

# FOCAL EPILEPSY IN THE STATE OF ALAGOAS, BRAZIL: CAUSES AND PSYCHOSOCIAL IMPACT

## *Epilepsia focal no Estado de Alagoas, Brasil: causas e impacto psicossocial*

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### ABSTRACT

**INTRODUCTION:** epilepsy is a common neurological disorder in developing countries, where its etiology is largely influenced by environmental irritants and the psychosocial consequences may be greater. The aim is to describe the clinical and psychosocial aspects of patients with focal epilepsy treated at a public hospital in the State of Alagoas. **METHOD:** a cross-sectional study involving 277 individuals with focal epilepsy, aged 12-82 years-old, attending University Hospital from Federal University of Alagoas. Subjects underwent a semi-structured interview, covering clinical and psychosocial data, and complementary exams. **RESULTS:** patients had a mean age of 32.2 years, 44.9% were illiterate or had not attended the first four years of primary education and 92.9% of patients had a monthly family income below 150 dollars per person. Among 37.5% of patients with epilepsy due to structural cause, perinatal injury was related to 27.9% of the cases. About 76.8% of adult patients reported some negative impact of epilepsy on their lives, which was related to female gender and low family income. **CONCLUSION:** patients have low education and family income a high frequency of epilepsy attributed to perinatal injury and of negative psychosocial impact of epilepsy in life.

**KEYWORDS:** Adults, Brazil, Developing Countries, Epilepsy, Epileptic Seizures.

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## RESUMO

**INTRODUÇÃO:** epilepsia é uma condição comum nos países em desenvolvimento, onde sua etiologia é amplamente influenciada por fatores ambientais e onde suas consequências psicossociais são maiores. O objetivo é descrever os aspectos clínicos e psicossociais de pacientes com epilepsia focal tratados em um hospital público no Estado de Alagoas. **MÉTODO:** estudo transversal envolvendo 277 indivíduos com epilepsia focal, com 12 a 82 anos de idade, acompanhados no Hospital Universitário da Universidade Federal de Alagoas. Os pacientes foram submetidos a uma entrevista semi-estruturada, que incluía dados clínicos e psicossociais, e a exames complementares. **RESULTADOS:** os pacientes apresentavam idade média de 32,2 anos, 44,9% eram analfabetos ou não completaram os primeiros quatro anos da educação fundamental e 92,9% apresentavam renda mensal familiar por pessoa abaixo de 150 dólares. Dentre os 37,5% dos pacientes com epilepsia secundária a causa estrutural, os agravos perinatais foram responsáveis por 27,9% dos casos. Cerca de 76,8% dos pacientes adultos referiram algum impacto negativo da epilepsia nas suas vidas, o que se relacionou a sexo feminino e baixa renda familiar. **CONCLUSÃO:** os pacientes apresentavam baixo nível educacional e de rendimento familiar e alta frequência de epilepsia secundária a agravos perinatais e de impacto psicossocial negativo da epilepsia.

**PALAVRAS-CHAVE:** Adultos, Brasil, Países em Desenvolvimento, Epilepsia, Crises epiléticas.

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## INTRODUCTION

Epilepsy is a disorder characterized by an enduring predisposition of the brain to generate epileptic seizures and the occurrence of at least one epileptic seizure.<sup>1</sup> The prevalence of active epilepsy is estimated at 4-10 cases per 1000 individuals, and is greater in developing regions such as Latin America, where it affects 12.4 per 1000 individuals.<sup>2,3</sup> The higher rates of prevalence found in developing countries are attributed to the frequency of epilepsy due to structural-metabolic causes such as neurocysticercosis (NCC) and others central nervous system infections, traumatic brain injury (TBI) and perinatal injuries.<sup>4,5</sup> These countries are characterized by intense social and economic inequalities between regions, states and even within the same municipality, which may be contribute to the great variability observed in etiology and prevalence rates of epilepsy.<sup>3</sup>

The current concept of epilepsy includes the psychosocial consequences of the condition<sup>1</sup> as, compared to the general population, people with epilepsy have more psychosocial problems,

such as feelings of stigma, psychological distress, unemployment, lowered self-esteem and interpersonal difficulties, including social isolation and low social competence.<sup>6</sup> In low-income regions, these consequences are more common and might intensify the psychosocial stigma felt by patients. The precarious condition of health care makes it difficult to manage the high prevalence of epilepsy, which in turn may increase the perception of stigma and reduce the possibility of social conformity.<sup>7</sup> The deficient educational system may also contribute to misconceptions about the disorder such that it is viewed as contagious or spiritual in nature, further increasing the isolation of patients.

