

Employment status and epilepsy

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Abstract

Objectives: To determine the influence of epilepsy, namely, nature of seizures, effects of anti-epileptic drugs and social stigma on the employment status of patients with epilepsy.

Methods: A hospital clinic based cross sectional study was conducted over a period of one month among 217 non schooling adult patients with epilepsy attending the Neurology clinic, NHSL. An interviewer-administered questionnaire that derived information on disease characteristics and employment status was used.

Results: Nearly 37% of the patients was currently employed. Of the unemployed, 45% were previously employed and 55% were never employed. Under-employment was not reflected among the employed patients. Although performance at work revealed a gender difference ($p < 0.01$), absenteeism related to epilepsy did not. Age of onset, duration and stigma of epilepsy were significantly related to current employment status ($p < 0.01$). Stigma was the only disease characteristic that was associated with poor performance at work ($p < 0.01$) and was the commonest reason for losing jobs and for remaining unemployed. Seizure severity was associated only with absenteeism. Anti-epileptic-drug effects did not associate with any variable considered ($p > 0.5$). Although educational status was poor among the unemployed ($p < 0.01$), it could not be associated with early age of onset of epilepsy ($p > 0.05$).

Conclusions: More than one facet of the employment status was affected by epilepsy in the majority of patients, stigma being the major contributor.

Key words: epilepsy, employment, stigma

Introduction

Epilepsy is by far, the commonest serious neurological disorder affecting nearly 50 million people worldwide (1). It assumed the

fifth position among all neuro-psychiatric disorders that contributed significantly to the global burden of disease in year 2001 (2). In Sri Lanka, it accounts for 202.6 disability adjusted life years and has an incidence of 25.74 per 100,000 population (3).

Although physical manifestations of epilepsy are transient and rarely fatal, the psychosocial effects of the illness are long-term and potentially damaging. Employment is one such aspect that is affected from a diagnosis of epilepsy.

Legislation pertaining to employment largely restricts career choices of persons with epilepsy. Inadequate educational qualifications inevitable due to ill health further restrict their employability. In addition, low performance, high absenteeism and occupational accidents are found to interfere with the sustainability of an occupation in a patient. These, in addition to misconcepts of the illness among employers, hinder job opportunities even for those with well-controlled epilepsy (4).

Recurrent seizures, particularly during adolescence, impair the development of self-esteem, sense of identity and social skills of a person that could lead to school avoidance and social-isolation. Adverse effects of anti-epileptic drugs is another crucial factor which causes cognitive dysfunction resulting in irreversible damage to future prospects of education and employment (5). Independence and opportunities for friendships at work are also threatened in these patients by the social stigma attached to epilepsy (6).

Evidence strongly suggests that satisfactory seizure control, with minimum adverse drug effects and good social acceptance of epilepsy minimizes long-term effects on employment status (7).

In the absence of substantial evidence in Sri Lanka to support this statement, the objective of this study was to determine the influence of epilepsy on the employment status of patients with epilepsy.

Methodology

This study was carried out at the Institute of Neurology in the National Hospital Sri Lanka (NHSL), where outpatient neurology clinics are conducted on a daily basis. A preliminary inquiry revealed that nearly 25% of clinic attendees consisted of patients with epilepsy who were either regularly followed up or referred from other sources. Recruitment of patients to this study was restricted to those clinics conducted by one Consultant Neurologist.

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Patients over the age of 13 years were selected if the following criteria were fulfilled.

1. A confirmed diagnosis of epilepsy obtained from either the out patient clinic record or the diagnosis card,
2. A minimum period of six months since the first seizure,
3. Patients are on anti-epileptic drugs at the time of recruitment,
4. A seizure free period of at least 24 hours prior to the interview.

The Exclusion criteria were-

1. Regular medication (other than anti-epileptic drugs) known to affect the central nervous system. Such as, sedatives, anti depressants, anxiolytics, anti psychotics, anti Parkinsonian drugs (this excludes 'as needed' drugs),
2. Unable to give rational answers on their own (E.g. mental retardation) as judged by the principal investigator based on responses to the first five questions in the study instrument and three other general knowledge questions,
3. Co-morbid physically disabling illness (E.g. stroke, Parkinson's disease, multi system disorders).
4. School going patients

Eligible patients were enrolled into the study during a period of one month. This convenience sampling technique was adopted to overcome repetition of patients who usually visited the clinic on a monthly basis.

The study instrument was a modified version of several validated questionnaires that assessed employment status and disease characteristics (8, 9). Modification via focus-group-discussions was necessary, in order to overcome the differences between and within communities of diverse socio-economic and cultural backgrounds in Sri Lanka. Recall of past events was limited to reasonable time periods.

