

# Perceived impact of epilepsy in teaching hospitals of Tehran University

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## Keywords

Epilepsy, Perceived Impact, Quality of Life

## Abstract

**Background:** Epileptic seizures would result in embarrassment in society and have some negative impact on the patients' social activities. The aim of this study was to show the perceived impact of epilepsy by patients on different aspect of their social activities including occupation, marriage and education.

**Methods:** We studied 179 epileptic patients aged 16 years and over using face to face interview. Nine domains including relation to spouses, relation to family members, social life, general health, interpersonal communications and friendships, feelings about success, hope for future, ordinary life and cope with others were considered.

**Results:** One hundred and seven men and 72 women were studied. Nearly 78% of the patients had generalized tonic-clonic seizures. More than half of the patients believed that epilepsy had affected their social life and activities. General health was negatively affected by this disease more than any other item. This may be due to uncontrolled attacks or taking medications. About 15.5% of married and 39% of the single patients considered epilepsy as an obstacle to marry with their ideal spouses and more than half of the employed persons considered epilepsy as an obstacle for their job promotions.

**Conclusion:** Epilepsy frequently impacts on several aspects of life. The disease negatively affects social life and activities, overall health, feelings about self, ability to work in paid

employments, relationship with spouses, friends, and other family members, future plans, standards of living and ambitions of epileptic patients. Decreasing such impacts should be considered as an important part of treatment and proper management can certainly increase various aspects of life in these patients.

## Introduction

Most chronic diseases have biological, social and psychosocial aspects. Epilepsy is not an exception to this rule and its psychosocial aspects play an important role in the management of such patients.<sup>1</sup>

Unpredictable seizures disrupt normal daily livings and patients experience fear of such spells through their life. Dependency and depression are more frequent in these patients and they have less opportunity to show their skills at work. Psychosocial aspects may be ignored by physicians because they usually pay more attention to the pathophysiology of the disease and controlling the attacks. In fact, epilepsy is a chronic condition with the potential to significantly affect a broad range of aspects of quality of life.<sup>2,3</sup>

Nowadays, treatment is not limited to controlling seizures. Increasing self-confidence and social abilities are important part of it. For proper treatment and increasing quality of life, we should have precise understanding of patients' views to the society and themselves. This study was conducted to evaluate perceived impact of epilepsy in such patients and also patients' views on marriage, fertility, education, occupation and social acceptance.

## Materials and Methods

This descriptive cross-sectional study was conducted in epilepsy clinics of teaching hospitals of Tehran University of Medical Sciences during one year from October 2008 to November 2009. Epileptic patients aged 16 or older were included in this study. Diagnosis was made by experienced neurologists according to clinical manifestations and electroencephalograms (EEG).

Subjects were collected with simple convenience sampling. Exclusion criteria were mental retardation, cerebral palsy and epilepsy with physical disabilities (blindness, deafness). Information was collected with face to face interviews and completing a questioner. The questioner contained a number of scales and questions covering personal information like age, sex, job, education, seizure type, frequency and the perceived impact of epilepsy. This study was approved by the ethics committee of Tehran University of Medical Sciences and written informed consent was obtained from all patients before entering the study.

To assess perceived impact of epilepsy, we used scales proposed by Jacoby et al.<sup>4</sup> Respondents were asked to state the extent to which social life and activities, overall health, feeling of self, relation to spouses, relation to family members, feeling about success, friendship, ordinary life and cope with others and hope for future were compromised by their condition. They were also asked whether they had seizures once or more per month, less than once a month or not at all in the last year.

## Results

During one year, 179 patients (107 male, 72 female) were studied. The mean age of the study population was 30.6 years. The average years from disease diagnosis were 10 years. 58% of participants were single and 39.1% were married. One female patient was separated and one woman was widowed. One hundred and forty patients (78.2%) had generalized tonic-clonic seizures and 21.8% had other types. Twenty four percent of the patients had no seizure during last year, 38.5% had less than one seizure per month and the remaining 37.5 % had more than one attack during a month. About 15.7% of married, and 39% of the single patients

considered epilepsy as an obstacle to marry with their ideal spouses. Two third of the patients informed their spouses before marriage about their disease. The divorced patient declared that epilepsy was the main cause of separation.