In the State of Alagoas, we live with the highest infant mortality rates (46.4 per 1000 live births) and the lowest life expectancy at birth rates (67.6 years) in Brazil; moreover, there is little data on the occurrence and characteristics of epilepsy.<sup>8</sup> This study aimed to characterize the clinical and psychosocial aspects of adolescents and adults with focal epilepsy who were treated at a public hospital in the State of Alagoas.

## MATERIALS AND METHODS

Patients included in this study were all at least 12 years old and attended the Epilepsy Clinic of the University Hospital from Federal University of Alagoas (HU-UFAL) from February 2006 to December 2010, on days when undergraduate students involved in the project were present. Following the appointment with their neurologist, patients with focal seizures were invited to participate in this study and were asked to take part in an interview consisting of a semi-structured questionnaire that included information on epidemiological, clinical and psychosocial factors. All patients were asked to undergo an electroencephalogram (EEG) and an imaging exam: skull computed tomography (CT) and/or magnetic resonance imaging (MRI). Medical records were reviewed after at least one year after the interview, in search of new data from additional tests.

Epilepsy was diagnosed according to the clinical diagnostic criteria of the International League Against Epilepsy (ILAE).<sup>9</sup> Those patients with single or acute symptomatic seizures were excluded. The HU-UFAL is part of the public National Health Service system. The local ethics committee approved this study and all subjects gave their informed consent before participation (Case No. 0900-2005-11).

Data collected were stored in the Microsoft Office Excel™ database and statistical analyses were performed using the SPSS v15.0 software (SPSS Inc., Chicago, IL, USA). Numerical variables are presented as mean  $\pm$  standard deviation. Categorical variables were analyzed by Fisher exact test or chi-square test.

## RESULTS

A total of 277 patients were included in this study ranging in age from 12-82 years old with a

mean age of  $32.2 \pm 14.8$ . A total of 143 females (51.6%) were interviewed. About 52 patients (18.8%) were illiterate and among those above 18 years old, 36 patients (15.4%) were illiterate, 69 (29.5%) had not attended the first four years of primary education, 61 (26.1%) had secondary education and 11 patients (4.7%) had a higher level of education. Family income information was available for 239 patients; of these patients, 30 (12.5%) showed no family income at all, 46 (19.2%) had an income of up to 50 dollars per person, 146 (61.1%) had a monthly income per person between 50 and 150 dollars while 17 (7.1%) had an income per person above 150 dollars.

The average age of seizure onset was  $18.1 \pm 17.1$  years, ranging from 0-78 years old. Fifty-three patients (19.1%) had a history of febrile seizure and 110 (39.7%) reported a family history of epilepsy. Of those who were on medication for seizure control, 153 patients (56.7%) were on monotherapy and 90 patients (32.5%) reported no seizures for at least 6 months.

In addition to the clinical interview, it was possible to conduct EEG tests in 209 (75.5%) and imaging studies in 209 (75.5%): CT in 199 (71.8%) and MRI in 42 (15.2%) patients. It was possible to determine the cause of epilepsy in 104 patients (37.5%). Etiologic diagnose was possible in 92 patients (44%) submitted to an imaging study and in only 12 patients (17.6%) of those who failed to have access to an imaging exam. Among patients submitted to MRI, 83.3% achieved an etiologic diagnose and among the group of 173 patients with epilepsy of unknown cause, 36 (20.8%) had a clinical picture highly suggestive of temporal lobe epilepsy and should undergo a MRI study. The causes of focal epilepsy are described in **Table 1**.

**TABLE 1** – Focal epilepsy due to structural causes: etiology and age of onset

Etiology	Age of onset				
	Total N (%)	0-11yo N (%)	12-18yo N (%)	19-59yo N (%)	≥ 60yo N (%)
Perinatal injury	29 (27.9)	26 (44.1)	3 (16.7)	0	0
MTLE	15 (14.4)	9 (15.3)	4 (22.2)	2 (9.5)	0
Intracranial neoplasms	13 (12.5)	3 (5.1)	1 (5.6)	8 (38.1)	1 (16.7)
Post-Meningitis	9 (8.7)	7 (11.9)	2 (11.1)	0	0
Post- Stroke	8 (7.7)	0	0	4 (19)	4 (66.7)
NCC	6 (5.8)	1 (1.7)	3 (16.7)	1 (4.8)	1 (16.7)
Cortical malformation	5 (4.8)	3 (5.1)	2 (11.1)	0	0
Post-TBI	4 (3.8)	1 (1.7)	1 (5.6)	2 (9.5)	0
Other	15 (14.4)	9 (15.3)	2 (11.1)	4 (19)	0
Total	104 (100)	59 (100)	18 (100)	21 (100)	6 (100)

Yo, years-old; MTLE, mesial temporal lobe epilepsy; NCC, neurocysticercosis; TBI, traumatic brain injury

Research on the psychosocial consequences of epilepsy was performed for 184 patients. A total of 117 patients (63.6%) reported some negative impact of epilepsy on their lives. Among patients bellow 18 years old, only 1 patient reported some negative impact. Among patients aged 18 or older, 116 (76.8%) reported some negative impact of epilepsy

(Table 2). Presence of perceived negative impact of epilepsy was positively related to female sex ( $p=0.02$ ) and to a lower family income ( $p=0.02$ ) but not to age of onset ( $p=0.6$ ), polytherapy ( $p=0.8$ ), seizure control ( $p=0.5$ ) or epilepsy due to structural causes as opposed to epilepsy of unknown cause (0.5).

