Paper

Demographic patterns from an epilepsy clinic in Sri Lanka

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Abstract

Introduction: Over half of the 50 million people with epilepsy worldwide are estimated to live in Asia. Although much research is done in Asia, information about the recognition of the burden created by the disease is scarce. Better understanding of the demographic distribution of epilepsy would improve our knowledge and understanding of this disorder at the population level.

Method: A retrospective hospital-based study was conducted to determine demographic patterns in patients attending the epilepsy clinic at the National Hospital of Sri Lanka for one year. An interviewer based questionnaire was used to collect data on demographic characteristics.

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.

The causes of epilepsy are: no identifiable cause 357 (71.4%), CNS infections 46 (9.2%), head trauma 25 (5%), peri-natal distress 32 (6.4%) stroke 22 (4.4%) and structural lesions 18 (3.6%).

Conclusion: Many epilepsy patients have fewer educational, marital, and employment opportunities which contributes towards poor interpersonal skills, social withdrawal and low self esteem.

CNS infections, though small in number in the above cohort remains an important cause of epilepsy. Early case detection and treatment of CNS infections may further lower the burden of epilepsy.

Index words: demographic patterns of epilepsy, burden of epilepsy in Sri Lanka, psychosocial consequences of 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[3].

The incidence of epilepsy in developed countries is estimated as being between 40 and 70 per 100,000 persons per year[4-7]. The incidence in resource-poor countries is much higher often above 120/100,000/year[4]. Poor sanitation, inadequate health delivery systems, and higher risk of brain infections and infestations may contribute to this[4,8].

Over half of the 50 million people with epilepsy worldwide are estimated to live in Asia which is a heterogeneous and resource-constrained continent[9]. Although much research is done in Asia, information about the recognition of the burden created by epilepsy is scarce.

The exact number of people suffering from epilepsy in the South Asian Region is largely unknown. Although South Asian countries compile and publish health data, epilepsy is not included as it is not a notifiable disorder[10]. "How many suffer from epilepsy?" is thus a difficult question to answer. However, various hospital-based and community-based studies have reported that it is a commonly encountered problem. As per some studies in the region, it is known that prevalence of epilepsy varies from 2-10 per 1000 population[10]. Studies from different parts of India reveal that the prevalence varies from 9/1000 in Bangalore, 5/1000 in Mumbai, 3/1000 in Calcutta to 4/1000 in New Delhi. In a survey in the Kandy district of Sri Lanka, it was observed that 9 out of 1000 people had epilepsy. It is also reported that epilepsy is the second commonest neurological condition after headache, in terms of the number of people affected[10].

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Better understanding of the demographic distribution of epilepsy and prevalence of more specific forms of epilepsy in the community would improve our knowledge and understanding of this disorder at the population level. Such studies in Sri Lanka are scarce[10].

The present study was conducted to identify demographic patterns in patients attending the epilepsy clinic at the National Hospital of Sri Lanka situated in the capital city Colombo. This tertiary referral center provides specialized outpatient clinics in Neurology including epilepsy, and caters for patients from all over the island.

Method

A retrospective hospital-based study was conducted to determine demographic patterns in patients attending the epilepsy clinic at the National Hospital of Sri Lanka. An interviewer based questionnaire was used to collect data on demographic characteristics, seizure semiology, delays in treatment and its causes, and underlying aetiology of seizures. Data were collected from patients attending the above clinic from January 2002 to January 2003. Definitions for the classification of aetiology and semiology were adopted from the International League Against Epilepsy guidelines for epidemiologic studies on epilepsy[11].

Statistical analysis was done through SPSS version[11]. Informed consent was obtained from the study population. Ethical approval was obtained from Ethics Review Committee of the National Hospital of Sri Lanka.

Results

Data were gathered from 500 patients who attended the clinic during the stipulated study period. Of these patients 260 (52%) were males. Two hundred and twelve patients (42.4%) belonged to the 16 to 30 age group while 140 (28%) were between 31 and 45 years. Forty patients (8%) were over 45 years of age and 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. 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.

Seizure type was classified according to semiology and EEG findings, and was as follows: generalized tonic clonic (191, 38.2%), absence (31, 6.2%), complex partial (156, 31.2%), simple partial (38, 7.6%), myoclonic (21, 4.2%) and secondary generalized seizures (63, 12.6%).

The possible causes of epilepsy in the above cohort of patients were as follows: no identifiable cause 357 (71.4%), CNS infections 46 (9.2%), head trauma 25 (5%), perinatal distress 32 (6.4%) stroke 22 (4.4%) and lastly structural lesions including hippocampal sclerosis, congenital brain malformation and brain tumours 18 (3.6%).