Around 1.7% of the cases were illiterate, 44.5% of them had primary and secondary school education, 47.5% had high school diploma and 8% had higher levels of education. Thirty nine percent of the patients were employed and the others were students, unemployed or housewives. Among the employed, 58% considered epilepsy as an obstacle for job promotions.

Perceived impact of epilepsy and different aspects of daily living are shown in table 1. More than half of the respondents believed that epilepsy substantially negatively affected their social lives and activities, overall health, feelings about self, and ability to work in paid employments. Additionally, more than one third of them also felt that it strongly had negative effects on relationship with spouses, friends, and other family members, future plans and ambitions and standards of living.

Overall, only 32.6% of the cohort believed that all aspects of daily living were unaffected at all by their conditions, whereas 19.1% reported little effects and 48.3% of them believed that their epilepsy strongly had negative effects on all mentioned domains (mean perceived = 48.3%).

## Discussion

Generalized tonic-clonic convulsion was the most common type of epilepsy in this study. We have had no large scale epidemiologic study in Iran, but the same results were seen in Turkey and Pakistan.<sup>5,6</sup>

Only 1.7% of the patients were illiterate which was lower than official statistics in Iran, this may be due to higher rate of urban than rural population in our study. Table 1 shows that general health was the item most negatively influenced by epilepsy. This may be due to taking medication or uncontrolled attacks.<sup>7</sup> 37.8% of our patients had more than one attack per month and just 24% of them had no attack during one year prior to the study.

The most benefits of decreased illness intrusiveness in

Table 1. Perceived impact of epilepsy on aspects of daily living

Aspect of daily living	Felt epilepsy and treatment affected		
	A lot or some	A little	Not at all
Relation with spouses	45.2	8.2	46.6
Relation with other family member	49.1	10.6	40.3
Social life and activities	57.6	17.6	25.8
Health over all	68.7	14.6	16.7
Relation with friends	35.3	20.7	44
Feeling about self	53	23.5	23.5
Hope to future	45.3	29	25.7
Ordinary life	47.5	33.5	19
Cope with others	33.5	14.5	52
Mean perceived impact of epilepsy	48.3	19.1	32.6

epilepsy occur when treatment leads to complete seizure control.<sup>8</sup> Park et al. found that affective symptoms are more important determinant of quality of life (QOL).<sup>9</sup> Cramer et al. demonstrated perceived decrements in health status ratings with seizures were greatest for patients with the least frequent seizures and the most recent seizures.<sup>10</sup> McLaughlin et al. showed that impaired health related to quality of life (HRQOL), and in older adults, the apprehension induced by even the possibility of a seizure may be sufficient to reduce HRQOL.<sup>11</sup> Therefore, overall health is directly related to seizure control, but number and types of medication, daily dosage and side effect profiles of antiepileptic drugs may also have effect on it, which were not evaluated in our study.

Second rank in the negatively affected items, was social life and activities. This may be explained by this fact that poorly controlled epileptic patients were always concerned about having seizures in the public. Such stresses may prevent them to participate in social activities in the one hand and could also exaggerate their seizures on the other hand.<sup>12</sup>

Feeling about self obtained the third rank among the negatively affected items but this aspect was somehow related to general health and social activities. Not to feel healthy and limitation of social activities could reduce patients self-esteem.

Because two-thirds of our patients had informed their spouses about their disease before marriage, almost half (46.6%) of the patients reported that their relation with spouse was not affected by epilepsy at all. It is important that only 33% of the patients had no limitation in their educations and the rest had difficulties in continuing it. Such perceived impact of epilepsy surely influences educations at all levels. In the other studies, the epileptic patients had also problems in higher education and

university degrees.<sup>7,13</sup> Epileptic patients showed a more avoiding coping style and this was more prominent in female patients.<sup>14</sup> Psycho-educational programs for adults with epilepsy improve knowledge, coping skills and level of felt stigma, at least in short period, although it may not be persistent over time.<sup>15</sup>

Although our study was limited to adult population, others showed that children have the same difficulties as adult; even child with the first seizure had negative change in perceived health.<sup>16</sup> The frequency of emotional and behavioral disorders including depress disorder, anxiety disorder and attention deficit disorder with hyperactivity (ADHD) was considerably high in children with epilepsy.<sup>17</sup> One-third of the children keep their epilepsy a secret from other people at some time for fear of being treated differently. They expected the condition to hinder their life in the future with impact on employment and education.<sup>18</sup>

One of our limitations was omission of epileptic patients younger than 16 years old due to different views and different effective items in childhood compared to adult age.

