

PROJECT REPORTS

A HISTORICAL STUDY OF EPILEPSY FROM 1900 AD TO 2005 AD*

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The project focussed on comprehensive study of the enigmatic disease called Epilepsy in the 20th and early 21st centuries (1900 AD to 2005 AD). The material was collected from different primary and secondary sources. This information was then painstakingly evaluated, collated and linked. Several experts in the field were consulted for critical evaluation, useful inputs and necessary corrections. The study was carried out under the following chapters as listed:

1. Epilepsy in the beginning of the 20th century
2. Magnitude of the disease in the 20th century
3. Types of Epilepsy
4. Diagnostic tools
5. Methods of treatment
6. Setting up of medical institutions
7. New insight into Epilepsy in the 20th century
8. Social problems associated with Epilepsy
9. Summary and Conclusions

Before studying the material pertaining to historical developments in the 20th century, an attempt was made to identify the knowledge about this disease at the beginning of the 20th century. Analysis of data on the knowledge of Epilepsy before the 20th century has revealed that five different systems of Medicine were practiced in India for diagnosis and treatment of Epilepsy. During the ancient and medieval period, *Āyurveda* remained in the forefront throughout the country except in southern parts of India where *Siddha* had a stronghold. During the Mughal period, the *Unāni* system of medicine was more popular, while *Allopathy* was introduced during the modern period and continues to be the most sought-

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after system of treatment for Epilepsy. *Homoeopathy* was introduced and practiced in many parts of India after 1810.

Though several clinical studies showed that Epilepsy was also prevalent towards the end of 19th century in India, the statistical data of the disease was not available. Moreover, in spite of the knowledge that Epilepsy was a neurological illness affecting the brain, the cause of epilepsy was believed to be supernatural or religious. The clinical history and X-Ray were the only diagnostic tools available. Epilepsy was considered as a type of insanity by some, and patients were locked up in mental asylums. In spite of facilities available in twenty major hospitals, majority of people sought the help of temple priests, quacks, *pīr*, *fakīrs* and charlatans who made their day by exorcism, *jādu-tona*, *jhār-phūk* etc. Very few of the educated, rich and influential people sought treatment in these hospitals. Potassium bromide, morphine, opium, tincture digitalis, chloral hydrate and narcotic anodynes were mainly being used for epilepsy. *Āyurvedic* treatment was preferred by the majority of Hindu communities and *Unāni* medicine by Muslim communities. Southern parts of India trusted the efficacy of *Siddha* medicine for treatment of Epilepsy. Epilepsy was considered as a social stigma and more than 90% of people did not reveal their disease and also faced problems in their schooling, education, job and marriage. They were not allowed to attend social functions for fear of having an epileptic seizure during these events. Thus, these individuals proved to be an economic burden for the family.

The magnitude of the disease can be gauged from the technical report by WHO entitled 'Epilepsy Atlas 2005' which states that presently there are about 50 million people in the world who are suffering from Epilepsy, of which about 8 to 10 million are in India. Currently, Epilepsy accounts for about 1% of the world's health burden and about 3 to 4 lakhs new cases are reported every year. The treatment of this disease involves taking medicines for a prolonged period ranging from 3 years to even lifetime and no cure has been found so far. The most unfortunate problem about epilepsy is that about 75% of people with epilepsy hardly receive any medical treatment. The WHO jointly with two non-governmental organizations (NGOs) announced in June 1997 in Geneva, the start of 'Out of the Shadows – A Global Campaign Against Epilepsy'. The 2 NGOs were the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The campaign was aimed at improving healthcare services, treatment and social acceptance of epilepsy, the world's most common serious, yet treatable brain disorder.

There are many different types of epilepsy that are distinguished by causes, extent, and effects. Among these, there are two major types of epilepsy: generalized epilepsy, in which seizures affect the entire brain, and partial (or focal) epilepsy, in which seizures begin in a specific portion of the brain. Besides these, there are several types of seizures/ epilepsy i.e. afebrile seizures, Hot Water Epilepsy, Myoclonic Epilepsy, Neurocysticercosis, and Hysteria (Non-epileptic seizures). Sometimes epilepsy becomes intractable or uncontrolled in spite of all types of treatment. The Epilepsy in women and elderly people presents a different picture than in the general population and management is also different.

The diagnosis of Epilepsy is based on three parameters i.e. the clinical history of the patient which is based on the eyewitness account of the seizures, the study of the electrical activity of the brain, and the visualization of the abnormalities of the brain using Imaging techniques. Several diagnostic tools or tests had been invented in the late 19th and 20th century to facilitate the early and accurate diagnosis of Epilepsy. These may be broadly divided into two groups for the sake of convenience; tools to analyze the electrical activity of the brain, i.e. Electroencephalography (EEG), Video E.E.G and imaging techniques, e.g. X-rays, Computed Tomographic Scanning, Magnetic Resonance Imaging, Ultrasound Scanning, Ventriculography, Cerebral Angiography, Positron Emission Tomography (PET) and Single Photon Emission Computed Tomography (SPECT) .

Treatment of Epilepsy involves a multi-pronged approach tailored to the disease as well as the needs of the individual. For the sake of convenience the treatment may be divided into medical treatment, surgical treatment, electrical brain stimulation and dietary modification.