**TABLE 2** – Negative impact of epilepsy on psychosocial aspects of adult patients

LIFE ASPECT	NUMBER	%
<b>Family life</b>	<b>76</b>	<b>50.3</b>
Incomprehension	26	17.2
Overprotection	30	19.9
Conflict	45	29.8
Rejection	10	6.6

LIFE ASPECT	NUMBER	%
<b>Professional Life</b>	<b>71</b>	<b>47</b>
Government benefit	15	9.9
Unfair dismissal	22	14.6
Difficulty in relationships with colleagues	7	4.6
Difficulty in finding employment	41	27.3
Abandonment of employment due to the risks involved	13	8.6
Redeployment	3	2
<b>Locomotion</b>	<b>46</b>	<b>30.5</b>
Lack of autonomy	49	32.7
Inability to drive	13	8.7
<b>Leisure</b>	<b>46</b>	<b>30.4</b>
Lack of motivation	32	21.2
Restricted circle of friends	14	9.3
<b>School life</b>	<b>34</b>	<b>22.5</b>
Drop in school performance	22	14.6
School dropout	20	13.2
<b>Affective Life</b>	<b>29</b>	<b>19.2</b>
Divorce	7	4.6
Sexual difficulties	6	4
Difficult relationships	15	9.9
<b>Prejudice</b>	<b>48</b>	<b>31.8</b>
<b>Low self-esteem</b>	<b>48</b>	<b>31.8</b>

## DISCUSSION

This study is the first to describe the clinical and psychosocial implications of focal epilepsy in the state of Alagoas. To this end, patients enrolled at an University Hospital underwent a broad analysis including a careful clinical interview based on a semi-structured questionnaire and complementary tests performed in accordance with the capabilities of the local health system. The data provides the first results

of an effort to understand the clinical forms, etiology and psychosocial implications of epilepsy in patients attending the public health system of the state.

In our study population, the rate of illiteracy (18.8%) was similar to than that reported in Alagoas for people older than 10 years old (18.4%), and the frequency of patients with a higher education level (4.7%) was lower than that reported in the state (5.7%). Kanno and collaborators compared data on the education of 362 patients with epilepsy and 362

control subjects and reported that the epilepsy patients had significantly higher frequency of illiteracy (10.2 and 5% respectively) and a lower frequency of high education level (6.6 and 15.5%).<sup>10</sup> In our study both results were not consistent with the literature as were almost the same results found in the local population. Family income, however, was considerably lower than that reported for Brazil population where about 50% of people earn more than 150 dollars. Although the study was conducted in one of the poorest states in the country, it is surprising that 12.5% of patients did not have any source of family income. There is a consistent relationship between poverty and poor health, as poverty influences risk exposure, disease severity and the use of treatments.<sup>11</sup>

The average age of seizure onset we reported is from young adults and there was no trend to an increased incidence in older patients, as demonstrated by studies in developed countries.<sup>12</sup> Jallon and colleagues demonstrated that in Martinique, 50.7% of patients had the first seizure, provoked or not, after 40 years of age.<sup>13</sup> Valencia and colleagues, studying the causes of seizures in Recife noted that of 210 patients, 53.3% had age of onset between 15 and 45 years old and 46.7% after 45 years of age.<sup>14</sup> These studies, however, did not restrict the analysis to epilepsy cases, which are defined as recurrent unprovoked seizures. In the study by Valencia and colleagues, the age profile of patients surveyed was not described. In our study many of the patients were under the age of 45, which may have contributed to this lower onset profile.

It was possible to determine the cause of epilepsy in 104 patients (37.5%). Until the 1990s, the probable etiology of epilepsy had only been defined in about 30% of cases.<sup>15</sup> The proportion of cases with defined etiology was 30% in a Rochester study, 39% in Italy and 27% in Ecuador.<sup>16-18</sup> With the advent of MRI, the possibility of etiologic diagnosis increased greatly, such that about 85% of patients with refractory focal epilepsy had the etiology of epilepsy demonstrated by MRI.<sup>19</sup> Our population consists of

patients seen at a public hospital in a state that have scarce access to MRI in the public health system.