While it is not possible to completely change the perceived impact of epilepsy, it can be reduced by increasing self-confidence of the patients and proper treatment to decrease frequency of seizures. Such strategy should be considered as an important part of treatment, because negative viewpoints indirectly affect quality of life in such patients.

#### Acknowledgement

The authors wish to thank Iranian Epilepsy Association for their contributions in patients' personal contacts.

#### Conflict of interest

The authors have no conflict of interest.

#### References

1. Fernandes P.T, de Barros NF, Li L.M. Stop saying epileptic. *Epilepsia* 2009; 50:1280-3.
2. Baker G.A, Jacoby A, Buck D, et al. Quality of life of people with epilepsy: A European study. *Epilepsia* 2005; 46:353-62.
3. Shackleton DP, Kasteleijn-Nolst Trenite DG, de Craen AJ, et al. Living with epilepsy: Long-term prognosis and psychosocial outcomes. *Neurology* 2003; 61:64-70.
4. Jacoby A, Baker GA, Smith D, et al. Measuring the impact of epilepsy: the development of a novel scale. *Epilepsy Res* 1993; 16:83-8.
5. Aziz H, Gurener. Comparative epidemiology of epilepsy in Pakistan and turkey: population based studies using identical protocol. *Epilepsia* 1997; 38:716-22.
6. Aziz H, Akhtar S, Zaki K. Epilepsy in Pakistan: stigma and psychosocial problems. Population based epidemiologic study. *Epilepsia* 1997; 38:1069-73.
7. Jacoby A. Epilepsy and the quality of every day life, finding from a study of people with well – controlled epilepsy. *Soc Sci Med* 1992; 43:657-66.
8. Poochikian-Sarkissian S, Sidani S, Wennberg R, et al. Seizure freedom reduces illness intrusiveness and improves quality of life in epilepsy. *Can J Neurol Sci* 2008; 35:280-6.
9. Park SP, Song HS, Hwang YH, et al. Differential effects of seizure control and affective symptoms on quality of life in people with epilepsy. *Epilepsy Behav* 2010; 18:455-9.
10. Cramer JA, Brandenburg NA, Xu X, et al. The impact of seizures and adverse effects on global health ratings. *Epilepsy Behav* 2007; 11:179-84.
11. McLaughlin DP, Pachana NA, Mcfarland K. Stigma, seizure frequency and quality of life: the impact of epilepsy in late adulthood. *Seizure* 2008; 17:281-7.
12. The REST-1 Group. Social Aspects of epilepsy in the adult in seven European countries. *Epilepsia* 2000; 41:998-1004.
13. Callaghan N, Crowley M, Goggin T. Epilepsy and employment, marital, education and social status. *Ir Med J* 1992; 85:17-9.
14. Westerhuis W, Zijlman M, Fischer K, et al. Coping style and quality of life in patients with epilepsy: a cross-sectional study. *J Neurol* 2011; 258:37-43.
15. Bandstra NF, Camfield CS, Camfield PR. Stigma of epilepsy. *Can J Neurol Sci* 2008; 35:436-40.
16. Hamiwka L, Singh N, Niosi J, et al. Perceived health in children presenting with a "first seizure". *Epilepsy Behav* 2008; 13:485-8.
17. Chen Q, Yan XX, Shang NX, et al. Emotional and behavioral comorbidities and the impact on the quality of life in epilepsy children. *Zhonghua Er Ke Za Zhi* 2010; 48:346-50.
18. Baker GA, Hargis E, Hsieh MM, et al. Perceived impact of epilepsy in teenagers and young adults: an international survey. *Epilepsy Behav* 2008; 12:395-401.