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SOCIOECONOMIC AND EPIDEMIOLOGICAL ANALYSIS OF INDIVIDUALS WITH NEUROMYELITIS OPTICA SPECTRUM IN PARAÍBA: A PILOT STUDY

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ABSTRACT

The neuromyelitis optica spectrum is a rare, autoimmune, inflammatory, demyelinating, and chronic disorder of the central nervous system, which mainly affects the optic nerves and spinal cord. It is a sensorimotor impairment, which causes pain, in its majority, in the dermatome corresponding to the area of injury, paresis of the limbs, paresthesias, sensory disorders and autonomic dysfunctions, optic neuritis that directly affects the reception and transmission of nerve stimuli, causing low visual acuity. Based on this, the purpose of this descriptive study, with a quantitative approach, was to analyze the socioeconomic and epidemiological profile with a focus on functional capacity by the Modified Barthel Index

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and fatigue by the Fatigue Severity Scale of individuals with neuromyelitis optica spectrum disorder in Paraíba. Data were collected using a digital self-responsive form, in which descriptive analysis was performed with frequencies, mean and standard deviation. The sample consisted of sixteen individuals, predominantly female (15:1), with a mean age at diagnosis of 32.5 years, with some higher education level, with associated comorbidities, sedentary, undergoing motor physical therapy rehabilitation, with high levels of fatigue and mild to moderate functional dependence. They are mainly impaired in activities involving the lower limbs, such as walking and going up and/or down flights of stairs.

Keywords: Fatigue. Functional Capacity. Neuromyelitis Optica. Epidemiological Profile. Socioeconomic Profile.

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INTRODUCTION

Neuromyelitis optica spectrum disorder (NMOSD) is a rare, autoimmune, inflammatory, demyelinating, and chronic disorder of the central nervous system, which mainly affects the optic nerves and spinal cord. Due to its relapse-remission characteristic, progression often increases the risk of functional disability and/or morbidity and mortality (Nascimento et al, 2024).

According to recent studies, NMOSD mainly affects females, in a ratio of 9:1, i.e., 90% of cases, with a prevalence of 1–2 per 100,000 population and an average annual incidence of 1/770,000 worldwide (Holroyd, Manzano, and Levy, 2020; ORPHANET, 2024; Hughes et al., 2022).

The most common clinical picture mainly involves the spinal cord, where transverse myelitis of the longitudinally extensive type occurs, that is, the injury affects more than three segments of the spine, which will determine its probable consequences. It is a sensory-motor impairment, which causes pain, for the most part, in the dermatome corresponding to the area of injury, paresis of the limbs, paresthesias, sensory disorders, and autonomic dysfunctions (Almeida et al. 2019).

The optic nerve, on the other hand, where inflammation occurs, called optic neuritis, which has a demyelinating characteristic and directly affects the reception and transmission of nerve stimuli, causing low visual acuity. In NMOSD, the lesions that most occur are in the areas of the chiasm and optic tract, in which they are often affected bilaterally (Ariello; Monteiro, 2024).

Other symptoms that may occur, but with less probability in NMOSD, are related to syndromes of the brainstem, diencephalic or cerebral syndrome (14%) and of the prostrate area (10%). In the brainstem, depending on the location, the clinical picture may include oculomotor dysfunction, diplopia, nystagmus, cranial nerve palsies, pruritus, hearing loss, facial paralysis, trigeminal neuralgia, ataxia, hypersomnia, seizures, and respiratory failure. And in prosperma syndrome, it can cause nausea, vomiting and hiccups lasting more than 72 hours (Holroyd; Manzano; Levy, 2020; Waliszewska-Prosólet al., 2021; Lobato et al. 2024).

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OBJECTIVES

GENERAL OBJECTIVE

To analyze the sociodemographic and clinical profile, functionality and fatigue of individuals with NMOSD in Paraíba.

SPECIFIC OBJECTIVES

a) To report the sociodemographic and clinical profile of users with NMOSD.
b) Verify the functional capacity of users to carry out their daily activities.
c) To assess the level of fatigue of individuals with NMOSD.

METHODOLOGY

The present study consisted of a descriptive research with a quantitative approach. The study was approved by the Research Ethics Committee of the Health Sciences Center of the Federal University of Paraíba with CAAE: 77485524.1.0000.5188.

Data collection was carried out through a semi-structured digital form, for self-application or remotely assisted application, containing sociodemographic and clinical data, evaluation of fatigue severity by the Fatigue Severity Scale (FHS) and functional capacity through the Modified Barthel Index (MBI) developed by Shah, Vanclay and Cooper (1989).

