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### **Social Perceptions and Impacts of Epilepsy**

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#### **Introduction**

Epilepsy is a chronic neurological disorder marked by sudden recurrent episodes of sensory disturbance, loss of consciousness or convulsions, due to disruption of the electrical communication between neurons resulting in 'seizures'. 'Active epilepsy' is defined as "the affected person has had at least one seizure in the previous 5 years, regardless of the antiepileptic drugs (AEDs) used," [1]. Epileptic seizures are unpredictable and can further lead to additional health problems. In India, epilepsy is also described by other words such as fits and in local languages by words such as *Miraji, Akadi and Apasmar*.

As per the information provided by the World Health Organization (WHO), worldwide there are nearly 50 million 'persons / people with epilepsy' (PWEs) and 80% of them reside in developing countries. Among them, nearly 12 million reside in India, amounting to nearly one-fifth of the global burden. The estimated proportion of the worldwide general population with Active Epilepsy at a given time is between 4 and 10 per 1000 people. However, in the low and middle-income countries, this proportion is much higher, ranging between 7 and 14 per 1000 people [2].

#### **Treatment modalities and the treatment gap in Epilepsy**

In majority of the patients, epileptic seizures can be controlled by medication. The type of treatment prescribed depends on several factors, including the frequency and severity of the seizures and the person's age, overall health and medical history. A PWE must visit the doctor, should go through the needful tests and must start the treatment as per the doctor's advice. An accurate diagnosis of the type of epilepsy is critical in deciding the best treatment.

Surgery is an alternative to patients whose seizures cannot be controlled by medication. It has been used for more than a century, but its use dramatically increased in 1980s and 1990s, reflecting its effectiveness as an alternative to seizure medicines, though the benefits of this surgery need to be weighed carefully against its risks.

The epilepsy treatment gap, defined as the proportion of people with epilepsy who require treatment but do not receive it, has been proposed as a useful parameter to compare access as well as quality of care for epilepsy patients across populations. The treatment gap in epilepsy, i.e., the percentage of people with untreated epilepsy, in India ranges from 22% in the urban setting to as high as 90% in villages [3]. Possible reasons for this treatment gap in India appear to be the lack of awareness about epilepsy, misunderstandings about the treatment and poverty.

## **Social aspects of Epilepsy**

Fear, misunderstanding, discrimination, and social stigma have surrounded epilepsy for centuries. There are many misunderstandings and misconceptions about epilepsy in the society. Unfortunately, this public's perception and misunderstanding further results in challenges often worse than the seizures itself.

In India, some diseases are considered as 'prestigious' while others as 'non-prestigious'. Epilepsy is one of the 'non-prestigious' disorders and has a huge social stigma. As a result, most people tend to hide the fact that they suffer from epilepsy. Furthermore, a common belief, especially prevalent in rural areas, is that a person with epilepsy is believed to be possessed by an evil spirit during the epileptic attack and as a result they are taken to faith healers or *Sadhus* for the treatment instead of qualified medical doctors.

### **Social aspects of epilepsy in children and women**

Epilepsy affects all age groups, but for children, a variety of issues exist that can affect one's childhood. Common causes of childhood seizures or epilepsy include fever, genetic causes, head injury, infections, lack of oxygen, and disorders of brain development. Many childhood seizures are benign, meaning that they are brief events that will not continue into adulthood and the child's development and intellect are usually normal. Other seizures are serious and often are associated with developmental delay or intellectual disability and persistent seizures.

Most children with epilepsy can attend school and can participate in most of the activities. Though many children are capable of functioning in a normal classroom environment, many may end up in special education schools. The social stigma can stand in the way, as the child is more prone to bullying. In some children, epilepsy may affect their education thereby leading to troubled learning and lower grades and may need extra help for the difficult subjects. Making sure that the school knows about the child's epilepsy would be best for the child's health. Good parenting also plays a key role in the development of these children.

Unfortunately, in India, many staff members in schools are not aware about epilepsy. Though there are schools which accept students with minor disabilities, they are very few in number. Because of this unawareness, parents tend to hide their child's epilepsy during the school admission process. However, if the child gets an epileptic seizure in the school, some school authorities may panic and may even think of removing such students from their school. Fortunately, some schools take a supportive role by initiating a dialogue with the parents and understanding their problems.

