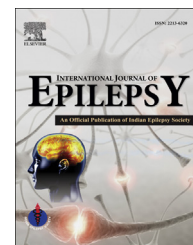


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Letter to the Editor

Revision of the name of ‘epilepsy’ to ‘electroencephalic disorder’: Hope for improved quality of life in patients with ‘epilepsy’



Keywords:

Epilepsia

Oldest disease

Psychosocial impact

Re-christening of epilepsy

To the Editor,

Epilepsy is one of the oldest diseases known in the history of mankind and derives its name from the ancient Greek ‘epilepsia’ which was from ‘epilambanein’ meaning ‘to take hold of’ or ‘to seize’.

Epilepsy, despite being one of the commonest neurological diseases, remains associated with a large number of myths and misconceptions even today; this is in spite of several epilepsy awareness and education programs regularly run by different organizations. In many underdeveloped and even developing countries, it is still believed that patients with epilepsy are possessed by demons or evil spirits and different forms of epilepsy are because of different types of spirits. It is also thought that epilepsy is a contagious disease and in earlier times the patients with epilepsy were quarantined and even imprisoned.

Epilepsy is associated with a strong psychosocial stigma that adversely affects the quality of life (QOL) of the epilepsy patients and because of which they continue to face significant discrimination in the society translating into difficulty in schooling, job procurement, and marital issues with a superimposed feeling of guilt. Patients with epilepsy also often exhibit comorbidity with anxiety and depression which possibly affects their prognosis albeit it does impact their QOL adversely.

This brief communication is intended to appeal for changing the name of ‘epilepsy’, which in the author’s opinion will exercise a favorable influence and impact on the QOL of the epilepsy patients and also attempts to present a justification for the same.

The term ‘epilepsy’ when constructed in early times depicted a typical grand mal attack (now commonly termed as a generalized tonic clonic seizure (GTCS)) when knowledge about other forms of epilepsy was absent and it is time that the term should now be treated as obsolete and be discarded in view of the large number of clinical forms of epilepsy known today and which vary fundamentally and immensely from the typical GTCS attack on the basis of which the term was first coined, as also that the term ‘epilepsy’ now appears impertinent to the large number of its varying clinical manifestations. Over the course of time, ‘epilepsy’ has already undergone a series of changed names from ‘sacred disease’ to ‘the falling disease’. Epilepsy term is also believed to be marked with psychiatric illness in some regions, especially in Asian countries and therefore its presentation as a misnomer exhibits an additional strong reason for warranting its re-christening.

The proposal of renaming ‘epilepsy’ is not altogether a novel one; earlier also, serious attempts have been made to rename it in Asia.¹ In 1980, Japanese epileptologists conducted a survey for “the action for epilepsy renaming”. In 2009, the Chinese Chapter Against Epilepsy conducted a campaign to have the public choose a new name, and very recently, a proposal has been published for changing the name of ‘epilepsy’ to ‘cerebroelectric disorder’ in Korea.¹ The main purpose of these attempts has been to improve the QOL of the patients with epilepsy.

Revision of definition of epilepsy also has been proposed earlier^{2–3} and currently the International League Against Epilepsy (ILAE) is finalizing the operational definition of epilepsy; in the same vein, revision of the name of the disease also

sounds justified. An additional justification is derived from the fact that the medical community is discussing even the labeling of the patients with epilepsy.⁴

Re-christening of the disease is likely to drive the epilepsy patients and/or their caretakers to seek medical advice early in the course of the disease and which will dissuade them from seeking unethical and unscientific advice from faith healers. A smaller time-gap between the index attack and institution of medical intervention is known to be associated with better control and prognosis of the disease.

Thus, there does appear a seemingly rational and justified requirement of renaming ‘epilepsy’ especially for improving the QOL of the patients afflicted with it in view of which it is suggested that a scientific term that adequately conveys the basic meaning of the disease be introduced and which can be accepted by the medical community.

In keeping with the above requirements, the author proposes ‘electroencephalic disorder’ (EED) as the new name of epilepsy bearing in mind that there is hardly any other brain disorder that is primarily and essentially associated with electrically aberrant behavior or nature of neurons in the brain.

The term ‘electroencephalic disorder’ (EED) appears well justified as it exhibits resemblance to its very basic nature (electrical aberration of the neurons in the brain). Further, the mainstay investigation of epilepsy i.e. EEG also bears compatibility with the new name of the disease. Thus, ‘electroencephalic disorder’ is a scientific term which conveys both, the essence of the disease as well as an indication of its pathophysiology akin to electrocerebral silence (ECS) which is the technical term (EEG nomenclature) for brain death and which conforms to the EEG interpretation of its state.

Admittedly, it will take time for acceptance of the new name but nevertheless this does appear assured with motivation from health professionals and education from

awareness programs and well-designed and organized propaganda; this is important also for changing the public attitude towards the epilepsy patients.

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Harinder Jaseja*

Vellore EEG Center, Gwalior 474002, India

*8, C—Block, Harishanker-puram, Lashkar, Gwalior 474002, MP, India. Tel.: +91 751 2631147.

E-mail address: dr_jaseja@yahoo.com

7 February 2014

2213-6320/\$ – see front matter

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<http://dx.doi.org/10.1016/j.ijep.2014.04.002>