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Employment and Quality of Life in Mesial Temporal Lobe Epilepsy with Hippocampal Sclerosis: is there a change after surgical treatment?

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ABSTRACT

Purpose: The aim of this study was to evaluate in patients with mesial temporal lobe epilepsy (MTLE) with hippocampal sclerosis (HS): (1) employment patterns before and three years after epilepsy surgery and their impact in Quality of Life (QOL); (2) demographic and clinical variables associated with employment. **Methods:** Data from 58 patients with diagnosis of refractory MTLE with HS who had corticoamygdalo-hippocampectomy were analyzed. The subjects answered to Brazilian validated version of the Epilepsy Surgery Inventory (ESI-55) before, and three years after surgery. In a semi-structured interview, sociodemographic and clinical characteristics were obtained. Changes in employment after surgery were classified in one of the three categories: (i) *improvement status*: those who were unemployed, no-formal employed, students, housewives and subjects who have never worked to employed category; (ii) *unchanged status*: no change in occupation; this category included subjects who were employed before and after the surgery, housewives, students, and the group who remained unemployed, receiving ill-health benefits or retired after the surgical treatment; and (iii) *worsened status*: loss of employment. **Results:** Employment status did not show any significant change after surgery: in 51 (87.9%) it remained unchanged, in six (10.3%) it improved, and one patient (1.7%), who was employed before the surgery, retired after that. In a subgroup of 22 patients employed after surgery, ten (45.5%) were seizure-free, seven (31.8%) had only rare auras, and five (22.7%) had seizures. In the group of improvement, 12 patients (70.5%) had no-formal employment and five (29.5%) had a formal job before surgery. After three years, 14 (63.6%) of 22 subjects were formally employed. Our data suggested that the employability was strongly correlated ($p < 0.05$) with a positive perception of health-related quality of life measured by ESI-55, before and after surgical evaluation. **Conclusion:** Our study demonstrated in a homogeneous group of MTLE with HS, a modest, but positive relationship between surgical outcome and work gain, and that QOL had strong correlation with the fact of being employed.

Key words: mesial temporal lobe epilepsy, hippocampal sclerosis, employment, quality of life, Epilepsy Surgery Inventory (ESI-55), surgery.

RESUMO

Emprego e qualidade de vida na epilepsia do lobo temporal mesial com esclerose do hipocampo: há uma mudança após a cirurgia?

Objetivo: Avaliar o estado empregatício e a qualidade de vida (QV) de indivíduos com epilepsia do lobo temporal mesial (ELTM) com esclerose do hipocampo (EH) antes e três anos após a realização de corticoamigdalohipocampectomia e verificar as variáveis demográficas e clínicas associadas ao emprego. **Metodologia:** 58 pacientes com ELTM com EH submetidos a corticoamigdalohipocampectomia foram avaliados

antes e três anos após a cirurgia. Todos responderam ao *Epilepsy Surgery Inventory* (ES-I55) – versão brasileira como medida da QV, bem como a um breve questionário contendo dados sociodemográficos e clínicos. Alterações na situação de emprego após a cirurgia foram classificadas do seguinte modo: (i) *melhora*: indivíduos desempregados, com emprego não-formal, estudantes, donas-de-casa e aqueles que nunca haviam trabalhado e que estavam empregados três anos após a cirurgia; (ii) *nenhuma mudança*: aqueles que não obtiveram modificações em sua situação ocupacional. Esta categoria compreendeu indivíduos que permaneceram empregados, continuaram com atividades domésticas, estudantes, em auxílio doença, aposentados e os que nunca trabalharam; e (iii) *piora*: perda do emprego. **Resultados:** A situação de emprego não mudou significativamente após a cirurgia: 51 (87.9%) permaneceram com o mesmo estado empregatício anterior à cirurgia, seis (10.3%) tiveram melhora, e um paciente (1.7%), que estava empregado antes da cirurgia, aposentou-se. No subgrupo dos 22 pacientes empregados após três anos, dez (45.5%) estavam livres de crises, sete (31.8%) tinham apenas auras esporádicas e cinco (22.7%) permaneceram com crises. No grupo que obteve melhora, 12 pacientes (70.5%) eram autônomos antes da cirurgia e cinco (29.5%), tinham emprego formal. Na avaliação do terceiro ano após cirurgia, 14 (63.6%) dos 22 indivíduos conseguiram um emprego formal. Nosso estudo verificou que a QV manteve relação estatística positiva com o estado de trabalho ($p < 0.05$). Aqueles que exerciam atividade remunerada tinham percepção mais positiva sobre sua QV, medida pelo ESI-55, antes e após o tratamento cirúrgico. **Conclusão:** Nosso estudo mostrou mudança modesta, mas positiva quanto à situação empregatícia após a cirurgia, bem como a importância de atividade produtiva para a QV, em um grupo homogêneo de indivíduos com ELTM e EH.