In the United States of America, there exists Federal Law for children with epilepsy. These laws are known as Individuals with Disabilities Education Act (IDEA) and section 504 of the Rehabilitation Act. It says that every child with any disability has the right to have education in any school. Indian government too has initiated Sarva Shiksha Abhiyan (2001) & Right to Education Act (2009), for ensuring the right to education of the people with disability and epilepsy is included under the disability section.

In women, epilepsy presents many more challenges compared to those in men. Epilepsy may affect sexual development, menstrual cycle, aspects of contraception, fertility, and reproduction. However, these problems will not occur in every woman with epilepsy.

There is also a strong social angle to this aspect. India is still a male dominant society and therefore women face more problems than men in leading normal life. As a result of this gender discrimination, conditions are favourable for men with epilepsy in receiving good parenting and education, in getting married, in getting a job and in getting an acceptance in the society. Furthermore, within the Indian system of 'arranged marriages' women with epilepsy face multiple challenges. Though, a well-educated and independent girl is living with controlled epilepsy and has to be on medication for life, most eligible boys and especially parents of these

boys would not accept her as their daughter-in-law. This happens mainly because of unawareness, misunderstandings and social taboo. Thus, it becomes difficult for these girls of marital age to get married. To some extent men with epilepsy too face such problems. As a result, parents tend to hide the epilepsy history of their daughter or son while arranging their marriage, but unfortunately in future, this itself may become a reason for separation in such couples.

Fortunately, in recent years, the gender discrimination in epilepsy patients appears to be reducing at least in the metro cities and hence, women here are becoming independent and getting good education. Further increase in awareness in the society is essential in changing the situation in favour of women.

### **Role of family members, counsellors and support groups**

Epilepsy and seizures can develop in any person at any age, but it is diagnosed more commonly in young children and old people [4]. The role of their caregivers and family members is certainly very important and in children the process of parenting also plays an extremely important role in their development.

Parents of epileptic children are always worried due to the fact that their child suffers from epilepsy, which is but natural. Most mothers tend to suffer from a “worried well syndrome”. A common question which troubles these parents is that ‘Why only our child has epilepsy?’ They do try to find a reason, but most of the time they cannot identify any. In this situation, counselling and epilepsy support groups are extremely helpful for the parents and the caregivers to cope up with the problem.

A counsellor can play a very important role in helping PWEs and their families. In India, people still consider epilepsy as mental illness and hence, PWEs feel stigmatized and marginalised, even though they have good control over their epileptic seizures with medication. Not only the PWEs but also their families go through a lot of stress and strain. Doctors may not be able to spend enough time with the PWEs, in which case the role of an epilepsy counsellor becomes important because she/he can spend more time with the patient and the family members and reassure them that they can successfully cope up with the problems associated with epilepsy. Furthermore, the counsellor helps them to overcome anxiety and fear, helps to understand the nature of the seizures, informs them about their rights and helps to improve the relationships within the family.

Epilepsy support groups, typically established and run by Non-governmental Organisations (NGOs), are other important agencies in giving confidence to PWEs and family members and can help them to overcome the stress, anxiety and loneliness. The members being people who face similar issues and concerns, and have common experiences, can provide emotional and moral support to one another. They can share among themselves various coping strategies and thus feel empowered and develop a sense of community. The help may take the form of providing and evaluating relevant information, relating personal experiences, listening to and accepting others' experiences, providing sympathetic understanding and establishing social networks. A support group may also work to inform the public or engage in advocacy.

Epilepsy support groups, also help the PWEs to solve various other issues, as per their age group. As mentioned earlier, if a child is being removed from the school because of epilepsy, then the support group can help parents to know about their rights and the related laws. They can inform the school authorities about these laws and guide parents on their approach about this issue.

Matrimonial meets for the PWEs are also arranged by epilepsy support groups. Pune is perhaps the only city in India, where “Epilepsy Marriage Bureau” is run by the NGO. This marriage bureau is only for the people with controlled epilepsy, and receives queries from all over India. Till date this NGO has conducted 4 epilepsy matrimonial meets and has arranged 24 marriages of the PWEs.

In summary, it is essential to acknowledge that there exists a need to create widespread awareness within the society about epilepsy, the neurological disorder. Firstly, PWE should start an immediate treatment from the neurologist, and should continue it uninterrupted with patience. Secondly, they should not hide epilepsy while making friends, joining the school, arranging the marriage, interviewing for the job, etc. Finally, NGOs should make regular awareness programs to remove the misunderstandings about epilepsy.

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