0	84	1	4	10	100	18	880	1100
2020	1	2	0	55	3	5	6	90	12	612	786
2000-2020	7	19	2	1004	14	72	94	4219	282	13949	19662

AI AN: American Indian or Alaskan Native; Hisp: Hispanic (ethnicity); HN PI: Native Hawaiian or other Pacific Islander; Unk: Unknown (race).

Table 5. Additional clinical data for veterans with ALS in cohort.

Enrolled in VA prior to diagnosis – no. (**%**)	15,007 (76.32**%**)
Number of primary care visits per year – Mean (s.d)	3.46 (2.64)
Charlson Score at time of diagnosis – mean (s.d)	1.83 (2.47)
Had electromyography-nerve conduction study – no. (%)	5668 (28.82%)
Had pulmonary function test – no. (%)	9100 (46.28%)
Had neuropsychological evaluation – no. (%)	1388 (7.06%)
Prescribed riluzole – no. (%)	8072 (41.54%)
Prescribed edaravone – no. (%)	271 (1.38%)
Had Tracheostomy – no. (%)	1223 (6.22%)
Had an Autopsy – no. (%)	150 (0.76%)

facility; and 1388 (7.06%) had neuropsychological evaluations. With regard to ALS-specific treatments, 8072 (41.54%) were prescribed riluzole, and 271 (1.38%) were prescribed edaravone. Phenylbutyrate-taurursodiol and tofersen were approved by the FDA only after the observation period for this study). Trachiostomies were done at a VHA facility on 1223 (6.22%) and 150 (0.76%) underwent an autopsy at a VHA facility.

Discussion

The VHA is the largest healthcare system in the US. Using ICD codes to identify cases, we have generated a cohort of 19,662 Veterans with a diagnosis of ALS. The comprehensive longitudinal dataset for this cohort of a nationwide population of individuals with ALS allows for tracking clinical trends over time. Our data set is far larger than previously reported ALS patient cohorts with EHR data (8,16,17). This creates unique opportunities for identify factors encoded in EHR that are linked to the risk for developing ALS or affecting the rate of progression.

Although our cohort is characterized by a marked male predominance and military experience (two characteristics that are risk factors for ALS (1)), analysis suggests factors that influence disease risk and progression can be identified. For example, in the cohort, the proportion of those in the Army at the time of departure from service (49.37%) is higher than that reported by others (41.4% (18)) and higher than expected based on the historical military strength by service the from 1954 to 2014 (37.30% (19)). This indicates that there may be military branch-specific factors that increase the risk for ALS. Interestingly, a slight over-representation of service in the Army was noted in a cohort for a traumatic brain injury (20), suggesting a possible correlation between traumatic brain injury and ALS. Although a previous study of veterans with ALS noted no branch-specific increase in relative risk (21), the earlier study was limited by the small sample size. A comparison of service branch distribution for our much larger cohort with an appropriate control group may help better determine whether there is an over-representation of service in the Army for Veterans with ALS.

As expected, following the designation of ALS as a compensable illness in 2009, there was a marked increase in the annual totals of individuals with a new diagnosis of ALS in VHA. This may have reflected an increased awareness of the disease with the designation or a lowered threshold for recording the diagnosis as resources would be available to those with a diagnosis of ALS. Surprisingly, after the designation of ALS as a compensable illness, there was not increase in the percentage of veterans who enrolled in VHA after the date of diagnosis, that is the number of veterans enrolling in VHA only after they have been diagnosed with this compensable illness did not increase.

Utilization of EHR was being adopted throughout the VA at the beginning of the time period for our cohort and characteristics in our population suggest that EHR data may have become more informative during the time period we examined. For example, there is a large number of cases listed as diagnosed in 2000 with a year-over-year decline to 2005. A potential explanation for this is that as health records for individuals were transitioned to EHR, the date of onset for established diagnoses may have been entered as the date of transfer to EHR such that someone originally diagnosed prior to 2000 would have the diagnosis date entered as the date that their medical records were transitioned to an electronic format. During the observation period of our study, there was also a large shift in race from unknown to a specified race in our cohort. The more specific designation suggests that there may have been a greater effort to identify demographic features as EHR became established.

A peculiar aspect of our cohort is that there is a prominent peak in the distribution of age of onset that increases in an approximately 1:1 ratio with the year of diagnosis (the early 50s in 2000 to early 70s in 2020). A similar pattern is not observed in the general population of the United States (22). The pattern in the Veteran data could be caused by a common historical exposure that occurred over a short time period and increased risk for ALS in an age-dependent manner with a variable delay in disease onset, similar to the increased risk for solid cancers in adults exposed to radiation from atomic bombs during childhood (23). However, our population is defined by two characteristics – ALS and military service. Therefore, it is possible that the prominent peak in the number of individuals enrolled in the military in the late 1960s (19) is the underlying cause for the increasing age at the time of diagnosis in our cohort. This may also explain why the median age at the time of diagnosis for our cohort trends older than previous studies (24). The older median age for our cohort may in turn explain the shorter median survival than typically reported (24).

The use of EHR data for research is complicated by the presence of inaccuracies and the limitations imposed by what data are readily available (25,26). In our cohort, data are only available for care provided directly by VHA and it is estimated that more than 30% of veterans who receive care within the VHA healthcare system also receive care from providers non-VHA providers (27). Thus, it can be assumed that a number of veterans in our cohort received care, including testing and

medications, from providers outside of the VHA system. This likely explains why the percentages of individuals who underwent electromyography-nerve conduction studies and pulmonary function tests and who received riluzole as a treatment are lower than previously reported for individuals with ALS (28). Despite these types of limitations, EHR data are an invaluable source for real-world clinical information and can be useful for understanding diseases and their treatments when analyzed appropriately (29,30).

Here we have described, to our knowledge, the largest cohort of individuals with ALS with associated EHR. With further analysis, in addition to revealing factors associated with an increased risk for ALS, characterization of the cohort can be used to uncover features that impact progression and potentially identify novel treatment approaches for the disease.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Data availability statement

Data cannot be publicly shared because it involves sensitive Veteran Information. Data may be available for researchers who meet the criteria for access to confidential data after IRB as well as VA Research and Development Committee approval for the specific project. As a VA national legal policy, VA will only share sensitive patient data if there is a fully executed contractual agreement in place for the specific project. Common contractual mechanisms utilized for this type of data sharing include a Cooperative Research and Development Agreement (CRADA), and a Data Use Agreement (DUA). These agreements are typically negotiated in collaboration with the VA national Office of General Council (OGC) as well as attorneys from the collaborating institution, and the VA Privacy Office. These national sharing policies and standards also apply to deidentified data. Data requests may be sent to: VA Information Resource Center (VIReC) Building 18 Hines VA Hospital (151V) 5000 S. 5th Avenue Hines, IL 60141 3030 708-202-2413 708-202-2415 (fax) virec@va.gov.

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