

## Research Article

# Knowledge and Attitude toward Epilepsy of Close Family Members of People with Epilepsy in North of Iran

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**Background.** Knowledge and attitudes are required for relatives of people with epilepsy to allow them to better understand and cope with this condition. This study evaluated the knowledge and attitudes of family members of people with epilepsy about the disease. **Methods.** This cross-sectional survey was conducted using a self-administered questionnaire completed by close family members of people with epilepsy at the outpatient clinic of a medical university. The questionnaire included 25 items that determined the demographics and information on the level of knowledge and attitudes about epilepsy. **Results.** The 124 participants had an average age of  $36.88 \pm 10.68$  years. The mean knowledge score was  $10.32 \pm 2.25$  (range: 4 to 15). 87.1% of respondents answered that epilepsy is a brain disorder, 39 (31.5%) said epilepsy is inherited. As a whole, 62 (50%) had good knowledge about the disease. The mean score of attitude was  $7.25 \pm 1.54$  (range: 2 to 10). 83.9% of respondents believed that a person with epilepsy can get married and get pregnant (76.6%). Overall, 15 (12.1%) had negative attitudes and 109 (87.9%) had positive attitudes. **Conclusion.** The main findings of this study indicated good knowledge and a positive attitude about epilepsy among family members of people with epilepsy.

## 1. Introduction

Epilepsy is a common neurological condition that affects personal and familial behavior and social support [1, 2]. About 50 million people worldwide suffer from epilepsy and the prevalence of active epilepsy in developing countries is 5 to 10 per 100 persons [3]. A prevalence of 0.7–1.8% has been reported in Iran [4]. Individuals with epilepsy may suffer from psychological issues such as depression, anxiety, and psychosis [5]. Accordingly, living with a person with epilepsy will provide some challenges, particularly at home. Studies have reported that relatives of people with epilepsy have an increased risk of anxiety [6]. Epilepsy can inflict an enormous burden on both the people with epilepsy (PWE) and their family caregivers, decreasing their quality of life and daily efficiency [7]. Awareness, knowledge, and attitudes are important qualities for relatives of people with epilepsy to better understand this condition [8]. Studies have shown that people with less awareness and knowledge about epilepsy tend to have negative attitudes toward the

disease and misperceptions such as epilepsy being a form of insanity, untreatable, contagious, and hereditary or a form of mental retardation [9–12]. Cultural beliefs, superstition, and lack of information about epilepsy have perpetuated such misconceptions in developing countries [13–16].

Several factors about people with epilepsy and their caregivers influence the quality of life of patients. These include social disadvantages, family circumstances, seizure frequency, and severity and rate of response to treatment [17]. Studies have demonstrated that people with epilepsy and their relatives do not have adequate basic information about epilepsy including seizure precipitants, types of seizures, and side effects of medications [18]. Misunderstandings and misinformation should be recognized and corrected for optimal care. In Iran, few studies regarding knowledge of people living with epilepsy and their relatives about epilepsy were conducted.

One study in Iran reported that knowledge about epilepsy of relatives of PWE was poor and they tended to have a negative attitude toward the disease [19]. The present study

evaluated the level of knowledge and attitudes of family members of people living with epilepsy about the disease.

## 2. Methodology

This cross-sectional survey was conducted using a self-administered questionnaire completed by adult family members of people with epilepsy at an outpatient clinic of a medical university (Tooba clinic) in Mazandaran province in the city of Sari in northern Iran. The patients have been referred to the clinic from all urban or rural regions of Mazandaran province. This clinic is a tertiary referral center. Approximately 250 neurological patients are seen at the clinic daily.

The participants were the relatives of people with epilepsy who had a close relationship with the patient, lived in the same house, and had heard of epilepsy. The participants were interviewed at the Neurology Outpatient Clinic during patient visits. The respondents included the mothers, fathers, brothers, sisters, or the husband/wife of patients that were over 15 years of age. Iran is a Muslim country with Islamic customs. The populations of Mazandaran province are primarily Shia Muslims.

The questionnaire comprised closed-ended questions to which the responses were either “Yes,” “No,” or “I do not know.” The participants filled out the questionnaire at a rearranged time and location and were not obliged to hurry in their responses. The investigators waited while the questionnaire was completed to offer help if there were any questions. The data was collected from April 2014 through May 2016.