The principle investigator and three trained interviewers administered the pre-tested study instrument. An educational brochure named 'Enjoy life with epilepsy' was given to those consenting to participate. Confidentiality of data was ensured.

Results

The study population consisted of 112 (51.6%) males and 105 (48.4%) females. Their ages ranged from 15 to 78 years with a median age

of 34.1 years. Most (35.4%) of them were young (15-29 years) while a fewer (6.8%) belonged to elderly (60 years and over) category. The majority (153, 72.8%) were Sinhalese.

Table 1. Distribution of employed patients by work-related-activities and gender

Category	Female No. (%)	Male No. (%)	Total No. (%)
Performance at work in relation to epilepsy:			
Unsatisfactory	16 (59.2%)	15 (28.8%)	31 (39.2%)
Satisfactory	11 (40.8%)	37 (71.2%)	48 (60.8%)
Absenteeism in relation to epilepsy:			
High	6 (22.2%)	14 (26.9%)	20 (25.3%)
Low	21 (77.8%)	38 (73.1%)	59 (74.7%)
Total	27 (100.0%)	52 (100.0%)	79 (100.0%)

Employment status:

Seventy nine (36.4 %) Subjects were currently employed. Of the 138 currently unemployed 45% were previously employed and the balance 55% were never been employed.

Of the currently employed, most were in the clerical field (27.8%) followed by the labour force (26.6%). Only 6.3% occupied administrative / managerial posts and there were no professionals. Almost all occupied jobs were appropriate for their educational level depicting minimum under-employment. Of them, 34 (43.0%) possessed an adequate education level (G.C.E.O/Level was considered the minimum qualification).

Table 1 gives the distribution of currently employed patients by work- related activities and gender. Performance at work was based on self-appraisal of the patients work over the preceding 4 weeks. 'Unsatisfactory performance' included patients whose work was affected more than 50% by events related to epilepsy. 'Satisfactory performance' included patients whose work was affected less than 50% by events related to epilepsy or by events other than epilepsy. There was a statistically significant difference between males and females in relation to work

Table 2. Comparison of disease characteristics by current employment status

Disease Characteristic	Employed No. (%)	Unemployed No. (%)	Total No. (%)	Level of Significance
Age of onset:				
0- 19 years	47 (59.5%)	75 (57.2%)	122 (58.1%)	$\chi^2 = 11.85$; df=2 p = 0.003
20- 39 years	15 (18.9%)	46 (35.1%)	61 (29.0%)	
≥ 40 years	17 (21.5%)	10 (7.6%)	22 (10.5%)	
Duration of epilepsy:				
6months-9 years	38 (48.1%)	64 (48.9%)	102 (48.6%)	$\chi^2 = 12.9$; df=2 p = 0.002
10 - 19 years	19 (24.0%)	45 (34.4%)	64 (30.9%)	
≥ 20 years	22 (27.8%)	22 (27.8%)	44 (21.0%)	
Seizure severity:				
No seizures	21 (58.2%)	35 (26.7%)	56 (26.7%)	$\chi^2 = 3.34$; df=1 p = 0.068
1 - 4 per year	37 (46.8%)	45 (34.3%)	82 (39.0%)	
5 - 20 per year	14 (17.7%)	33 (25.2%)	47 (22.4%)	
> 20 per year	7 (8.9%)	18 (13.7%)	25 (11.9%)	
Seizure activity:				
Remitted epilepsy	10 (12.7%)	14 (18.3%)	34 (16.2%)	$\chi^2 = 0.19$; df=1** p = 0.664
Active epilepsy				
Last week	26 (32.9%)	45 (34.3%)	71 (33.8%)	
Last month	24 (30.4%)	45 (34.3%)	69 (32.9%)	
Last 2 years	19 (24.1%)	27 (20.6%)	46 (21.9%)	
Anti-epileptic Drug effects:				
No side effects	64 (81.0%)	108 (82.4%)	172 (81.9%)	$\chi^2 = 0.07$; df=1** p = 0.794
Side effects				
Few	4 (5.0%)	14 (10.7%)	18 (8.6%)	
Some	8 (10.1%)	6 (4.6%)	14 (6.6%)	
Many	3 (3.8%)	3 (2.3%)	6 (2.9%)	
Stigma due to epilepsy:				
Present	32 (40.5%)	72 (54.9%)	104 (49.5%)	$\chi^2 = 4.12$; df=1 p = 0.042
Absent	47 (59.5%)	59 (45.1%)	106 (50.5%)	
Total	79(100.0%)	131(100.0%) *	210 (100.0%)	

* Includes only those who were currently unemployed but eligible for further work and those with premature retirements.