Unitermos: Epilepsia do lobo temporal mesial, esclerose do hipocampo, emprego, qualidade de vida, *Epilepsy Surgery Inventory* (ESI-55), cirurgia.

INTRODUCTION

Multiple factors determine the quality of life (QOL) experienced by patients with epilepsy. Being employed is an important issue for self image, self esteem and QOL.^{7,15} Working and earning a living are external signs of integration into the acceptance by others in society.¹⁶ The World Health Organization also recognizes the importance of employment as a part of social health, and therefore improving the QOL.

The consistent nature of employment problems (e.g. unemployment, underemployment, promotions) among people with epilepsy have revealed a complex interrelationship, which cannot be reduced by the seizure severity.¹⁶ The lack of education and information, family support, social isolation, fear and discrimination of the employers appears to influence the employment status in epilepsy.⁴

Surgery is an effective treatment for mesial temporal lobe epilepsy (MTLE) associated with hippocampal sclerosis (HS).⁹ It has been estimated that 60 to 85% of patients are seizure free after this procedure, at least in the short term.^{13,20}

Surgical candidates often identify improvement in employment as a major expectation.^{19,22} Despite the lack of consensus regarding the net effect of epilepsy surgery on employment rates, most investigators agree that seizure-free patients have a better level of employment.^{2,6,18}

Methodological problems further contribute to different interpretations about the employment gains after surgery. Investigators have often grouped the employed with unemployed in these analysis of improvement rates, making it impossible to determine which factors influence the outcome. Students and homemakers have been grouped

with employed or unemployed in analysis, and level of employment (part-time versus full-time) and changes in job (e.g. promotion) after surgery may not be considered.¹⁷

The aim of this study was to evaluate in patients with MTLE with HS: (1) employment patterns before and three years after epilepsy surgery and their impact in QOL; (2) demographic and clinical variables associated with employment.

METHODS

1 Subjects and evaluation

Data from 58 patients with diagnosis of refractory MTLE with HS who had corticoamygdalohippocampectomy performed at UNIPETE/UNIFESP were analyzed.

Diagnostic pre-operative procedures included 1.5T MRI with T1- and T2-weighted images in axial, coronal, and sagittal planes. MRI scans were qualitatively evaluated for the presence of hippocampal atrophy and signal alterations indicative of HS represented by signal hypointensity on T1-weighted inversion recovery and hyperintensity on FLAIR sequences. No patients were included in the present study if MRI indicated lesions outside the mesial temporal lobe region or if lesions other than HS were identified. Patients having normal MRI scans were also excluded. Left or right temporal lobe seizure origin was further established via scalp/sphenoidal video-electroencephalographic monitoring.

The subjects answered the Brazilian validated version of the Epilepsy Surgery Inventory -ESI-55¹ in order to assess the QOL before and three years after surgery. In a semi-structured questionnaire patients were asked to answer questions related to psychosocial issues, like educational level, employment status, duration of epilepsy, and seizure outcome three years after surgical treatment.

2 Employment status

Employment information was registered for each patient before and three years after surgery. The patients were classified in three groups: (A) those who had an active work based on monthly income (formal or no-formal employment); (B) those unemployed, receiving ill-health benefits or retired, individuals who were identified as inactive; and (C) others who were students, housewives or subjects that have never worked.

Change in employment after surgery was classified in one of the three categories: (I) improvement status: those who were unemployed, no-formal employed, students, housewives and subjects who have never worked-to employed category; (II) unchanged status: no change in occupation; this category included subjects who were employed before and after the surgery, housewives, students, and the group who remained unemployed, receiving ill-health benefits or retired after the surgical treatment; and (III) worsened status: loss of employment.