In this study, we found perinatal anoxia as the main etiological factor of epilepsy due to structural causes, in a similar proportion to that found in Italy during the 1970s (20%) and much higher than that reported in recent studies, even in developing regions as Ecuador (9%).<sup>17,18</sup> In Santa Catarina (SC), a Brazilian state with social indicators well above the state of Alagoas, the proportion was 0.8%.<sup>20</sup> Although the role of perinatal injuries in the genesis of epilepsy is controversial, our patients who were diagnosed with epilepsy after perinatal anoxia had a defined history of complications in childbirth and, in most cases, compatible imaging exam. These data thus seem to reflect local deficiencies in maternal and child health care. The second most common cause was mesial temporal lobe epilepsy (MTLE), the diagnosis of which was possible by performing MRI in some patients. Notably, 36 patients from the epilepsy of unknown cause group had clinical features suggestive of MTLE, but these cases could not be confirmed by MRI. If this suspicion had been confirmed, the MTLE would be responsible for 51 cases of epilepsy due to structural causes (29.5%), and as such would have been the major cause of epilepsy in these patients.

Brain-vascular disease is the leading cause of epilepsy in people over 60 years.<sup>21</sup> Despite the small number of people with the onset age over 60 years, stroke was the most frequent cause of epilepsy due to structural cause. Neurocysticercosis (NCC) is a disease of high prevalence in our country.<sup>22</sup> In other studies conducted in Brazil, NCC appears to be an important cause of epilepsy, eventually being responsible for 19% of cases in SC and 8.8% in Recife.<sup>14, 20</sup> In our study, however, the role of NCC as a cause of epilepsy was lower than in other states (5.8%). Pig farms are not common in Alagoas. According to the Brazilian Institute of Geography and Statistics (IBGE), the quantity of pigs in the state in 2008 was 150,578 heads (0.04 *per capita*), whereas it reached 7,846,398 heads in SC (1.28 *per capita*).<sup>8</sup>

The psychosocial consequences of epilepsy are of complex and variable etiology, and its evaluation is difficult and often neglected. Thus, the patient's perception about effects of epilepsy on aspects of daily life was incorporated into the clinical evaluation questionnaire. There is a model of theoretical distinction between the stigma that is felt (the shame and fear of discrimination) and the stigma that is experienced (real episodes of discrimination), but they are interrelated mechanisms in a process that can lead to serious repercussions on the quality of life of people.<sup>23</sup>

When asked, most patients reported suffering some negative impact of epilepsy, particularly in aspects of family life and professional life. The existence of family conflict in the cost of treatment was the most common complaint, which could be related to the low income of patients. People with epilepsy, in poverty, are significantly less likely to be taking medications and one possible reason is the acquisition cost.<sup>24,25</sup> The difficulty in finding employment was a common complaint in these individuals. Also a considerable proportion reported having suffered unfair dismissal because of epilepsy. The professional activity is an important factor in quality of life because, in addition to economic considerations, it contributes to the self-esteem of the individual. In this population, epilepsy appears to be an aggravator of economic conditions, restricting the possibilities of employment and generating family conflicts related to treatment cost.<sup>24,25</sup>

The restricted ability to drive cars is a relevant limitation to people with epilepsy.<sup>26</sup> In this population, lack of autonomy to get around was a much more frequent complaint than the impossibility of driving, which might result from the fact that most families do not have cars and use public transport or alternative means, such as bicycles. Still, epilepsy has a deleterious influence generated by the fear of walking alone outside the home, which could contribute to professional, educational and leisure restrictions. The main cause of interference in leisure time was the lack of motivation felt by the patient, which could relate to

the sense of stigma. Thus, 31.8% affirmed suffering prejudice and 31.8% reported low self-esteem.

Socioeconomic status and female gender have previously been related to lower quality of life in patients with epilepsy.<sup>27-32</sup> In part, that could be attributed to less accessibility to social and health care. In addition, female patients with epilepsy are exposed to specific biological and psychological factors as reproductive concerns. The relationship between quality of life and seizure control has been demonstrated by some studies, but it is challenged by other researches who showed that clinical variables are mediated by variables such as education and perception of limitations imposed by having epilepsy.<sup>25</sup>

This study is limited by the inherent deficiencies of the descriptive study design itself in a sample of patients attending a referral epilepsy center, and therefore the conclusions will require further validation through controlled and population-based studies. Many patients could not undergo the full complementary tests required to properly diagnose epilepsy causes, specially MRI.

The results of this study outline the profile of adolescents and adults with focal epilepsy who use public service in Alagoas. In addition to demographic and clinical data as etiologies in epilepsy due to structural causes, it describes the patient's point of view on the role of epilepsy in various aspects of their daily life. Thus, it is expected that these results will not only contribute to the knowledge of characteristics of epilepsy in Brazil and developing regions but also might be valuable in the structuring of better local care and research in epilepsy, including a broader approach to the role of epilepsy in individuals' lives.

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