

Factors Associated with the Employment Situation and Driving License of Patients with Epilepsy

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ABSTRACT

Introduction: It is estimated that approximately 50% of patients with epilepsy have difficulty finding employment. **Objective:** Evaluate the employment situation and driving license of patients with symptomatic or probably symptomatic focal epilepsy and correlate it with clinical and socio-demographic aspects. **Methods:** Ninety-two patients were classified into 3 groups: “employed”, “unemployed” and “retired/on leave”. The relationship between employment and socio-demographic aspects and those of epilepsy was studied, and also whether the patients were holders of national driving licenses. **Results:** Thirty-one (33.7%) of the patients were employed, 19 (20.7%) unemployed and 33 (35.9%) retired/on leave. Patients with formal education of less than 9 years predominated ($p < 0.05$) in the “retired/on leave” group and non-white patients were more frequently unemployed. Of 58 patients who lost their jobs, 27 (46.6%) reported that epilepsy was the main reason ($p < 0.05$). There was a significant relationship between the occurrence of ES at work and unemployment and “leave/retirement” ($p < 0.05$). There was no relationship between clinical aspects and the employment situation. Nineteen (33.9%) of the 56 surveyed reported being holders of driving licenses. **Discussion:** There was a high index of unemployment and retired/on leave individuals. There was a relationship between unemployment and the occurrence of ES at work and with a low scholastic level. **Conclusion:** The low scholastic level/professional qualifications and the stigma aggravated the employment perspectives of these individuals, contributing to their social exclusion.

Keywords: Epileptic seizures, epilepsy, employment, driving license, psychosocial aspects.

RESUMO

Fatores associados a situação laboral e licença para dirigir em pacientes com epilepsia

Introdução: Estima-se que aproximadamente 50% dos pacientes com epilepsia têm problemas para encontrar emprego. **Objetivo:** O objetivo desta pesquisa foi avaliar a situação laboral e a licença para dirigir de 92 pacientes com epilepsia focal sintomática ou provavelmente sintomática e, correlaciona-la a aspectos clínicos e sociodemográficos. **Resultados:** 31 (33,7%) pacientes estavam empregados, 19 (20,7%) desempregados, 33 (35,9%) afastados/aposentados. Os pacientes com maior escolaridade formal, da cor branca, e do gênero masculino estavam mais empregados (ANOVA; $p < 0,05$). 30 (46,1%) pacientes referiram que a epilepsia motivou a demissão. Houve relação significativa entre ocorrência de CE no trabalho com desemprego e afastamento/aposentadoria (χ^2 ; $p = 0,03$). Não houve relação entre aspectos clínicos da epilepsia e situação ocupacional. **Discussão:** Foram observados índices elevados de desemprego e afastamentos/aposentadoria. Houve relação entre desemprego e ocorrência de CE no trabalho, e baixa escolaridade e qualificação profissional. **Conclusão:** A baixa escolaridade/qualificação profissional e o estigma agravaram a perspectiva de empregabilidade dos indivíduos, contribuindo para a exclusão social.

Unitermos: Crises epilépticas, epilepsia, emprego, licença para dirigir, aspectos psicossociais.

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INTRODUCTION

There are diverse etiologies for epilepsy with different types of evolution and gravity. One of the characteristics of epilepsy is recurrent epileptic seizures (ES), which are transitory and unpredictable and can produce a feeling of insecurity and also decrease the self confidence and autonomy of the individual.^{22,28}

It is known that depression, fear, rejection or overprotection by family members, discrimination at work, lack of professional qualifications and low scholastic level can be present in patients with epilepsy, compromising the independence and self esteem necessary to develop their role in society.^{5,18,22,28}

Thus a study of the occupational situation of patients with epilepsy involves an analysis of the characteristics of epilepsy, of psychosocial aspects and of the job market.

Some studies have reported that approximately 50% of patients with epilepsy have difficulty in finding and keeping down a job, and sub-employment and unemployment are greater amongst those with epilepsy than amongst the general population.^{5,8,9,15,23}

On the other hand some jobs offer risks to people with epilepsy and there may be a negative impact caused by the antiepileptic drugs, reducing their work performance.^{22,28}

Amongst the limitations to the autonomy of patients with epilepsy, the inability to drive and restrictions on getting a driving license influence the quality of life of these individuals.^{11,12,20}

No matter how much the health professionals involved in treating patients with epilepsy concern themselves with the etiology, prognosis and treatment, some psychosocial factors are frequently neglected.²¹ In Brazil, as also in the international literature, there is insufficient information on patients with epilepsy in the productive stage of life and their occupational situation.^{17,21}

Thus the objective of the present survey was to study the occupational situation of patients with symptomatic or probably symptomatic focal epilepsy, evaluating its relationship with clinical and socio-demographic aspects, the occurrence of epileptic seizures at work, and epilepsy as a factor in losing one's job and taking out a driving license.