For sociodemographic and epidemiological assessment, data such as place of residence, gender, age, social class, family income, occupation, education level, marital status, comorbidities, year of diagnosis of the NMOSD, smoking, alcohol consumption and physical activity, use of medications, and treatment and/or rehabilitation were obtained.

The IBM is used to measure the functional capacity individuals have and their impairments in performing activities of daily living. The scale has 10 categories of basic activities: personal hygiene, bathing, feeding, toilet, going up/down stairs, locker room, bladder and anal sphincter control, ambulation (or wheelchair use) and chair/bed transfers. The categories are analyzed and scored according to the amount of physical assistance that the individual needs to perform them, ranging from "unable to perform the task" to "totally independent".

In this study, we followed the stratification suggested by Shah, Vanclay and Cooper (1989), where the scores vary between 0 and 15 depending on the item evaluated. The final score is formed from the total sum of the items, and is classified as: total dependence, score less than 25 points; severe dependence, score between 26 - 50 points; moderate

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dependence, score between 51 - 75 points; mild dependence score between 76 - 99 points; and totally independent scores of 100 points.

Fatigue is one of the main symptoms of NMOSD, being one of the main complaints of these individuals. The FHS was developed by Krupp et al (1989) and is an instrument widely used to assess the intensity of fatigue in individuals with chronic diseases. It is a scale composed of 9 items and each item is rated from 1 to 7, in which 1 indicates strong disagreement and 7 indicates strong agreement. For the interpretation of the results, it is considered that: values lower than 28 points indicate absence of fatigue; from 28 to 39 points: mild fatigue; from 40 to 51 points: moderate fatigue; and from 52 to 63 points: severe fatigue.

The data obtained in the study were organized in an Excel® database (2016 version), in which descriptive analysis was performed with frequency, mean and standard deviation.

RESULTS

The sample consisted of 16 individuals living in the state of Paraíba, 50% (n= 8) of whom lived in the greater João Pessoa, capital of Paraíba, 25% (n= 4) in the city of Campina Grande and 25% (n= 4) in other cities in the hinterland of the state. 56.2% (n= 9) of the sample had a closed diagnosis between 2020 and 2023.

There was a predominance of females (93.8%, n=15), married or in a stable union (50%, n=8). Ages ranged from 24 to 67 years, with 87.5% (n= 14) in adulthood, 6.3% (n= 1) in youth, and 6.3% considered elderly. Regarding education, 50% of the sample (n=8) has at least higher education. Regarding social class based on per capita family income, 37.5% (n= 6) of the sample declared themselves to belong to Class D - Between 1 and 3 minimum wages, as shown in table 1.

Table 1 – Socioeconomic and epidemiological data of individuals with NMOSD in Paraíba.

Variables	n=16	Average ± SD	Percentage
Sex			
Female	15	-	93,8%
Male	1	-	6,3%
Marital status			
Married	6	-	37,5%
Single	7	-	43,8%
Stable Union	2	-	12,5%
Divorced	1	-	6,3%
Age	-	37 years ± 10.83	-

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< 25	1	-	6,3%
25 – 40	10	-	62,5%
40 – 65	4	-	25,0%
> 65	1	-	6,3%
Schooling			
Fundamental	1	-	6,3%
Medium	7	-	43,8%
Superior (Undergraduate)	5	-	31,3%
Postgraduate studies	3	-	18,8%
Social class			
Class A: < 15 SM	1	-	6,3%
Class B: from 5 to 15 MW	3	-	18,8%
Class C: from 3 to 5 MW	3	-	18,8%
Class D: from 1 to 3 MW	6	-	37,5%
Class E: > 1 SM	3	-	18,8%
Year of diagnosis			
2014 - 2018	7	-	43,8%
2019 - 2023	9	-	56,2%
Legend: n: sample number; SD: standard deviation; SM: Brazil's minimum wage in the year 2024.			

Source: Prepared by the author (2024).

Correlating the year of birth with the year of diagnosis, it was observed that the mean age of diagnosis was 32.5 years, with the earliest age at 22 years of age (12.5%, n= 2) and the latest at 57 years (6.3%, n= 1). Regarding occupation, 56.3% (n= 9) are professional, 25% (n= 4) are exclusively domestic and 18.8% (n= 3) are retired or on some social benefit.

In the clinical evaluation, 62.5% (n= 10) had some comorbidity, the most prevalent being anxiety (43.8%, n= 7), obesity (31.3%, n= 5), asthma (25%, n=4), diabetes, depression, and fibromyalgia (12.5%, n= 2 for each of the comorbidities). Regarding the consumption of substances such as alcohol and tobacco, 25% are alcoholics (n= 4), 75% of whom (n= 3) consume weekly and there are no smokers in the sample.

