

Impact of epilepsy

Epilepsy itself should not impair performance.

According to a study in India, 39% of students with epilepsy had difficulty with their studies, while 9% of the employed faced difficulties at work. Work performance was affected in 26% of patients and 39% had personality problems. Surprisingly, 15% had concealed their illness from their employers and colleagues. While the situation will improve over time, it is currently a matter of increasing concern for all.

The role of a medical care provider is not limited to controlling seizures, but extends to helping the patient improve the overall quality of his/her life.

Epilepsy affects every sphere of an individual's life, cutting across age, gender and social differences. The overall quality of life is hampered due to the nature of the illness and associated effects. Major areas of education, employment, marriage and social functioning are affected and the individual experiences personal problems. The discriminating attitude of society makes the situation worse. It is indeed the sociocultural attitudes rather than the illness itself which worsen the quality of life of people with epilepsy.

Impact on education

The fundamental requirement of a growing child is education. Children with epilepsy are not sent to school because of parental fears. In school, teachers display segregational attitude such as separating, neglecting or barring such children from school activities. A seizure in the classroom is regarded as "a horrible scene and a nuisance" by teachers and other children. The major problems encountered by school-going children with epilepsy are coping with studies, difficulty in making friends, fear of seizures occurring at school, disliking school, fear of teachers, drowsiness due to medication, decreased attention and low performance. It should be noted that epilepsy by itself does not impair the intellectual performance of the child. Usually, the impairment is due to the side-effects of medications or the social stigma inflicted on the patient. There is virtually no facility to provide first-aid for children in case of a seizure, and to educate and involve other children in school. These attitudes cause the child to drop out and discontinue education. At such times, parents and society aggravate matters by labelling the child a failure. Due to the precious years of schooling lost, peer groups, parents and neighbours look down on the child, thus creating an inferiority complex. The positive strengths of these children are never brought out, making them possible failures in later life.

Impact on employment

Good education is an essential factor in acquiring gainful employment. Once children lag in education, they will find, as adults, that jobs are not easily available in today's competitive world. Employers do not want to employ a person with epilepsy; when employed and if prone to uncontrolled attacks, the person with epilepsy faces a worsened situation. They are not given normal jobs but placed in sundry peripheral low-income assignments. Often these jobs are terminated. Loss of

a job or low income from a job renders the person to be less productive and a “burden” on the family.

Recent studies indicate a slightly higher risk of accidents at the workplace. The employer’s fear of compensation further segregates the person. At the end of a four-year follow-up study from India, 2% had stopped going to work and the work status had changed for 6% of patients due to uncontrolled seizures. Deterioration was noticed in 25% of the patients when seizures were uncontrolled, leading to a significant drop in work efficiency. The costs of medical management and travel to hospitals added to the existing burden.

Impact on the family

A number of social problems such as interpersonal conflicts and rejection surface later in life, leading to strained relations. Over a period of time, this leads to feelings of helplessness, hopelessness and worthlessness, often driving the person to the extreme step of suicide or running away from home.

The combined effects of epilepsy on the family, the school and in the workplace have a significant impact on the psychosocial functioning of the patient. The family’s reactions vary from mixed feelings of overprotection, to rejection, to using the patient as a scapegoat. Emotional responses include horror, guilt, anxiety, sadness, worry, confusion, depression and even avoidance. These reactions lead to various behaviours such as overindulgence, poor monitoring, sibling jealousy and decreased parental expectations. Further, these cause disturbed family dynamics, leading to guilt and concealment, adoption of a sick role, dependence and low self-esteem. The emotional adjustment and coping strategies for these problems thus begin with the individual and extend to the family, acting as major stressors. These behaviours and limited coping patterns lead to changes in personality, apart from the illness itself. Such personality problems coupled with the disease process and medication lead to difficulties in adjustment in interpersonal areas, education, employment and family life. This results in decreased productivity of the person, both in financial and other areas. The patients are already struggling with seizure problems and must face other difficulties as well, which only serve to aggravate the situation.

In the absence of a sound education and a good job, getting married and leading a healthy family life is much more difficult. In traditional societies, getting a daughter with epilepsy married is an extremely difficult task.

Attitude towards marriage for people with epilepsy...

“Revealing is dangerous and acceptance is risky” sums up the situation for family members.