** Categories of each disease characteristic are amalgamated into 2 major groups.

performance ($\chi^2=6.89$; df=1; $p<0.01$). Absenteeism from work was based on leave taken over the preceding 4 weeks. 'High absenteeism' included patients who were absent for ≥ 2 working days due to reasons related to epilepsy while 'Low absenteeism' included patients who were not. Although the majority (53.2%) did not keep away from work, 8.8% did so for > 7 consecutive working days due to reasons related to their illness. There was no statistically significant difference between males and females in relation to absenteeism ($\chi^2=0.21$; df=1; $p>0.5$).

Status of epilepsy:

Disease characteristics, namely, nature of seizures (age of onset, duration, seizure severity-SS and seizure activity-SA), anti-epileptic drug effects and stigma caused by epilepsy were used as surrogate measures in objectively evaluating the status of epilepsy in each patient. SS was assessed by the number of seizures during past one year and was

classified as 'low' and 'high' according to its frequency of <5 and ≥ 5 seizures, respectively. SA was assessed by the length of seizure free period and was further classified as 'remitted' and 'active' depending on a seizure free period of < 2 years and ≥ 2 years, respectively (9). For determining stigma, raw scores of a culturally acceptable Likert scale were added to obtain a grand score, of which a score $>50\%$ indicated presence of stigma.

Influence of epilepsy on employment status:

Among the currently employed, 25 (31.6%) had their first seizure before school admission (0-5 years) and 22 (27.8%) during or soon after leaving school (6-20 years) while in the unemployed, it was 34 (25.9%) and 41(31.3%), respectively. Only 5 (1.9%) had an onset after retirement age of 60 years. A similar percentage of patients (48%) in both employed and unemployed groups had epilepsy for less than 10 years. The majority had active epilepsy, with the last seizure

Table 3. Comparison of work performance of employed patients by disease characteristics

Disease character	Performance		Total no. (%)	Level of significance
	Poor	Good		
Age of onset:				
< 20 years	22 (55.0%)	25 (64.0%)	47 (59.5%)	$\chi^2 = 1.9$; df=1* p = 0.386
20-39 years	10 (25.0%)	5 (12.8%)	15 (18.9%)	
≥ 40 years	8 (20.0%)	9 (23.1%)	17 (21.5%)	
Duration of epilepsy:				
< 20 years	31 (77.5%)	26 (66.6%)	57 (72.1%)	$\chi^2 = 1.15$; df=1 p = 0.283
≥ 20 years	9 (22.5%)	13 (33.3%)	22 (27.8%)	
Seizure severity:				
Low severity	28 (70.0%)	30 (76.9%)	58 (73.4%)	$\chi^2 = 0.48$; df=1 p = 0.486
High severity	12 (30.0%)	9 (23.1%)	21 (26.6%)	
Seizure activity:				
Remitted	34 (85.0%)	35 (89.7%)	69 (87.3%)	Yates $\chi^2 = 0.09$; df=1 p = 0.767
Active	6 (15.0%)	4 (10.3%)	10 (12.7%)	
Anti-epileptic drug effects:				
Side effects +	34 (85.0%)	30 (76.94%)	64 (81.0%)	$\chi^2 = 0.84$; df=1 p = 0.36
Side effects -	6 (15.0%)	9 (23.1%)	15 (19.0%)	
Stigma due to epilepsy:				
Stigma +	24 (60.0%)	8 (20.0%)	32 (40.5%)	$\chi^2 = 12.78$; df=1 p = 0.0004
Stigma -	16 (40.0%)	31 (80.0%)	47 (59.5%)	

*Categories of each disease characteristic are amalgamated into 2 major groups.

occurring within the last month being the commonest. Nearly 80% in each group did not have any side effects to drugs. Of those who developed side effects, the employed had 'some' side effects (51.7%) as opposed to only 'few' in the unemployed (58.1%). The findings of the relationship between employment status and epilepsy are summarized in Table 2. There was a statistically significant difference between the employed and the unemployed in relation to age of onset, duration of epilepsy and stigma ($p < 0.01$).