With regard to physical activity, not including physical therapy rehabilitation, 56.2% of the sample (n= 9) is sedentary. Regarding physical therapy rehabilitation, 56.2% (n= 9) and physical activity, 43.8% (n= 7) of the sample performed at least one of these activities weekly.

Regarding functional capacity, based on the IBM classification, it was observed that the entire sample presents some level of dependence. Of these, 56.2% (n= 9) had mild dependence and 43.8% (n= 7) had moderate dependence. Of the activities evaluated by the IBM, the two with the greatest functional limitations were, respectively, "climbing stairs" (56.2%) and "walking" (37.5%). In the activity of "climbing stairs", 9 individuals had some degree of limitation, among them, 33.3% (n= 3) considered incapable of performing the

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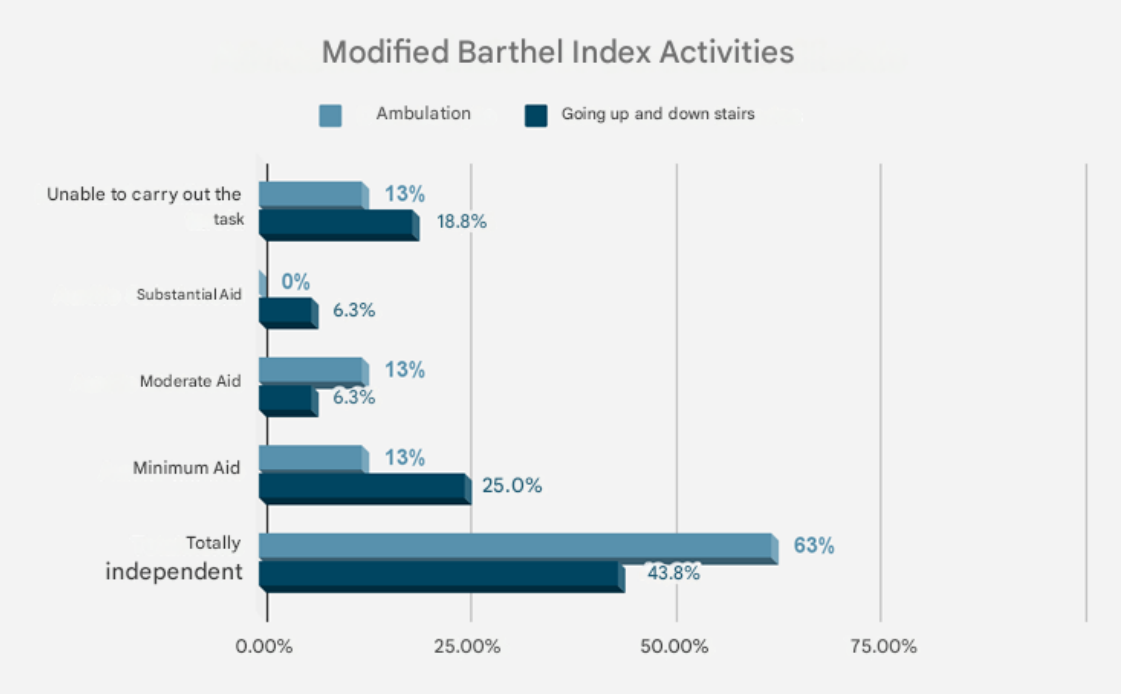
task, 11.1% (n= 1) requires substantial help, 11.1% (n= 1) requires moderate help, and 44.4% (n= 4) requires minimal help to perform the activity. In the "ambulation" period, 6 individuals had some degree of dependence, among them, 33.3% (n= 2) are unable to perform the activity, 33.3% (n= 2) moderately need help and 33.3% (n= 2) need minimal help, as shown in Graph 1.

Graph 1. Activities with greater functional limitations in individuals with NMOSD in Paraíba, according to IBM.



Source: Prepared by the author (2024).

When analyzing the fatigue indicator, it was observed that 93.8% of the sample presented some indication of fatigue, with 12.5% classified as mild, 31.3% as moderate and 50% as severe fatigue (Graph 2). As for the statements with the highest levels of agreement with the reality of the sample, that is, that 6 or 7 points were attributed, items "1. My motivation is lower when I'm fatigued." (68.7%) of, "2. Exercise makes me fatigued." (75%) and "4. Fatigue interferes with my performance." (62,5%).