Clinical characteristics

The seizure outcome at the third year after surgery was assessed by classifying patients in one of three groups: (1) seizure-free; (2) auras only, and (3) seizures. The duration of epilepsy was classified in three groups: (1) one to 15 years; (2) 16 to 30 years, and (3) over 30 years.

Statistical analysis

The association between occupational level and QOL was explored by t-Student test. Analysis of variance (ANOVA) and Fisher tests were used to determine the association between demographic and clinical variables and occupational level. For statistical analysis *p values* <0.05 were considered statistically significant.

RESULTS

1 Characteristics of the sample

Data from 58 subjects, 34 (56.6%) women and 24 (41.4%) men, mean age of 35.5 and 26.7 years of epilepsy, respectively, were analyzed. Their educational level was: 31 (53.4%) primary and 27 (46.6%) secondary school or higher education. Thirty-nine (67.2%) had left, and 19 (32.8%) right MTL with HS. At the third year after epilepsy surgery, 29 (50.0%) of the patients remained seizure-free, 13 (22.4%) had only rare auras and 16 (27.6%), persistent seizures. The employment status of responders is summarized in Table 1.

Employment status did not show a significant change after surgery: in 51 (87.9%) it remained unchanged; in six (10.3%) it improved; and one patient (1.7%), who was employed before the surgery, retired after that.

In the group which improved, composed by 22 patients, four had never worked before surgery, and two who received

ill-health-benefits at baseline returned to work. Twelve patients (70.5%) had no-formal employment and five (29.5%), a formal employment before surgery. After three years, fourteen (63.6%) had a formal employment.

The outcome of employment status and seizure frequency at the third year was the following: In *group I* (22 patients who were employed at the third year), 10 (45.5%) were seizure-free, seven (31.8%) had only auras, and five (22.7%) remained with seizures. In *group II* (24 subjects, characterized as inactive) 17 were receiving ill-health benefits, and seven were retired at the baseline and after surgical treatment, ten (41.6%) had seizures, and three (12.5%), only auras. At third year, nine (75%) subjects of 12 who were classified as *group III* (others) were seizure-free; among these, five (41.6%) were housewives and seven (58.4%) remained unemployed.

The duration of epilepsy, age, side of the lesion and educational level were not associated with employment status. A strong correlation was identified between QOL and employment status, showing better QOL scores before and after surgery in the employed group. At baseline evaluation, six of 11 domains were associated with better QOL, and after surgery, eight of 11, as shown in Tables 2 and 3.

Table 1. Employment status and surgical treatment

Employment status N=58	Before surgery	After surgery
A – Employed	17 (29.3%)	22 (38.0%)
B – Unemployed, receiving ill-health benefits, retired	25 (43.1%)	24 (41.4%)
C – Other*	16 (27.6%)	12 (20.6%)

* Other: students, housewives, and subjects that had never worked.

Table 2. Employment status and QOL before surgical treatment*

ESI-55 domains	Group A	Group B	Group C	<i>p values</i>
	Mean scores N=17	Mean scores N=25	Mean scores N=16	
Physical Function	91.2	85.6	90.0	0.477
Role Limitations due to Physical Problems	82.4	53.6	75.0	0.021**
Pain	71.7	54.8	67.3	0.044**
Role Limitations due to Emotional Problems	76.5	41.6	65.0	0.008**
Health Perception	58.2	58.1	56.1	0.269
Social Function	70.3	54.2	72.2	0.049**
Cognitive Function	63.9	47.3	60.8	0.089
Role Limitations due to Memory Problems	78.8	54.4	79.6	0.020**
Emotional Well-being	55.5	47.0	60.5	0.185
Energy/Fatigue	67.1	48.3	61.3	0.031**
Overall Quality of Life	54.7	56.0	60.6	0.508

* **Group A:** who had an active work; **Group B:** unemployed, receiving ill-health benefits or retired; **Group C:** students, housewives or subjects that have never worked. ** *p*<0.05 was considered statistically significant.