The influence of epilepsy on current unemployment was assessed subjectively. Among those who had ever been employed, 58.2% claimed that they lost jobs due to reasons related to epilepsy such as stigma of the illness (38%) worsening of seizures (29.6%) adverse drug effects (17%) and occupation related minor accidents (12.3%). Among those who had never been employed, 96% attributed unemployment to epilepsy for reasons, namely, stigma of the illness (48.5%) less educational qualifications (42.6%) and

Table 4. Comparison of attendance of employed patients by disease characteristics

Disease characteristic	Attendance		Total No. (%)	Level of significance
	Poor	Good		
Duration of epilepsy:				
< 20 years	47 (79.6%)	10 (50.0%)	57 (72.1%)	$\chi^2 = 6.54$; df=1 p = 0.01
≥ 20 years	12 (20.3%)	10	22 (27.8%)	
Seizure severity:				
Low severity	49 (83.0%)	9 (22.2%)	58 (73.4%)	$\chi^2 = 11.08$; df=1 p = 0.0008
High severity	10 (17.0%)	11 (77.8%)	21 (26.6%)	
Seizure activity:				
Remitted	53 (89.8%)	16 (80.0%)	69 (87.3%)	Yates corrected $\chi^2 = 0.57$; df=1 p = 0.451
Active	6 (10.2%)	4 (20.0%)	10 (12.7%)	
Anti-epileptic drug effects:				
Side effects +	34 (74.2%)	30 (76.9%)	64 (81.0%)	Yates corrected $\chi^2 = 1.26$; df=1 p = 0.261
Side effects -	6 (25.8%)	9 (23.1%)	15 (19.0%)	

unwillingness of employers to employ (34.7%).

The relationship between epilepsy and work-related activities was determined among the currently employed patients and is given in Tables 3 and 4. Only stigma related to epilepsy had a significant influence on work performance ($p < 0.01$). The duration of epilepsy and SS were significantly associated with absenteeism ($p < 0.01$).

Educational level was assumed to be the main confounder in the relationship between epilepsy and employment status. Although there was a significant difference in the educational level between the employed and the unemployed (excluding retired patients), there was no difference in the educational levels between those who had an onset of epilepsy before/during and after school going age.

Discussion

Employment status has been identified as a potentially useful and statistically efficient indicator of psychosocial well being in research focused on rarely fatal diseases such as epilepsy (10). It is also been shown that quality of medical care, employability and past history of employment are inter-connected in important ways (11).

This study adopted a cross sectional design that permitted a snapshot view of the current status of employment and epilepsy among individuals in a well-defined clinic population. The main limitation inherent in this design is difficulty in discerning a temporal relationship between epilepsy and their present employment status. The wide range of confounding factors other than epilepsy could also distort its true relationship. Although it was impossible to ascertain all these factors by a lengthy questionnaire especially in a clinic setting, choosing a well-defined population with a homogenous health seeking behaviour enabled to minimize most of them.

Despite the declaration of Government policy on reserving 3% of jobs for mentally and physically handicapped in Sri Lanka, unemployment was found to be significantly higher among patients with epilepsy (63.6%). It is similar to figures reported in other studies done both in developed and developing countries (12, 13, 14, 7).

Under employment is a Known consequence of epileptics leading to less income generation (7, 12). In this study the overall type of employment was found to be appropriate to their education level.

Previous studies strongly suggest that social handicap of epilepsy is less with decreasing seizure frequency and increasing length of remission (15). This study demonstrated in the employed group that only SS was associated with high absenteeism, and that neither SS nor SA was associated with poor work performance. This finding could be interpreted by the variation in the type of employment status. A seizure could interfere with only certain types of employment such as those requiring skilled or intellectual performance. On the other hand, any seizure would require them to be absent from any employment during the acute phase, irrespective of its type. It is also supported by the observation of no significant gender difference in relation to absenteeism, despite gender being significantly associated with work performance.

Early age of onset and long duration of epilepsy were significantly associated with unemployment highlighting the long term impact of the illness irrespective of its present status of seizure severity and activity.

Stigma is widely known to be a crucial factor associated with employment status as reported in studies done in developed and developing countries (16, 17). Similar results were found in the study ($p < 0.01$). In addition stigma affected work related activities even among the employed patients.

The relationship between anti epileptic drug effects and employment status was obscured in this study when compared to studies done elsewhere (18).

Poor performance at school examinations attributed to adverse drug effects (46%) and worsening fits (21%) was consistent with previous studies (12, 18). Also, the significant differences between employed and unemployed patients of age of onset, duration and stigma of epilepsy probably explains the differences in their educational status. However, it is not conclusive since age of onset before/ during school age did not associate well with poor educational level.

In conclusion, this study has demonstrated that more than one facet of the employment status is affected by epilepsy in the majority of patients. It has also demonstrated that stigma contributes significantly to employment status in the long term than most other disease characteristics considered.

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