The 25 items were developed after an extensive review of the international literature [20–23]. The questions were translated into Farsi from the English version and then back-translated by psychiatrists and neurologists. Straightforwardness, accuracy, and meaning were carefully checked. A pilot study was conducted with 20 randomly selected family members of people with epilepsy on two separate occasions two weeks apart to determine the feasibility and reliability of the Farsi version of the questionnaire. The reliability of the questionnaire was tested by Cronbach's alpha which resulted in an internal consistency of 0.74.

The questions were divided into three sections. Section 1 requested demographic information including age, gender, marital status, educational level, and occupation. Section 2 investigated the level of knowledge about epilepsy (15 items) and Section 3 explored the attitudes, perception, and beliefs of the respondents toward epilepsy (10 items). Knowledge and attitude were evaluated separately for each participant. Each correct answer was awarded one point and incorrect or “I don't know” responses were awarded scores of zero. For evaluation of total attitude and knowledge of participants, the scores were summed up for each participant. The range for knowledge was 0–15 and for attitude was 0–10. The knowledge score was further categorized as poor (0–5), fair (6–10), or good (11–15). The attitude score was categorized as negative (0–5) or positive (6–10) [21, 24–26].

This project was approved by the ethics committee of the Medical School of Mazandaran University of Medical

Sciences. The study was conducted in accordance with the Helsinki declaration on research ethics. Participation was voluntary and the responses were anonymous. After obtaining informed consent, 124 literate subjects were enrolled in the study.

The data was analyzed using SPSS version 20.0. The demographic data and epilepsy knowledge and attitude scores of close relatives were analyzed using descriptive statistics (mean, percentage, and frequency distribution). Chi-square ( $\chi^2$ ) was used to determine the association between variables and demographic data. To assess the relationships between demographic information and the knowledge and attitude scores, regression analysis was conducted. Pearson's correlation was used to determine the association between attitude and knowledge. The results were considered significant at  $P < 0.05$ .

## 3. Results

Of the 124 participants, 35.5% ( $n = 44$ ) were males and 64.5% ( $n = 80$ ) were females. The ages ranged from 18 to 58 years with a mean of  $36.88 \pm 10.68$  years. The majority (34.7%) of subjects were 37–47 years of age. Table 1 shows the demographic characteristics of the respondents. There were no differences between males and females regarding age distribution, educational level, or number of family members, but there were differences between gender and marital status and also occupation. The majority of females were married and unemployed.

**3.1. Knowledge about Epilepsy.** The mean knowledge score was  $10.32 \pm 2.25$  (range: 4 to 15). Of the 124 participants, 4 (3.2%) scored as having poor knowledge; 58 (46.80%) had fair knowledge; and 62 (50%) had good knowledge. The results are summarized in Table 2. When asked about the cause of epilepsy, the majority of participants (108; 87.1%) answered that epilepsy is a brain disorder, 39 (31.5%) said that epilepsy is inherited, 58 (46.8%) said that it is without a specific cause, 54 (43.5%) said that epilepsy is a mental disorder, and also 5 (4%) believed that it is contagious. Of the 124 responders, 10 (8.1%) believed epilepsy to be demonic possession or of supernatural origin. In terms of knowledge about trigger factors for repeated seizures, the responses were as follows: specific foods and drinks (53.5%), sleep deprivation (66.9%), starvation (56.5%), and watching TV or using the computer for a long time (66.1%). In comparison with other disorders, 64 (51.6%) of respondents said that epilepsy is more dangerous than diabetes mellitus but only 17 (13.7%) of participants believed that epilepsy is more violent than malignant carcinoma.

To assess the relationships between demographic information and knowledge, regression analysis was conducted. A significant association was found between the knowledge score and the level of education and larger family size, but not for age, gender, marital status, or occupation.

**3.2. Attitudes toward Epilepsy.** The mean score for attitude was  $7.25 \pm 1.54$  (range: 2 to 10). Of the 124 responders, 15

TABLE 1: Demographic characteristics of the respondents (n = 124).