A delay in treatment was defined as a delay in seeking western medical treatment for a period of over 3 months following the onset of epilepsy. Such a delay was only seen in 84 patents (16.8%). Of these patients 40 (47.6%) did not receive alternative treatment or did not sought relief in ritualistic practices. Only 4.8% (n=4) chose native medical treatment modalities ("Ayurveda" – a traditional medical practice in Sri Lanka). Spiritualistic healing by way of rituals such as *"Bali-Thovil"* and charms had been sought by 23.8% (n=20).

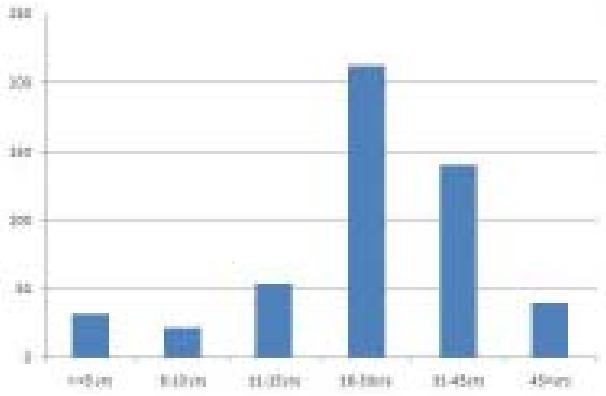

Figure 1. Age distribution in patients attending the epilepsy clinic.

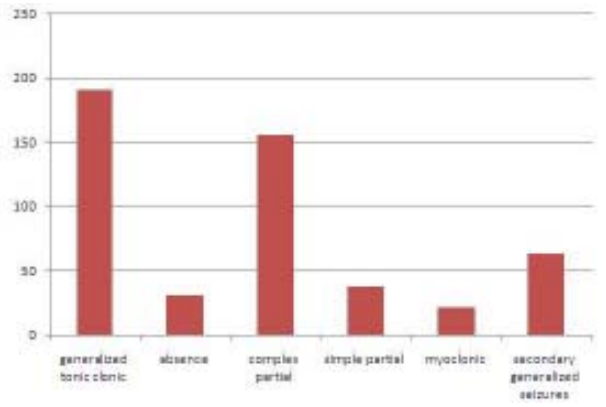

Figure 2. Seizure type.

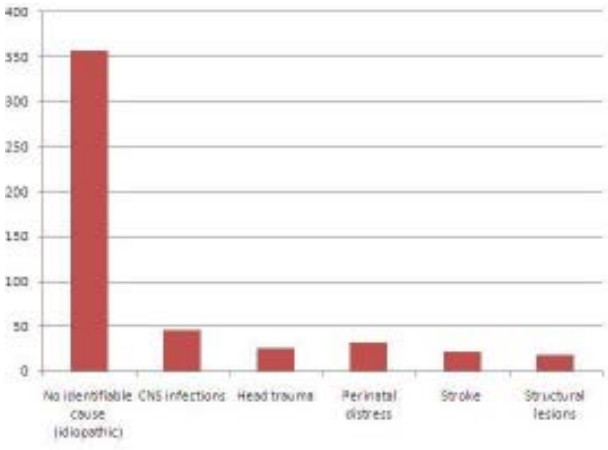

Figure 3. Causes of epilepsy identified.

Discussion

In developed countries, the incidence and prevalence of epilepsy both follow a bimodal distribution with a first peak in childhood and another in old age[9]. Most studies conducted in the Asia show one peak age for incidence in children and another peak age for prevalence in young adults[9, 12-19]. The postulated reason for the missing peak in the older age groups in many Asian countries is the relatively young population compared with that in more developed regions[9]. In the study population the absence of the old age peak may reflect this trend in Asia although Sri Lanka has population demographics which depict an increasing aging population[20]. The possible explanation for the low representation of very young age groups in the study population is that paediatric neurology clinics provide care for children with epilepsy.

In most studies in the region, epilepsy is slightly more common in men than in women but the sex-specific prevalence is not, in general, significantly different[9,13,15 16,19]. This trend is also reflected in the above study population.

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[21]. 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[22]. Discrimination against people with epilepsy in the workplace and with respect to access to education is not uncommon[21]. 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[23]. 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[24]. People with epilepsy also consistently appear at greater risk of problems in relation to educational achievement[25-27] and employment[28-30]. Issues of social withdrawal and isolation have been also reported with knockon effects for marriage and other close interpersonal relationships[31,32].