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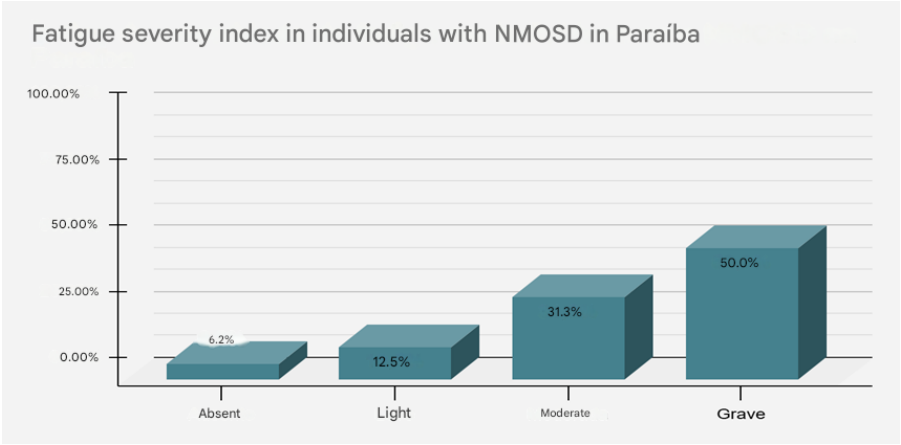
Graph 2 – Fatigue indicative in individuals with NMOSD in the state of Paraíba according to the Fatigue Severity Scale



Source: Prepared by the author (2024)

DISCUSSION

The analysis of the research data showed that the individuals were mostly women (15:1), which corroborates the findings in the studies by Cunha et al. (2020), Beekman et al (2019) and Silva Junior, Dourado and Silva (2020) in the ratio 8:1, 6:1 in Paolilo (2021), 4.6:1 in Papp et al (2018) and 6:1 in Bukhari et al (2017). It is also consistent with a study carried out in Brazil by Lana-Peixoto et al (2021), in which of the 69 patients, 87% were female. It can be seen, therefore, that the NMOSD has a female preponderance.

The prevalence of the age group of users was between 25 – 40 years, with the average age at the onset of diagnosis of the disease being 32.5 years, which corroborates Papp et al (2018) who brought in their research an average age at the onset of diagnosis of 35.5 years and Lana-Peixoto et al (2021) who demonstrated in their research an average of 39 years, Both studies are in agreement with our findings.

In a study by Beekman et al (2019), the demographic profile of a total of 193 individuals diagnosed with NMOSD was evaluated and among the results analyzed by the authors is the educational level of this population, where, as well as the data from this research, approximately 50% of the sample has at least an undergraduate degree. This may be correlated with the average age of diagnosis, since when following the expected school flow in Brazil and accessing the university soon after, the average age of graduation is around 24 years old.

Zhang et al (2023) brought in their study with elderly patients diagnosed with NMOSD that the majority of the sample has some type of associated comorbidity, highlighting atherosclerotic cardiovascular disease, hypertension, and diabetes mellitus, as

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observed in the present study, where 62.5% of the sample has some comorbidity, the most prevalent being anxiety, obesity, and asthma.

According to the study by Silva (2019), in his sample of 72 individuals with NMO/NMOSD, the mean BAI score is 76.8 points, that is, moderate to mild functional dependence predominated, as observed in the data presented in this study, since the mean BAM was 81 points, which means that moderate to mild functional dependence also predominated in the execution of activities of daily living.

Fatigue is one of the main symptoms found in the NMOSD, Akaishi et al (2021) and Soares, Alvarenga Filho and Alvarenga (2022) brought in their studies, in which they evaluated the presence of fatigue in individuals with NMOSD using the Chalder Fatigue Scale and the Modified Fatigue Scale, respectively, that fatigue is a symptom present in 76% and 59% of the samples, corroborating the findings of our study.

As in other studies with rare diseases, the sample size was the main limiting factor in the research, however, despite being rare, these individuals exist and need approaches that target their characteristics and needs, proposing appropriate physical therapy treatments for the individuality of each one.

CONCLUSION

The study provided a brief perception of the sociodemographic and clinical profile of individuals diagnosed with NMOSD living in the state of Paraíba. In which there is a predominance of women, aged between 24 and 67 years and with a predominance of the age group between 25 and 40 years, with a diagnosis closed at 32.5 years on average, sedentary, with at least complete higher education and who still exercise their occupational activity.

Despite the high rates of fatigue, mild to moderate levels of functional dependence were observed. They are mainly impaired in activities involving the lower limbs, such as walking and going up and/or down flights of stairs. Future studies with larger sample sizes and more comprehensive evaluation screening are needed for this population, in order to obtain more robust data to foster future intervention research, as well as to better support physical therapy treatment in this population.

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