METHOD

Participants

Ninety-two consecutive adult patients were included in this study, all patients of the Neurology Clinic of the Celso Pierro Hospital & Maternity Hospital (PUC-Campinas), and diagnosed with symptomatic or probably symptomatic focal epilepsy, according to the International Classification of Epilepsy and Epileptic Seizures.¹⁰

Patients suffering from cognitive deficit that compromised their understanding of the questions or from other chronic incapacitating diseases were excluded.

The Ethics Commission for Research with Human Beings of PUC-Campinas approved the project, and the subjects signed an informed consent form.

Procedures

- a) An anamnesis to raise the data concerning the ES including starting age, type, frequency and control; use of AEDs; personal case history and comorbidities. The hospital files of the patients were used to obtain data from the electroencephalogram, computerized tomography and/or magnetic resonance of the brain in order to characterize the epileptic seizure.
- b) Questionnaire, elaborated by the authors, to obtain socio-demographic and occupational data: age, race and/or color (as referred to by the patient), scholastic level, professional qualifications, marital status, profession, current occupation, job (formal or otherwise), previous job, unemployment, leave or retirement, and whether they had a national driving license or not and if so, which category and how they got it.
- c) Information was also obtained from the patient concerning his/her perception of situations involving discrimination or prejudice at work. The patients were also questioned about a possible loss of job as a consequence of an ES, if they had been passed over for promotion and if they received orientation concerning possible risks at work attached to their epilepsy. They were also asked if they had informed their employer of their disease and, if they had a driving license, about their perception of possibly being involved in automobile accidents due to an ES.
- d) Neurological examination.

Data analysis

The following concepts were used in this study: *Employment* – daily activity with responsibility, remunerated or otherwise; *Formal employment* – registered employment or one that includes the payment of taxes; *Informal employment* – unregistered employment without payment of taxes; and *Home* – non-remunerated activity exclusive to the home.⁶

The occupational situations of the patients and the data concerning driving licenses were compared to those of the Brazilian population of the same gender, age and geographical region, obtained from the Brazilian Institute of Geography and Statistics (IBGE).¹⁴

All the patients presented focal epilepsy, classified as: epilepsy of the temporal lobe or epilepsy in other locations according to the criteria of the International Classification of Epilepsy and Epileptic Seizures.¹⁰

The epilepsy was considered under control in cases where they had been no ES for the last 12 months.¹⁶

The relationship between the socio-demographic and occupational aspects and the clinical aspects was studied. The Statistical Packages for Social Sciences program (SPSS, version 10.0) was used for the statistical analysis of the data, using parametric or non-parametric tests depending on the nature of the data, with a significance level of $p < 0.05$.

RESULTS

Socio-demographic, clinical and occupational aspects

Table 1 shows the data obtained for the socio-demographic and occupational aspects.

In this casuistry, the male gender was discretely, but not significantly, predominate (56.5% of the cases). The mean age was 43.2 (± 13.3). Individuals with a low formal scholastic level (≤ 8 years in 60.8% of the cases) were predominate, and only 21 (22.8%) of the patients referred to any technical professionalizing course.

Table 2 shows the mean age when the first epileptic seizure occurred, the type of seizure (generalized and focal with generalization or focal without generalization), occurrence of seizures during the previous 12 months, psychiatric co-morbidities, occurrence of ES at the place

or time of work and the reason for losing their job according to the occupational situation.

Twenty-seven (27.2%) of the patients had suffered no ES during the previous year, and of those in the active phase of epilepsy, 15 (22.4%) showed a frequency of at least one seizure a month. Most of the patients informed good adherence to the treatment and 65 (70.7%) of the patients used mono-therapy.

Post-seizure symptoms (tiredness, mental confusion, headache and/or muscle pain) were referred to by the majority of the patients, although only 14 (20.8%) referred to them lasting more than 10 minutes.

Altered neurological exams were observed in 15 cases. Fifty-nine (64.1%) of the patients presented co-morbidities, predominating psychiatric disturbances, which were present in 35 (59.3%) of the cases.