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 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 socio-economic problems patients with epilepsy have to face. As mentioned in other studies social withdrawal and isolation may contribute towards these problems[31,32]. Fewer educational, marital, and employment opportunities in turn worsens social withdrawal, thus a vicious cycle ensues.

In most regional studies the range of patients with generalised seizures was 50-69%, and 31-50% had partial seizures[9]. This trend was seen in the above study population as well. There are only few studies on the causes of epilepsy in Asian populations, and there are particularly only a few case-control or cohort studies[9]. From the available literature, the major causes seem to be: head injury, birth trauma, and intracranial infections, such as neurocysticercosis or meningoencephalitis[9]. In places of greater socioeconomic development, head trauma and stroke are the leading causes of epilepsy[9]. In this study in majority of the patients an identifiable cause was not detected. The high incidence of idiopathic epilepsy in this study is probably an over estimation and may indicate a shortage of more elaborate investigative procedures in finding a cause.

The prevalence of central nervous system infections was low in this study. In developing countries in other regions of the world, CNS infections seem to explain the high prevalence of epilepsy[9]. The listed causes of epilepsy are, malaria, tuberculosis, schistosomiasis, AIDS, and cysticercosis and among these, the latter seems to be the most common cause of epilepsy[33]. Neurocysticercosis was the cause of epilepsy in about 50% of patients in

some studies[34,35]. In Asia, many studies report the presence of cysticercosis[9] but Neurocysticercosis is not found in Sri Lanka[36]. This is unexpected when considering the geographical proximity of India which has a high prevalence of cysticercosis[35]. The unimpeded human migration to and from either country has not resulted in an increase in the prevalence of cysticercosis.

Malaria is still widely endemic in Asia, with more than 3 million cases per year[9]. In a retrospective survey in Thailand 7.7% of patients with childhood malaria (with or without the presence of cerebral malaria) had convulsions 37. In another study convulsions were found to be present in 60% of patients with cerebral malaria[38]. The link between epilepsy and malaria is supported by a case-control study in Gabon and a cohort study in Mali in Africa as well[39]. However in Sri Lanka the incidence of Malaria is negligible and has reached the pre-elimination stage due to effective treatment and preventive programmes[40].

In Asia, post-traumatic epilepsy is one of the most common complications of head injury[9]. A study claimed that post-traumatic epilepsy accounted for 5% of total epilepsy and 20% of symptomatic epilepsy[41]. In our study patients with epilepsy due to trauma are comparable with regional data. It may also be an underestimation due to the fact that most of patients with head trauma may be followed up at neuro-surgical clinics. Therefore the above numbers may be an underestimation of the true impact of trauma on epilepsy.

Ideas and opinions about treatment of epilepsy are often based on beliefs about the disease. Since epilepsy is often seen as a spiritual affliction, some patients with epilepsy or their carers assume that traditional treatment in the local community is appropriate. This is commonly seen in most developing nations[42]. An increase in the sustained use of effective treatment is closely linked to improved awareness of epilepsy, as beliefs and explanations about epilepsy influence health-seeking and treatment-seeking behaviour[42]. In many developing nations, notions about epilepsy are rooted not in medical sciences but in spiritual beliefs[43]. In Sri Lanka such spiritual beliefs do exist and are reflected in ritualistic practices such as *"Bali-Thovil"* and various types of charms. In our study a treatment delay was seen in only a minority of patients and of these patients only a small proportion of people had sought relief in such spiritualistic practices. Such ritualistic practices had a small role to play in causing treatment delays in the above population which might suggest better health seeking behaviour observed among Sri Lankan communities compared to communities in other developing nations. This may be due to greater awareness of the disease which in turn may be due to high literacy rates observed in Sri Lanka[20] and effective health education programmes. However this observation may also be due to selection bias.

Conclusion

Utilization of a healthcare system depends on socio-demographic factors, social structures, level of education, cultural beliefs and practices, gender discrimination, status of women, economic and political systems, environmental conditions, the disease pattern and attributes of the healthcare system itself. When considering the healthcare system itself health seeking behaviour is influenced by availability, accessibility, affordability and acceptability[44]. The data above suggest that the healthcare system in Sri Lanka may have the above attributes, thus providing the necessary confidence to the community towards such health seeking behaviour.

Although health seeking behaviour remains high in the above cohort it seems epilepsy may still be highly stigmatized. Many patients in the above population have fewer educational, marital, and employment opportunities which contributes 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.

CNS infections, though small in number in the above cohort remains an important cause of epilepsy. Early case detection and prompt treatment of CNS infections may contribute towards further lowering the burden of epilepsy.

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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