For treatment of Epilepsy, the British and the Indian governments established several medical colleges and hospitals to train the doctors as well as provide treatment to the patients. The number of medical colleges in India has climbed from 30 at the time of independence to 250 presently; the annual intake of students has crossed 20,000. Every year more than 14,000 pass the MBBS examination and more than 6000 postgraduates are trained in different disciplines of medicine. There are nearly six lakhs of registered MBBS doctors, one doctor for every 1800 population. Today there are at least 15 centres of excellence where skull based surgery, vascular surgery, neuroendoscopy, radiosurgery, interventional neuroradiology, complex spinal instrumentation, deep brain stimulation and every conceivable type of neurosurgical procedure is carried out. We have also a National Brain Research Centre in New Delhi. Tele-consultation in

neurosurgery to remote villages is offered through satellites orbiting in outer space, which the Department of Space, Government of India has indigenously made and launched. There are only seven countries in the world, which have this capability. At present, there are 800 neurosurgeons, 110 neurosurgical trainees in 55 residency programmes (5 National Institutes, 4 Deemed Universities, 25 Medical Colleges, 21 Corporate, Private and Trust Hospitals) in India. Ninety of 160 medical colleges have neurosurgical departments; 45 out of 275 corporate hospitals have neurosurgical units and about 125 small to medium nursing homes have facilities for basic neurosurgery. Many Government Hospitals in India provide the most complex neurosurgical services free of cost.

It is gratifying to note that from a humble beginning at Vellore, Madras, and Bombay between 1949 and 1954, the country has now a multitude of neurosurgical services. Yet the total number of neurosurgeons outside major cities is inadequate even to provide uniform minimum basic neurosurgical facilities. It is expected that this shortfall will soon be overcome.

Growth of mental asylums in British India was a less conspicuous form of social control which reflected the colonial mindset of the prevailing societal norms. The first lunatic asylum in India was established in Bombay (Mumbai) in the year 1745, followed by Calcutta (Kolkata) in 1787. Subsequently number of such asylums increased significantly and by the year 1947, there were 31 mental hospitals in India. After independence mental hospitals were opened in various states. A recent survey revealed that there are 59 mental hospitals in the country. Anyhow the consolation is that Epilepsy is treated in the Neurology departments of various hospitals and one does not have to face the agony and stigma of treatment in the mental hospitals.

Research on Epilepsy has been directed towards four aspects of the disease i.e. the causes of Epilepsy, the diagnostic tools, different types of treatment and sociocultural and economic factors associated with the disease. The common causes of Epilepsy are head injuries due to road accidents, infections of the brain like tapeworm infestation (neurocysticercosis), tuberculosis and malaria, brain injury before birth caused by infection or lack of oxygen to the brain, genetic disorders due to consanguineous marriages (among blood relatives) and prolonged high grade fever, degenerative (cerebrovascular) diseases of the brain and brain tumors. An unusual type of epilepsy (hot water epilepsy) has been reported from South India in which seizures are induced by pouring hot water rapidly over the head.

Physicians and neurologists are concerned mainly about the causes, diagnosis, prognosis, and treatment of epilepsy. For patients with epilepsy and their families, however, the social implications of the disease are a primary concern. Social issues for patients with epilepsy include the reflections of the disease on education, employment, marriage, driving, insurance, leisure time activities, sports activities and on the overall quality of life and stigma, which may differ depending on the sociocultural attitudes in the country where the patient lives.

Unfortunately, all over the world, the social consequences of epilepsy are often more difficult to overcome than the seizures themselves – more so in developing countries. In some rural areas of India, for instance, attempts are made to exorcize evil spirits from people with epilepsy by tying them to trees, beating them, cutting a portion of hair from their head, squeezing lemon and other juices onto their head and starving them. However, fear, misconceptions and stigma are associated with this disorder not just in developing countries. In the United Kingdom, a law forbidding people with epilepsy to marry was repealed only in 1970. In the USA, many individual States prohibited people with epilepsy from marrying. The last State to repeal this law did so in 1980. Misunderstandings about epilepsy and economic barriers play an important role in keeping treatment out of reach of millions of people in developing countries

Conclusion

It is medically possible for up to 70% of people with epilepsy to have their condition brought under successful control. However, mainly for social reasons, 3-quarters, or approximately 30 million, of those affected with the disorder do not receive any treatment at all, and these people are mostly in developing countries.

It is hoped that this study will bring about increased consciousness and awareness about Epilepsy, the disease that has assumed epidemic proportions all over the world including India and is an issue of global concern. Myths and fallacies about this disease can be dispelled and all laymen can learn the true facts about it. Correct knowledge of this disease can lead to its proper and early diagnosis and treatment and save the individuals from the clutches of the quacks and spirit-specialists. This may help in uprooting the social discrimination against the epileptic patients and they can lead a normal life like other individuals. The true picture of the disease can be highlighted in the society so that the governmental and non-governmental organizations can bring about a sympathetic approach

towards the patients and treat them at par with normal individuals and give them equal democratic and social rights.

For the epileptic individuals themselves, this study should bring a change in perception towards the disease and they should be able to interact like other individuals and lead a normal life with no taboos on games, exercise, employment, driving, marriage, sex and social gatherings. Since Allopathic treatment cannot cure the disease, alternative therapies like Āyurveda, Siddha, Unāni, Yoga, Naturopathy, Homeopathy, Acupuncture etc. should be encouraged and scientific studies should be undertaken into their respective efficacies, given the faith of our people in these systems. According to Dr. Satish Jain, a senior Neurologist from AIIMS, “just like the Polio Eradication Programme, a nation-wide Epilepsy Control Programme should be initiated to effectively deal with this disease”

Thus it is our duty to increase the awareness about this disease and dispel the myths and fallacies associated with this treatable disorder and help the people with epilepsy to come out of their closets and seek not only treatment but also their democratic rights as normal individuals. This is also one of the major objectives of this project.

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