

## A Cross Sectional Study Evaluating Perceived Impact of Epilepsy on Aspects of Life

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### Article information

#### Article history:

Received: 12 Dec 2011

Accepted: 24 May 2012

Available online: 30 May 2012

#### Keywords:

Epilepsy

Perceived impact

Quality of life

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### Abstract

**Background:** Unpredictable spells of 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.

**Materials and Methods:** We studied 179 epileptic patients age 16 years and over with 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 spells 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 impact on several aspects of life. The disease negatively affects social lives 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.

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### Introduction

Most chronic diseases have biological, social and psychosocial aspects. Epilepsy is not an exception to this rule and its psychosocial aspects plays an important role in the management of such patients [1]. Unpredictable seizures disrupt normal daily livings and the patients experience fear of such spells through their lives.

Dependency and depression are more frequent in the 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 potential to affect significantly the broad range of aspects of quality of life [2, 3].

Nowadays treatment is not limited to controlling seizures and 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 (Oct 2008-Nov 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). Cases were collected with simple conventional 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; It 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 Jocoby et al [4].

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 per month or not at all in the last year.

## Results

During one year 179 patients (107 male, 72 female) were studied. Demographic and clinical characteristics of respondents and the mean age of the study population was 30.6 years.

The average years from disease diagnosis were 10 years. Higher proportion were single (58.6%) 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 educations.

Thirty nine percent of the patients were employed and the others were students, unemployed or housewives. Among the employed 58% consider epilepsy as an obstacle for job promotions. Perceived impact of epilepsy and different aspects of daily living are shown in Figure.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.

About 57% had trouble with their Social life and activities. Around 68% had a lot of problems with Health overall while only 16.7% did not have affected. Nearly 53% had bad feeling about self, 23.5% did not have good feeling of self.

Around 45% did not have any hope to better future while 25% still keep hope for future. 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. Roughly 45% complained of significant difficulties in relations with spouse, 49% with other family members and 35.3% with their friends.

Over all only 32.6% of the cohort believed that all aspects of daily living were unaffected at all by their

conditions, where as 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%)

**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

## Discussion

Generalized tonic – clonic convulsion was the most common type of epilepsy in this study. Although we had no exact epidemiologic study in Iran, but the same results were seen in Turkey and Pakistan [5, 6]. 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 show some items that has been most negatively influenced by epilepsy is general health.

This may be due to taking medication or uncontrolled attacks [7]. Because 37.8% of our patients had more than one attack per month and just 24% of our cases had no attack during one year prior to the study. The most benefits of decreased illness intrusiveness in epilepsy occur when treatment leads to complete seizure control [8].

Park et al found affective symptoms is more determinant of quality of life (QoL) [9]. Cramer et al demonstrate perceived decrements in health status ratings with seizures were greatest for patients with the least frequent Seizures and the most recent Seizures [10]. McLaughlin showed that impair health related quality of life (HRQoL), and in older adults, the apprehension induced by even the possibility of a seizure may be sufficient to reduce HRQoL [11]. Therefore, health overall is directly related to satisfactory seizure control, but number and types of medication, daily dosage and side effect profiles of antiepileptic drugs may also effect this item, which are not evaluated in our study.

Second rank in negatively affected items, is 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 view, such

stresses may prevent them to participate in social activities in one hand and could also exaggerate their seizures on the other hand. [12]

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

Because two third 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 is not affected by epilepsy at all. It is important that only 33% of the patient had no limitation in their educations and the rest had difficulties in continuing it.

Such perceived impact of epilepsy surely influence educations at all levels. In other studies the epileptic patients had also problems in higher education and university degrees [7, 13].

Epileptic patients showed a more avoiding coping style, and this is more prominent in female patients [14].

Psycho-educational programs for adults with epilepsy improves knowledge, coping skills and level of felt stigma, at least in short period ,although it may not be persistent over time [15]. Although our study limited to

adult population; others showed that children have the same difficulties as adult: even child with first seizure has negative change in perceived health [16]. The frequency of emotional and behavioral disorders including depress disorder, anxiety disorder and ADHD was considerably high in children with epilepsy [17]. 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 lives in the future with impact on employment and education. [18] One of our limitations was omission of epileptic patients younger than 16 years old due to different views and effective items in childhood and 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 with decreasing 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 of patients' personal contacts.

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*Please cite this article as:* Motamedi M, Sahraian M, Moshirzadeh S. A cross sectional study evaluating perceived impact of epilepsy on aspects of life. *Zahedan J Res Med Sci (ZJRMS)* 2012; 14(4): 33-36.