At the moment of the evaluation, 31 (33.7%) of the individuals were employed, with a mean average employment time of 6.8 years. The employment was formal in 20 cases. Leave and/or retirement were referred to in 33 (35.9%) of the patients, with a mean retirement time of 9 years. Nineteen (20.7%) were unemployed (mean time of 7.1 years), and amongst the unemployed, 63.1% had no professional qualification for specific functions obtained by courses or training.

Table 1. Socio-demographic data according to the occupational situation of 92 patients with focal epilepsy.

Socio-demographic data	Total	Retired/leave	Unemployed	Employed	Home	p
	N = 92	n=33 (35.9%)	n=19 (20.7%)	n=31 (33.7%)	n=9 (9.8%)	
Mean age in years (standard deviation)	43.2 (± 13.3)	47.8 (± 16.3)	41.6 (± 11.5)	38.5 (± 8.7)	45.9 (± 12.9)	0.017 ^{1*}
Gender						
Feminine	40 (43.5%)	13 (39.4%)	8 (42.1%)	11 (35.5%)	8 (88.9%)	0.034 ^{2*}
Masculine	52 (56.5%)	20 (60.6%)	11 (57.9%)	20 (64.5%)	1 (1.1%)	
Race						
White	51 (55.4%)	22 (66.7%)	5 (26.3%)	19 (61.3%)	5 (55.6%)	0.034 ^{2*}
Non white	41 (44.6%)	11 (33.3%)	14 (73.7%)	12 (38.7%)	4 (44.4%)	
Scholastic level						
≤ 8 years	56 (60.9%)	26 (78.8%)	9 (47.4%)	15 (48.4%)	6 (66.7%)	0.044 ^{2*}
> 8	36 (39.1%)	7 (22.2%)	10 (52.6%)	16 (51.6%)	3 (33.3%)	

¹ One-Way Anova considering the retired/leave, unemployed and employed groups; ² χ^2 test; * $p < 0.05$.

Table 2. Clinical data of focal epilepsy according to the occupational situation of 92 patients.

Clinical data	Total	Retired/leave	Unemployed	Employed	Home	p
	N = 92	n=33 (35.9%)	n=19 (20.7%)	n=31 (33.7%)	n=9 (9.8%)	
Mean age for the 1 st ES	20.7 (14.1)	22.2	23.39	16.42	22.75	0.314 ¹
Type of ES						
Generalized or with gen.	50	17	13	20	6	0.579 ²
Focal	33	16	6	11	3	
Occurrence of seizures in last 12 months						
With seizures	67 (72.8%)	25	13	22	7	0.633 ²
No seizures	25 (27.2%)	8	6	9	2	
Psychiatric co-morbidities	35	16 (48.4%)	8 (42.1%)	7 (22.5%)	4 (44.4%)	0.188 ²
Reason for losing job (n=58)						
Epilepsy	27	5	14	8	-	0.018 ²
Others	31	16	5	10	-	
Occurrence of ES at work	36	18 (54.5%)	13 (68.4%)	5 (16.1%)	-	0.000 ²

¹ One-Way Anova; ² χ^2 test; ES = epileptic seizure.

Twenty-one individuals (22.8%) belonging to the retired/on leave or unemployed groups, had never had a job.

Relationship between socio-demographic aspects and occupational situation

With respect to age there was a significant difference between the groups (ANOVA, $p=0.017$), shown to be significant between the employed and retired/on leave groups by the post hoc Duncan test (Table 1).

With respect to gender there were 8 women to one man in the *Home* group, but no significant differences with respect to gender in the other groups.

With respect to the job situation there was a significant difference between 'whites' and 'non-whites' (χ^2 , $p=0.034$), with more 'non-whites' than 'whites' in the unemployed group.

The patients with lower scholastic level were present in greater proportions in the retired/on leave group than those with more than 8 years of formal education (χ^2 , $p=0.044$).

A greater level of scholastic level was found in younger individuals (ANOVA; $p=0.002$) who denominated themselves as white (ANOVA; $p=0.008$) and in those with professional qualifications (ANOVA; $p=0.002$).

Relationship between the aspects of epilepsy and the occupational situation

There was no significant relationship between the job situation and the age of the first seizure, type of seizure, occurrence of seizures within the last 12 months or psychiatric co-morbidities (Table 2). There was also no significant difference with respect to employment between the patients with epilepsy of the temporal lobe and those with epilepsy in other locations (χ^2 , $p=0.579$).

