Factors associated with the time taken for diagnosis of amyotrophic lateral sclerosis (ALS) in Brazil. An online population-based inquiry

Alisson V. Pereira-Elizeu, Juliana de Ávila-Panisset, Miguel L. Rodrigues-da Silva Jr., Leonardo P. da Silva-Paz, Katiane da Costa-Cunha, Marianne L. da Silva, Natan Monsores

Objective. This study evaluated factors associated with the time, in months, between the onset of symptoms and the diagnosis (time taken for diagnosis) of ALS for patients in Brazil, in the year 2014.

Patients and methods. An electronic questionnaire composed of 38 questions was developed and applied through internet-based social networks of patients. From the 210 replies, 194 were considered (86 from women, 108 from men). Most respondents were 51 to 60 years old. The Mann-Whitney test was used to compare the time taken for diagnosis between the strata of the sample.

Results. The mean time taken for diagnosis was 14.21 (±16.87) months. There was a statistically significant difference only for higher education conditions (p = 0.009) and low education status (p = 0.042). There was no statistically significant difference between sexes, bulbar onset, age groups, and the presence of spouse, or 'partnership with ALS patients associations or exchange of experiences'.

Conclusion. These data suggest that the time taken for diagnosis of ALS is influenced by socioeconomic conditions that promote access to information and/or health services.

Key words. Amyotrophic lateral sclerosis. Delayed diagnosis. Diagnosis. Epidemiology. Neurodegenerative diseases. Online self-assessment.

Introduction

Amyotrophic lateral sclerosis (ALS) is the most common adult motor neuron disease and is almost invariably fatal three to five years after the onset of symptoms [1]. The classic presentation of ALS involves signs of both upper motor neuron (UMN) and lower motor neuron (LMN) dysfunction with the brainstem and multiple regions of the spinal cord affected [2]. Patients may have bulbar manifestations that limit their ability to speak and swallow early in the course of the disease, and limit limb movement as the disease progresses. Exclusive UMN or LMN dysfunction is less common, the latter of which involves progressive limb muscle atrophy.

Diagnostic criteria are provided by the World Federation of Neurology Consensus for ALS diagnosis and Awaji [3]. However, the diagnosis of ALS can be delayed or erroneous given the similar clinical presentations of other neurological syndromes [4,5]. The length of time from the onset of symptoms to diagnosis varies between 12 and 16 months [4,6]. Factors that can increase the time taken for diagnosis of ALS include pending surgical operations, early presentations of the disease that don't involve bulbar signs [4], when the patient is 65-75 years old, the initial symptom is fasciculation [7], incorrect initial diagnosis, refusal to accept diagnosis suggested by the patient, and failure to refer the patient to a neurologist [8,9].

A rapid and accurate diagnosis is important for the programming of palliative care. The only universally accepted medication is riluzole, which has a small effect on survival but not on the progressive loss of strength and functional capacity [1]. As the patient's dependence increases, so does the demand for medical equipment [10] and social costs. The decline in quality of life indicates the importance of the work done by patient associations that offer support, guidance, and mediation with patients and families [11].

Despite the increasing number of epidemiological studies, the findings contain inconsistencies and the existing literature on ALS is largely limited to Europe [6]. As of the 2008 amendment to the United States ALS Registry Act, patients with ALS can register online to be put into databases [12]. In Bra-

Observatory of Rare Diseases. Faculty of Health Sciences. Campus Universitário Darcy Ribeiro (A.V. Pereira-Elizeu, J. de Ávila-Panisset, N. Monsores). Health and Health Sciences Technologies Programme. Universidade de Brasilia (L.P. da Silva-Paz). Department of Collective Health. Collective Health Course. Universidade de Brasilia. Brasilia (M.L. da Silva). Centre for Biological and Health Sciences. Universidade do Estado do Pará. Amapá, Marabá, Brazil (M.L. Rodrigues-da Silva Jr., K. da Costa-Cunha).

Correspondence:
Dr. Miguel L. Rodrigues-da Silva Jr. Centre for Biological and Health Sciences. Universidade do Estado do Pará. Av. Hiléia, s/n. Amapá, Marabá - PA, Pará, Brazil. Postal code: 68502-100.

E-mail:
miguel.junior@aluno.uepa.br

ORCID:
https://orcid.org/0000-0003-4310-5083 (M.L.R.S.).

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zil, comprehensive and up-to-date epidemiological data is not available for ALS. In most cases, the studies cover a specific region of the country [13-19]. According to one national survey, the incidence of the disease is similar to other countries [20].