Table 3. Employment status and QOL after surgical treatment*

ESI-55 domains	Group A	Group B	Group C	<i>p</i> values
	Mean scores N=22	Mean scores N=24	Mean scores N= 12	
Physical Function	97.3	89.8	92.9	0.158
Role Limitations due to Physical Problems	97.3	67.5	93.3	0.001**
Pain	75.6	69.9	77.7	0.583
Role Limitations due to Emotional Problems	91.8	59.2	75.0	0.007**
Health Perception	85.1	70.0	86.8	0.021**
Social Function	89.8	66.4	90.1	0.013**
Cognitive Function	70.0	54.0	61.1	0.194
Role Limitations due to Memory Problems	83.6	51.7	73.3	0.011**
Emotional Well- being	81.3	55.2	68.0	0.004**
Energy/Fatigue	80.7	62.1	75.0	0.022**
Overall Quality of Life	80.6	64.1	66.4	0.014**

* **Group A:** who had an active work; **Group B:** unemployed, receiving ill-health benefits or retired; **Group C:** students, housewives or subjects that have never worked.
** $p < 0.05$ was considered statistically significant.

DISCUSSION

This study revealed a modest, but important net employment gains after surgical treatment. After three years, the number of patients in each group did not change substantially, which is consistent with other researches in developed countries.^{6,8} However, employment rates changed from 29.3 to 38.0%, and the proportion of subjects who had a formal employment increased from 36.4 to 63.6%, indicating a favorable outcome. According to other reports, surgery had a significant positive impact on psychosocial outcomes in terms of employment, independent living, driving, and financial independence.^{3,11,14}

Among our 17 patients who received disability benefits before surgery, only two returned to work. The study of Reeves et al.¹⁴ showed that these patients were less amenable to occupational gains or recovery. Another important difficulty is that postoperative rehabilitation in epilepsy differs from the usual concept of rehabilitation since these individuals must learn to live without help of an accustomed handicap.¹⁷ The acquisition of a new vocational role may be tangible evidence that the patient is learning to “become well” and reentering society.²¹

In our series, the demographic and clinical characteristics like age, schooling, duration of epilepsy and side of the lesion did not influence employment status. In the literature, age at surgery was a variable that significantly differed between those who remained unemployed.¹⁷ The continually unemployed patients tended to have been younger at onset of seizures, and had showed a longer duration of disease.² Because epilepsy is a chronic

disorder that usually begins in childhood, it often has huge repercussions on school achievement, level of education and professional orientation.⁸ On the other hand, the research of Chin et al.⁵ supported that side of surgery did not affect willingness to undergo surgery gain, but right-sided surgery was associated with more positive follow-up impact after 12 and 24 months. This finding may be related to verbal memory impairment following speech-dominant hemispheric resection.

The analysis of the employment group in our data showed that 45.5% were seizure-free, and 31.8% had only sporadic auras after the surgery. The finding of Sperling et al.¹⁷ (1995) confirmed that the presence of seizures hamper the employability in people with temporal lobe epilepsy who come to surgery. The relationship between postoperative seizure control and occupational status is the fact that most convincingly demonstrates the direct role that seizures play in limiting employment. The importance of postsurgical seizure control in determining work outcome is further emphasized by other reports.^{2,6,10-11,14,18}

Our results suggested that the employability was strongly correlated with a positively perception of health-related quality of life (HRQOL) measured by ESI-55, even in preoperative evaluation. Full employment gain is a good predictor of overall well-being, patient satisfaction postoperatively, and an important factor in psychosocial adjustment.^{16,18}

Health Perception, Emotional Well-being, and Overall Quality of Life domains were also statistically associated with employment status after three years. In epilepsy, the greatest levels of dysfunction are seen in domains of Mental Health and General Health.¹²

Although many studies focused the importance of employment on HRQOL, they do not use standardized measures to evaluate the correlation between the changes in QOL when people are employed. Our study demonstrated a positive and significant relationship between employment status and QOL in a homogeneous group of MTLE with HS.

Limitations of this investigation should be considered. The sample was modest in size, and long-term follow-up is needed to confirm the results and to provide more information regarding the employment difficulties. Future studies will investigate the complex influence of psychosocial issues, psychiatric comorbidities, and family dynamics on the employability.

CONCLUSION

Our study demonstrated in a homogeneous group of MTLE with HS, a modest, but positive relationship between surgical outcome and work gain, and that QOL had strong correlation with the fact of being employed.

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