	Male = 44 (%)	Female = 80 (%)	Total (%)	P value
Age (years)				
15–25	11 (61.2)	7 (38.8)	18 (14.5)	0.51
26–36	11 (26.2)	31 (73.8)	42 (33.9)	
37–47	13 (30.24)	30 (69.76)	43 (34.7)	
≥48	9 (42.9)	12 (57.1)	21 (16.9)	
Marital status				
Single	16 (57.14)	12 (42.86)	28 (22.6)	0.007
Married	28 (29.16)	68 (70.84)	96 (77.4)	
Educational level				
Under diploma	10 (21.73)	36 (78.27)	46 (37.09)	0.134
Diploma	19 (41.31)	27 (58.69)	46 (37.09)	
University education	15 (46.87)	17 (53.13)	32 (25.91)	
Number of members in family				
Small (<3)	9 (31.04)	20 (68.96)	29 (23.4)	0.39
Average (3–5)	30 (40)	45 (60)	75 (60.5)	
Big (>5)	5 (25)	15 (75)	20 (16.1)	
Occupation				
Employed	11 (64.71)	6 (35.29)	17 (13.73)	0.0001
Unemployed	33 (63.47)	19 (36.53)	52 (41.92)	
Housewife	0	55 (100)	55 (45.35)	

TABLE 2: Responses to questions on knowledge of epilepsy.

Questions	Yes %	No %	Don't Know %
(1) Epilepsy is a hereditary disorder	31.5	66.9	1.6
(2) Epilepsy is a disorder of the brain	87.1	12.1	0.8
(3) The cause of epilepsy is unknown	46.8	51.6	1.6
(4) Epilepsy is caused by demon possession or supernatural powers	8.1	88.7	3.2
(5) Malnutrition is the cause of epilepsy	33.1	65.3	1.6
(6) Epilepsy is an infectious disease and contagious	4	96	0.0
(7) Epilepsy is a form of mental illness	43.6	54.8	1.6
(8) Starvation can cause attacks of seizure in epileptic patients	56.5	43.5	0.0
(9) Inadequate sleep can cause attacks of seizure in PWE	66.1	31.5	1.6
(10) Some certain foods or drinks make a seizure	53.2	44.4	2.4
(11) Looking at the TV or computer for a long time is caused of epileptic attacks	66.1	32.3	1.6
(12) Epilepsy is more <i>violent</i> than			
(i) Diabetes mellitus	51.6	46	2.4
(ii) AIDS	24.2	73.4	2.4
(iii) Malignant carcinoma	13.7	83.1	3.2
(iv) Stroke	26.6	72.6	0.8

(12.1%) had negative attitudes and 109 (87.9%) had positive attitudes. The results are summarized in Table 3. The majority of responders, 109 (83.9%), believed that a person with epilepsy can get married and get pregnant (76.6%). One hundred and four (83.9%) of the 124 respondents said PWE can have a collage education while thirty-one (25%)

believed PWE have lower intelligence than other people. Three (2.4%) of respondents believed that PWE are insane and 9 (7.3%) of participants believed that magic and religious practices improve epilepsy. In terms of treatment, 74 (59.7%) of respondents believed that PWE require lifelong treatment. Sixty-three (50.8%) believed that it is safe for people with

TABLE 3: Responses to questions related to attitudes toward epilepsy.

Questions	Yes %	No %	Don't Know %
(1) It is possible for a person with epilepsy to get married	83.9	15.3	0.8
(2) PWE can get pregnant	76.6	21.8	1.6
(3) PWE can drive safely	50.8	47.6	1.6
(4) PWE can swim	54.8	44.4	0.8
(5) PWE can get opportunities of appropriate occupation	77.4	22.6	0.0
(6) PWE require lifelong treatment	59.7	40.3	0.0
(7) PWE can have a collage education	83.9	15.3	0.8
(8) PWE are insane	2.4	97.6	0.0
(9) PWE have lower intelligence than other people	25	74.2	0.8
(10) Cure is achievable by magic/religious practices	7.3	92.7	0.0

PWE: people with epilepsy.

epilepsy to drive and 68 (54.8%) believed that they can swim. Regression analysis showed a significant association between a positive attitude score and the female gender and level of education but no association with age, marital status, or occupation.

**3.3. Correlation of Knowledge and Attitude toward Epilepsy.** 64 (61.5%) of the 83 respondents who said “epilepsy is not hereditary” believed that people with epilepsy can marry. There was significant difference among this groups ( $P = 0.014$ ).

Of the 68 respondents who thought “epilepsy is not a form of mental illness,” 66 (97.05%) believed people with epilepsy are not insane ( $P = 0.1$ ), 57 (86.36%) of respondents believed persons with epilepsy can get opportunities of appropriate occupation ( $P = 0.017$ ), and also 60 (88.23%) said persons with epilepsy can have university education (0.039). Of the 110 respondents who said “epilepsy is not caused by demon possession,” 106 (92.2%) of them believed that religious practices are not effective in improvement of epilepsy (0.0001).