The generation of qualified epidemiological information supports the planning of public health policies. As such, the main objective of this study was to describe the epidemiological profile of ALS in Brazil in 2014. To do so, we utilized communities of patients living with ALS and their associates.

Patients and methods

This is a cross-sectional, analytical and observational study based on an epidemiological pilot survey in which patients with amyotrophic lateral sclerosis (ALS) responded online. The entire study population lived in Brazil and were invited to participate through social networks (i.e. the snowball model) [21].

An electronic questionnaire consisting of 38 items, most of which were closed multiple choice, was answered by patients or their caregivers. As this was a pilot study, prior statistical predictions about the number of answers that would be obtained were unavailable. In a three-month period, 210 questionnaires were answered. Sixteen responses were discarded because they repeated answers and two answers didn't properly encapsulate basic issues stipulated in the inclusion criteria.

The data was tabulated and analyzed using SPSS version 2.0 using the statistical test of Kolmogorov-Smirnov to verify the distribution of the data. The Mann-Whitney test was used to compare the time from the onset of symptoms to the diagnosis (time taken for diagnosis) in months between the strata of the sample. The sample was divided into layers organized to form dichotomous variables based on sex, form of initial presentation of the disease, level of education, family income, in addition to questions about the realization of the achievement 'exchange of experience' and 'partnership with associations'.

The null hypothesis was that there would be no differences in the time taken for diagnosis between the different levels of the sample. Significance was considered $p < 0.05$.

This project was approved by the Ethics Committee in Research of Health Sciences of the University of Brasilia with CAAE 16110413.6.0000.0030 record, and ethical guidelines were respected at all stages of the study.

Results

All participants (n = 192) had been diagnosed with ALS. There were 107 men and 85 women, and the mean age was 54.35 (±54.50) while the age at the time of diagnosis was 49.50 ± 12.58 years (Table). The youngest and oldest participants were 24 and 88, respectively.

Of the patients studied, 24.22% had completed elementary school, 30.41% had completed high school, 31.95% had a university degree, 7.21% had incomplete higher education, 3.6% had master's degrees, and 0.51% had a doctorate. With regard to monthly family income, 8.24% had an income of up to one minimum wage, 38.65% ranged from one to three minimum wages, 22,68% had an income ranging from four to six minimum wages and, 30.41% reported having a higher income to six minimum wages.

The average time taken for diagnosis was 14.21 (± 16.87) months (Table). Comparing the strata was statistically significant difference only for higher education conditions (p = 0.009) and low education status (p = 0.042). On the other hand, the comparisons between sexes, symptoms at the onset of bulbar type, different age groups, for the presence of spouse, or partnership with ALS patients associations or exchange of experiences did not reach statistical significance.

Discussion

The present cross-sectional study utilized a semi-structured online evaluation through which patients diagnosed with ALS provided clinical and functional information. The internet has been used as a tool by agencies in the United States to identify patients with ALS [12]. Maier et al (2012) conducted a comparative study of classroom and online distance modes using the Revised scale of functional capacity for patients with ALS. The study had a high rate of adherence and the authors observed a good agreement between the classroom and distance ratings [22].

The Internet is useful for census studies because it may be accessible to people that do not meet the criteria in order to be registered in official databases, and also to those that have other economic or social barriers [23]. The use of the Internet in this study allowed for the direct participation of patients with ALS from all regions of Brazil, and detailed demographic data will be published elsewhere. The latest study census conducted in the

Table. Sample diagnostic time and statistical data (data with statistical significance are in bold).