No relationship was observed between losing a job and age, time with epilepsy or frequency of ES (ANOVA; $p>0.05$).

Of the 58 (63.0%) patients who lost their jobs, 27 (46.1%) referred to epilepsy as the reason for losing their

jobs. When the reasons for losing jobs related to epilepsy were compared with other reasons, epilepsy was cited in greater proportions amongst the unemployed patients than by those in other groups (χ^2 ; $p=0.018$) (Table 2).

There was a non-significant tendency for the occurrence of co-morbidities, progressively greater amongst the unemployed, employed and on leave or retired individuals (χ^2 ; $p=0.188$) (Table 2).

The occurrence of ES at work (time/place of work) was more common amongst the retired/on leave and unemployed individuals than amongst the employed (Table 2).

Amongst the patients who had suffered ES at work (time/place of work), 23 (34.3%) referred to difficulty in their job activities or reduced productivity during the period after the seizure. This phase had an average time greater than 10 minutes in 44.7% of the cases.

Short term absenteeism due to epilepsy (current or previous job) was referred to by 24 (19.6%) of the patients.

Thirty six (47.3%) of the patients mentioned that the employer and/or colleagues knew nothing about epilepsy. Rejection at work (employer and/or colleagues) was referred to by 11 (15.2%) of the patients.

Some work and/or unemployment related personal aspects were spontaneously referred to by the patients, such as: insecurity, fear of having an ES or embarrassment with respect to colleagues (30.8%); unsatisfactory salary (69.1%); passed over for promotion or salary increase due to epilepsy (8.6%) and that working "helps" the quality of life and "appeases" the epilepsy (30.8%).

National Driving License

Fifty six patients were questioned about having a valid driving license and Table 3 shows the data concerning age, gender, time with epilepsy and the number of cases with controlled ES.

There were more male patients with valid driving licenses ($p=0.001$). Nineteen (33.9%) of the individuals had valid driving licenses and 2 developed remunerated

Table 3. Socio-demographic and clinical data and valid driving license of 56 patients with focal epilepsy.

Socio-demographic and clinical data	With valid driving license N=19	Without valid driving license N=37	<i>p</i>
Gender			
Masculine	17 (89.5%)	15 (40.5%)	0.001 ¹ *
Feminine	2 (10.5%)	22 (59.5%)	
Mean age (years)	43.9	42.58	²
Mean time with epilepsy (years)	18.5	22.1	²
Controlled epilepsy	8 (42.1%)	11 (29.7%)	0.116 ¹
Omission of disease in obtaining driving license	14 (73.6%)	-	
Reason for not requesting driving license			
Fear due to epilepsy	-	24 (64.8%)	
Others not related to epilepsy	-	13 (35.1%)	

¹ χ^2 test; ² t test; * $p<0.05$.

work using their driving licenses. Eleven of the patients had been involved in automobile accidents, but only one referred to a relationship between the accident and the occurrence of an ES.

Table 3 also reports aspects such as the omission of information concerning the epilepsy in order to take out a driving license and also reasons for not taking one out.

DISCUSSION

Socio-demographic aspects and the occupational situation

Individuals in the productive phase of life, diagnosed with symptomatic or probably symptomatic focal epilepsy, difficult to control in the majority of cases, were included in this study (about 75%).

Only about 30% of the patients were employed at the time of the survey, values below those of the Brazilian population in the same age range¹⁴ and of other studies concerning patients with epilepsy.^{2,3,5,19,21,26} The predominance of individuals with non-controlled epilepsy in the present casuistry could be an important factor in these findings.

The formal employment rate observed was also below that of the Brazilian population.¹⁴

There was a significantly greater number white race individuals employed, when compared to non white individuals. No significant difference was observed with respect to color and/or race of the patients when compared with the data for the Brazilian population for the same geographical region.¹⁴ In Brazil the employment rate for the dark-skinned and negro members of the population is lower than for the rest, but in the present casuistry it was even lower.¹⁴ A low formal scholastic level and little professional qualification was also observed amongst this group of patients in proportions similar to that of the Brazilian population¹⁴ and of other studies with patients with epilepsy.^{2,19,21,26}

White married patients with a higher formal scholastic level or professional qualifications showed a higher employment rate. It is well known that amongst the fundamental factors for getting and keeping a job are the formal scholastic level and professional qualifications in the area.