As a whole, in terms of relationship between knowledge and attitude toward epilepsy, there was no significant difference between knowledge and attitude.

#### 4. Discussion

This study assessed the levels of knowledge and attitudes about epilepsy of close family members of people with epilepsy. Although most people with epilepsy manage their disease on their own, family members play an important role in the follow-up and treatment of patients. The care of people with epilepsy is emotionally overwhelming and relatives are at an increased risk for depression [27]. Few studies have been done in developing countries, especially Iran, on the knowledge and attitudes of relatives of people with epilepsy about epilepsy. The present study showed that close family members of people with epilepsy had strong conceptions and good knowledge about epilepsy. They believed that epilepsy is a brain disorder (87.1%) or an infectious disease or contagious

(96%) and is not of supernatural origin (88.7%). They had less information about triggers of epilepsy. Overall attitudes toward epilepsy among family members were positive. Most respondents believed PWE can marry, hold an appropriate occupation, receive university education, and are as intelligent as nonepileptics. These findings are similar to results of studies among school teachers in Iran [4] and in the UK [28]. Nevertheless, there were negative attitudes in some aspects. One less than positive finding was that persons with epilepsy can swim and drive safely. Singh and Arora found that the majority of people believed that PWE should not swim or drive [20]. The results of the present study suggest that this erroneous belief can be dangerous for the patient and other people. Religious and cultural beliefs influence the treatment and follow-up of persons with epilepsy. In the present study, 8.1% of respondents believed that epilepsy is of supernatural origin and 7.7% believed epileptic patients can be cured by magic/religious practices. Masoud and Kochaki found that 14.4% of respondents believed religious practices can affect the treatment of people with epilepsy [19]. The respondents of the present study also reported supernatural origins as the cause of epilepsy, but this is much lower than other studies and this is a positive finding of our study [20, 29, 30]. In Iran few studies about knowledge of epilepsy in different population groups including teachers, people with epilepsy, general public, and relatives were conducted [4, 19, 31–33]. These studies have shown different results. A previous study in Iran found that knowledge about epilepsy of family members of patients was poor and relatives lacked information about the disease [19]. Also survey on stigma and discrimination experienced by persons with epilepsy in Tehran revealed a moderate level of stigma experiences [33]. Another study in Iran reported poor knowledge of epilepsy and that patients with the disease were thought to have compromised mental health [34]. On the other hand, other studies in between different ethnic groups and school's teachers in Iran indicated that the level of awareness about epilepsy was quite high and teachers had positive attitude about epilepsy [4, 31]. Public awareness of epilepsy in Iran showed similar to studies conducted in high income western

countries [32]. There was a significant association between an increase in knowledge score and an increase in family size and educational level in the present study that correlates with the findings of other studies [29, 34]. A higher level of education and larger family size correlated with a higher percentage of correct responses to the knowledge questions. This result is consistent with findings of other study [32]. A relationship was found between increased level of education and the female gender with attitudes about epilepsy. Sidig et al. reported that 26% of respondents had good knowledge and 43% had poor knowledge about epilepsy [30], while, in the present study, only 3.3% of participants showed poor knowledge. In the present study, there was no significant association between attitude and knowledge. Saengsuwan et al. reported a weak and negative correlation between knowledge and attitude toward epilepsy [29]. This finding is different from other studies who found good knowledge to be correlated with more positive attitudes [8, 35].

## 5. Conclusion

The results of the present study showed that family members of PWE have a high level of knowledge and positive attitude about most aspects of epilepsy. They mostly underlined physical causes of epilepsy and rejected demon possession or supernatural powers which is a metaphysical cause. They had a positive attitude about getting an appropriate occupation and to get married. With respect to their attitudes toward the treatment of epilepsy, one-half of the interviewees believed PWE require lifelong treatment. They also declined spiritual healing as method of treatment for epilepsy. Insufficient information and incorrect beliefs about some issues related to epilepsy remain, however. Almost one-half of respondents thought epilepsy is a form of mental illness and also PWE can drive or swim safely. Family members and relatives require more education and training about epilepsy through community education programs to ameliorate misconceptions and increase understanding about this disease.

## Disclosure

This study was Dr. Seyyed Ali Akbarian's dissertation doctorate towards the graduation of general medicine.

## Competing Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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