	Categories	*n*	Sex *(n)*		Age (years)		Diagnostic time (months)		*p*-value
			Men	Women	Mean ± SD	Median	Mean ± SD	Median	
Sample		192	107	85	54.35 ± 54.5	54	14.21 ± 16.87	10	
Sex	Men	107	107	0	53.9 ± 11.04	54	14.04 ± 17.56	9	
	Women	85	0	85	54.93 ± 13.63	55	14.42 ± 16.05	12	0.504
Bulbar presentation	Other presentations	159	90	69	53.73 ± 12.07	54	15.06 ± 18.17	10	
	Bulbar presentation	33	17	16	57.36 ± 12.76	55	10.09 ± 6.83	8	0.252
Age 45 years old	Age > 45 years old	150	84	66	58.96 ± 8.77	56	15.04 ± 18.56	11	
	Age < 45 years old	42	23	19	37.9 ± 7.92	41	11.24 ± 7.9	10	0.701
Age 55 years old	Age > 55 years old	84	44	40	64.52 ± 7.81	63	14.20 ± 17.75	12	
	Age < 55 years old	108	63	45	46.44 ± 8.68	49	14.21 ± 16.24	10	0.596
Age between 65 - 75 years old	Other age groups	168	93	75	52.2 ± 11.5	53	13.31 ± 14.69	10	
	Age between 65 - 75 years old	24	14	10	69.42 ± 3.34	69	20.5 ± 27.38	12	0.27
Higher education	Low education level	109	56	53	55.36 ± 12.81	55	17.14 ± 20.74	12	
	Higher education	83	51	32	53.04 ± 11.36	54	10.36 ± 8.38	6	**0.009**
Low-income family	Don't has low-income	103	64	39	55.29 ± 11.26	56	12.7 ± 17.21	8	
	Has a low-income	89	43	46	53.27 ± 13.25	54	15.96 ± 16.39	12	**0.042**
Has spouse	No	55	15	40	52.15 ± 15.04	55	15.89 ± 19.07	12	
	Yes	137	92	45	55.24 ± 10.84	54	13.53 ± 15.93	10	0.508
Partnership with associations	No	98	57	41	53.58 ± 10.94	53	14.63 ± 20.62	8	
	Yes	94	50	44	55.15 ± 13.45	55	13.77 ± 11.86	12	0.178
Exchange of experiences	No	45	23	22	55.89 ± 11.98	55	11.13 ± 7.88	10	
	Yes	147	84	63	53.88 ± 12.31	54	15.15 ± 18.7	10	0.536

SD: standard deviation.

country was performed by Dietrich-Neto et al (2000).

ALS is an incapacitating and ultimately fatal disease [24] that causes a significant burden on health services [25]. It has a median survival time of three to five years and there are no interventions that effectively slow the progressive loss of strength and functional capacity [26]. A clinical diagnosis may take months, which delays appropriate pharmacological and supportive interventions for the disease,

its symptoms, and its associated psychological effects [27].

Over the past 20 years, much attention has been paid to the identification of risk factors for ALS. It is difficult to study for many reasons, including its low incidence, variable course, and complex etiology [28].

The benefits of a rapid diagnosis are clear given the number and variety of medical technologies and interventions needed throughout the progression of the disease. The costs increase linearly from the second stage of the disease [10]. There are no biological markers well established in the literature [26], and there is no effective intervention for the management of these patients [1].

Analyzing the information in the Clinical Protocol and Therapeutic Guidelines for Amyotrophic Lateral Sclerosis [29], published by Brazil's Ministry of Health in 2009 found that, on average, ALS patients are waiting from 10 to 13 months to get their first diagnosis. In the present study, the average waiting time of the first diagnosis was 14.19 months, this time similar to that reported in other studies [8,30]. Although there are reports of a smaller period of time regarding symptoms onset, such exceptions can be diagnosed within 9 months [7] 11 months [9,29] 12 months [31] or 16 months later [8].

Patients with rapidly progressive ALS tend to be investigated more quickly because they call more immediate attention from physicians. As a result, they can be diagnosed sooner because a delayed diagnosis has been recognized as a prognostic factor [26]. These factors did not affect the time diagnosis of this study.

Psychosocial factors are important determinants of motor neuron diseases. It is clear that there is a correlation between quality of life and the amount of support from caregivers. This support can include paying for home care services and encouraging the formation of informal care networks that can provide psychosocial support and psychoeducational programs [32]. Socioeconomic factors are not as well studied as psychosocial factors [33] despite their important influence on access to, and choice of, medications [26].

The communication and mobility difficulties resulting from ALS restrict social participation, and efforts should be made to maintain social networks [34]. Social support is an important predictor of quality of life. The efforts of social support can compensate for the loss in quality of life [34]. In addition, low social status may be related to a higher mortality rate [35]. In the present study, patients with lower income had an increased time taken for diagnosis.

In a case-control study carried out in Denmark, patients with ALS had less income than the control population, although a higher proportion of these patients receive government benefits compared to normal controls [25].

The World Health Organization defines health literacy as the ability of people to access, understand, make decisions and implement this information in the care of their own health in order to protect or improve their well-being [36]. A low level of health literacy is related to quality of health. It is suggested that a low level of health literacy can directly affect the medical condition, because it restricts the personal, social and cultural development, including the size of the self-care and adherence to health care. The ability to interpret the medical literature can make an individual more active in their health decisions and make their lives more meaningful, including health-related issues [37].