On the other hand patients with epilepsy may have less conditions to maintain their studies and to qualify;⁹ some patients related prejudice on the part of teachers and colleagues as a blocking factor to the continuation of their studies.

In the present study, approximately 50% of the unemployed patients had no professional qualifications, which contributed to their unemployment.

Approximately half of the employed patients had not informed their employer about their health situation, other studies suggesting that such individuals did not inform their employers for fear of discrimination.^{22,28}

High levels of absenteeism were observed, mostly short term. To the contrary, other studies have referred to long term absenteeism as being more frequent in patients with epilepsy.¹⁸

This population showed a high level of retired individuals or of those on leave, higher than the mean value for that region of Brazil¹⁴ or found in other studies on patients with epilepsy.^{19,26} This aspect suggests, at least in part, an employment problem with this group of individuals. It has been questioned if part of the leaves and/or retirements were due to insistence by the patients and of his/her family members, in obtaining the benefit, more as a complement to the salary than due to a real incapacity to work.^{7,8}

In this study the patients reported their epilepsy as the most frequent reason for losing a job, suggesting that discrimination at work is one of the main barriers to patients with epilepsy finding and maintaining a job.^{5,9,18,21,22,23,28} Nevertheless recent studies have distinctly shown that patients with their ES under control are in a more favorable situation.^{3,17}

Relationship between the clinical aspects and occupational situation

There was no relationship between the type of ES and the occupational situation. This data is similar to that referred to by Salgado & Souza¹⁹ but distinct from the findings of other studies.^{6,7,13}

It is known that the control of the ES is an important factor in employability,^{9,17,22} although in the present study no significant difference was found between the employed/unemployed situation and the control or otherwise of the ES. O'Donoghue et al. (1999¹⁸) observed that 34% of the patients with an elevated ES frequency were unemployed, as compared to 11% of those in a seizure remission period.

The occurrence of ES at work, prolonged post-seizure period and difficulty in returning to work with the same productivity were referred to by the patients as important factors in the stigma on the part of employers and work colleagues and also in compromise of their employability. Studies suggest that the discomfort of having a colleague with epilepsy, considering the impact of the unpredictability of the ES, is the factor most contributing negatively to the integration of these individuals at work.^{5,8,13}

It is known that patients with non-satisfactorily controlled epilepsy, but who manage to live with a certain autonomy and who have some type of social and occupational activity, present better quality of life, reinforcing the aspect

that work implies in a sense of being useful and of being of value.^{2,12,19,20,21,22,28} The social and legal dilemmas of people with epilepsy can sometimes be more challenging than the ES themselves and their treatment.^{25,27}

National driving license

Driving a vehicle is a factor facilitating mobilization in a person's daily activities, and especially for going to work.

As expected considering the casuistry with difficult to control epilepsy predominating, there was a low prevalence of patients with valid driving licenses, particularly amongst the feminine gender, when compared with the Brazilian population as a whole¹⁴ of the same age range and international data.^{22,24}

The patients were unaware of the pertinent Brazilian legislation, and the main reason for not trying to obtain a driving license was fear of an ES leading to an accident.

Being forbidden to drive leads to restrictions in autonomy, to employment and to individual freedom.^{1,11,12,20} The *ad hoc* commission of the International League Against Epilepsy recommends permission to drive for individuals with their ES controlled for at least 1 year and for specific epileptic syndromes^[11]. In most countries, including Brazil, there are laws restricting driving licenses to individuals with epilepsy.^{1,11,22,24}

There is controversy concerning the risk of accidents for these patients. In patients with complex or generalized ES, or even those free of ES for a prolonged period, a greater occurrence and gravity of accidents is described than for the rest of the population^{1,2,20,24} although in a longitudinal study, it was distinctly stated that accidents caused by SE were rare and not very serious.⁴

In the present study, although 11 patients had been involved in automobile accidents, the occurrence of ES was apparently only determinant in one case.

In the present study 40% of the patients omitted informing the examining doctor of the presence of the disease in the process of obtaining or renewing their driving licenses, a value inferior to that found in other studies suggesting a greater tendency for individuals to hide the occurrence of ES and epilepsy from the examining doctor, in an attempt to obtain permission to drive.^{1,20}

CONCLUSIONS

Epilepsy is associated with an elevated proportion of unemployment, leave and/or retirement. In the present study the main factors connected to unemployment were the occurrence of ES at work and a low formal scholastic level.

Public policies directed at informing and demystifying the relationship between epilepsy and work are required in order to conquer a better quality of life for individuals with epilepsy.

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