Paper

The burden of epilepsy: data from an epilepsy clinic

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Abstract

Introduction: Over half of the 50 million people with epilepsy worldwide are estimated to live in Asia, but information about the recognition of the burden created by the disease is scarce. Studies in the region and in Sri Lanka focusing on the burden of epilepsy are limited.

Design/Setting: A retrospective hospital-based study was conducted to determine educational, marital, and employment opportunities of patients with epilepsy attending the epilepsy clinic at the National Hospital of Sri Lanka for one year. An interviewer based questionnaire was used to collect data.

Results: Data was gathered from 500 patients. Male to female ratio was 1.08:0.92. Two hundred and twelve patients (42.4%) belonged to the 16 to 30 age group while 140 (28%) were from the 31 to 45 age group. Most of the patients in the aforesaid age groups (n=352) were unemployed (n=211, 59.94%) and only 89 (25.3%) were employed. Two hundred and sixty four patients (75%) were unmarried while 7 (1.9%) were divorced. The number of patients who received primary and secondary education were 44 (24.4%) and 93 (51.6%) respectively. Two (1.1%) patients went to university. Forty one (22.8%) had no schooling.

Interpretation: Many epilepsy patients have fewer educational, marital, and employment opportunities which contribute towards poor interpersonal skills, social withdrawal and low self-esteem. This emphasises that epilepsy is a chronic disabling neurological disorder which causes many psychosocial tribulations that need to be addressed by healthcare professionals.

Index words: Burden of epilepsy in Sri Lanka. Psychosocial consequences of epilepsy. Educational, marital, and employment opportunities of patients with epilepsy

Introduction

Epilepsy is a neurological condition that knows no geographic or social boundaries, occurring in men and women and affecting people of all ages. It has been estimated that at least 50 million people worldwide have epilepsy[1,2]. More than 80% of people with epilepsy live in developing countries, where effective treatment of this condition is scarce[2]. Over half of the 50 million people with epilepsy worldwide are estimated to live in Asia which is a heterogeneous and resource-constrained continent[3]. Although much research is done in Asia, information about the recognition of the burden created by epilepsy is scarce. There has been a long standing concern that, although progress continues to be made in relation to medical management of epilepsy, including the development of a number of new antiepileptic drugs, attention to the social adjustment of individuals with the condition is still limited[4]. People with epilepsy in developing regions carry a heavy burden of stigma with associated poor social and economic status[5]. Studies in the region and in Sri Lanka focusing on the burden of epilepsy are limited.

The present study was conducted at the epilepsy clinic, National Hospital of Sri Lanka to assess the educational, marital, and employment opportunities of patients with epilepsy.

Design/Setting

A retrospective hospital-based study was conducted to determine educational, marital, and employment opportunities of patients with epilepsy attending the epilepsy clinic at the National Hospital of Sri Lanka. An interviewer based questionnaire was used to collect data on educational, marital, and employment opportunities. Data was collected from patients attending the above clinic from January 2002 to January 2003. Statistical analysis was done through SPSS version[10]. Informed consent was obtained from the study population.

Results

Data was gathered from 500 patients who attended the clinic during the stipulated study period. Of these patients 260 (52%) were males. Two hundred and twelve

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patients (42.4%) belonged to the 16 to 30 age group while the second highest number, 140 (28%) were between 31 and 45 years. Forty patients (8%) were over 45 years of age while 54 (10.8%) patients were between the ages of 11 and 15. Twenty two (4.4%) were from the 6 to 10 age group and 32 (6.4%) were 5 years and below. Most of the patients between 16 and 45 (n=352) were unemployed (n=211, 59.94%) and only a minority were employed (n=89, 25.3%). Fifty two (14.7%) were certified unemployable. Two hundred and sixty four patients (75%) in the aforesaid age group were unmarried while 7 (1.9%) were divorced. The remaining 81 were married (23.01%).

While the majority of patients who were above 30 years (n=180) had received secondary education (n=93, 51.6%) a significant proportion of patients (n=44, 24.4%) received only primary education. Only 2 (1.1%) patients went to university. Forty one (22.8%) had no schooling.

Discussion

People with disabilities are among the most vulnerable in any society. The psychosocial and economic consequences of epilepsy in less developed countries are generally acknowledged to contribute substantially to the burden of this disease as it is associated with social stigma[5]. Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behaviour in many spheres of life, over many centuries and in many cultures[7]. Stigma has a severe impact on individuals and their families, as well as on the effectiveness of public health programmes. Despite enormous cultural diversity across the world, the areas of life affected are remarkably similar. They include marriage, interpersonal relationships, employment, education, mobility, leisure activities and attendance at social and religious functions. Discrimination against people with epilepsy in the workplace and with respect to access to education is not uncommon[4]. In a study done in Hong Kong 94.1% of respondents thought that people with epilepsy could be married, but only 67.8% would allow their child to marry a person with epilepsy[7]. Thus people with epilepsy may have fewer educational, marital, and employment opportunities. The findings of this study may lend support to the supposition that people with epilepsy in developing regions suffer social stigma with associated poor social and economic status.

It has also been shown that people with epilepsy are generally more prone to poorer self-esteem and higher levels of anxiety and depression than people without epilepsy[8]. People with epilepsy also consistently appear at greater risk of problems in relation to educational achievement[9-11] and employment[12-14]. Issues of social withdrawal and isolation have been also reported with knock-on effects for marriage and other close interpersonal relationships[15,16].

The majority of the patients followed up at the clinic were between the ages of 15 and 30. The second largest patient population was between the ages of 30 and 45. These age categories contribute maximally towards the workforce (the labour pool in employment). The majority in the above age categories were unemployed thus contributing poorly towards the workforce which in turn adds on to the economic burden of the country. Many of the patients in the above age categories were also unmarried and also showed poor educational achievements which reinforces the socioeconomic problems patients with epilepsy have to face. As mentioned in other studies social withdrawal and isolation may contribute towards these problems[15,16]. Fewer educational, marital, and employment opportunities in turn worsens social withdrawal, thus a vicious cycles ensues.

Conclusion

WHO defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease". Many patients in the above population have fewer educational, marital, and employment opportunities which contribute towards poor interpersonal skills, social withdrawal and low self-esteem which negatively affect their capacity for health. This emphasizes that epilepsy is a chronic disabling neurological disorder which causes many psychosocial tribulations that need to be addressed by healthcare professionals.

Strategies to improve the well-being of people with epilepsy need to be multi-modal in nature, addressing stigma-mediated disadvantage through education and advocacy of influential groups, promoting empowerment among people with epilepsy, expanding opportunities for education and employment.

While this study represents institutional data and may have an element of referral bias it highlights psychosocial tribulations in epilepsy patients and the need for intervention. However further community based epidemiological studies are necessary to assess the burden of epilepsy in the community.

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