The information available on the Internet could compensate for inequities in access to health services [38]. However, even the material developed for patients with neurological diseases on the Internet, even on the most popular websites, is considered 'difficult' to interpret and requires a high level of education [39]. Those with health literacy skills find and understand the health-related content more easily [40,41]. This corresponds with the findings of the present study in which patients with higher level of education obtained the diagnosis of ALS earlier.

In Brazil, a survey developed at Unicamp revealed that most patients were unaware of the possibility of home care in ALS [15]. This shows that a national and regional structuring of public home care in ALS, plus the specialized multidisciplinary work, is needed [15].

These data reinforce the importance of organizing health services to arrange lines of care for patients and families, as these patients require numerous procedures and medical equipment to support life and maintain quality of life. It is essential to establish a national database on the disease, which already has clinical protocols and medicine distributed by public health system. This can extend this need to other rare diseases. The mandatory reporting by health facilities could be a way forward in understanding the epidemiological indicators of the disease and its impact on the health system structure and social security.

We therefore propose the creation of a national registry of all patients with ALS, in partnership

with patient associations and health managers of federal units, which will allow the generation of information and knowledge about the disease, and will support the planning of health policies.

The difficulty of obtaining qualified data, which requires research in conjunction with health professionals and patients' associations, seems to be recurrent in studies of the disease. Adding to the situation, the concentration of reference centers in regions further south of the country, as evidenced by the low number of patients in more northern regions of Brazil, historically poorer and has fewer diagnostic resources.

In this context it is evident the need for the public health system to adapt to the reality of people with ALS patients. The Brazilian public health system presents immense difficulties in providing quality care to neurodegenerative diseases as in localities within states have no reference centers for these diseases, thus patients are forced to seek assistance, exams, materials in more different places, making for difficult and fragmented care.

The multi-professional relationship with the patient is also very important to provide a humanized and comprehensive care. We should seek to build a network of care that takes into account the views of all stakeholders involved in the care of that patient process, creating real opportunities to improve care.

It is important to highlight the role of the family in this process, however that care is of good quality, the family has an important role, since one can provide a complete treatment when individual responsibilities and family come together, contributing to the increase quality and life expectancy of patients with ALS in Brazil.

We hope that the information obtained through this study will serve as a tool for the managers of health services to formulate new public policies related to information technology and analyze whether health services in Brazil are properly structured to meet such patients. The associations involved with the theme of ALS may also make use of such data and through them seek new achievements, such as the incorporation of new drugs and new procedures in the list of the public health system.

Conclusion

Data from this online study census suggests that socioeconomic factors such as education and income were related to the time taken for diagnosis of ALS for patients in Brazil.

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Factores asociados al tiempo necesario para el diagnóstico de esclerosis lateral amiotrófica (ELA) en Brasil. Una encuesta poblacional en línea

Objetivo. Este estudio evaluó los factores asociados con el tiempo, en meses, entre el inicio de los síntomas y el diagnóstico (tiempo necesario para el diagnóstico) de esclerosis lateral amiotrófica (ELA) de los pacientes en Brasil en 2014.

Pacientes y métodos. Se elaboró un cuestionario electrónico compuesto por 38 preguntas y se aplicó a través de redes sociales de pacientes basadas en Internet. De las 210 respuestas, se consideraron 194 (86 de mujeres y 108 de hombres). La mayoría de los encuestados tenía entre 51 y 60 años. Se utilizó la prueba de Mann-Whitney para comparar el tiempo transcurrido hasta el diagnóstico entre los estratos de la muestra.

Resultados. El tiempo medio transcurrido hasta el diagnóstico fue de 14,21 (±16,87) meses. Hubo una diferencia estadísticamente significativa sólo para las condiciones de educación superior (p = 0,009) y bajo nivel educativo (p = 0,042). No hubo diferencias estadísticamente significativas entre sexos, inicio bulbar, grupos de edad y presencia de cónyuge, o colaboración con asociaciones de pacientes con ELA o intercambio de experiencias.

Conclusión. Estos datos sugieren que el tiempo que se tarda en diagnosticar la ELA está influido por las condiciones socioeconómicas que favorecen el acceso a la información y/o a los servicios sanitarios.

Palabras clave. Autoevaluación en línea. Diagnóstico. Diagnóstico tardío. Enfermedades neurodegenerativas. Epidemiología. Esclerosis lateral amiotrófica.