

Investigation of Behaviors of the Epilepsy Patients' Relatives During Seizure and its Association with Their Knowledge Regarding Epilepsy

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Abstract

Objectives: Relatives of epilepsy patients tend to intervene their patients during epileptic seizure with an intention to help them. Usually not based on a medical knowledge, these behaviors may harm the patient rather than providing benefit. This study aimed to investigate interventional behaviors to the seizure to build a base for informing epilepsy patients and their relatives.

Methods: In this study, a questionnaire prepared by us was applied to the participants who met the inclusion criteria.

Results: A total of 23 subjects, consisting of 20 females and three males, participated to the survey. Mean age of the participants was 42. There were four patients who thought the event to be epilepsy. The percentage of participants who declared that they observed a seizure before was 47.8%. When the interventions were grouped, it found that 52.2% of participants intervened to the surrounding, while 47.8% intervened to the patient. About half of the participants said "epilepsy is a brain disorder." No participants associated epilepsy with magic or supernatural power.

Conclusion: As our study based on questionnaire about witnessing a seizure, we sought answers to the question of "what you did during the seizure." Approximately half of the relatives of the patients (47.8%) chose to intervene in their patients; the conclusion that it is important to inform the society becomes meaningful when considering that the interventions may have the potential risk to their patients.

Keywords: Epilepsy; intervention of seizure; seizure.

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Introduction

Epileptic seizure is originated from increased, rapid, and focal electrical discharges of neuron clusters in the cerebral cortex. A short-term and transient alteration with sudden onset is seen in consciousness, and behavioral, emotional, motor and/or perceptive functions during the seizure.^[1]

As one of the most common chronic neurologic conditions in both developed and developing countries, epilepsy has negative impacts on morbidity, mortality, and work productivity.^[2]

It is estimated that the prevalence of epilepsy is 6 and 18.5/1000 people in developed and developing countries, respectively; as determined by epidemiological studies performed with the protocol of the World Health Organization. Eight studies published in Turkey between 1995 and 2010 reported prevalence of the epilepsy as 7.35/1000.^[3-10]

The diagnosis of epilepsy is mainly established by clinical manifestations, based on the detailed description of the seizures by the patient and its witnesses.

In this context, we aimed to understand what kind of interventions is made in a disease whose diagnosis and intervention are based on witnessing, and the state of knowledge and awareness in the society.

Materials and Methods

This is a survey-based study to assess behaviors of witnesses of generalized tonic-clonic seizures during the seizure and to show the association of these behaviors to their knowledge regarding epilepsy. The survey consisting of a questionnaire was prepared by us and applied in a face-to-



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Epilepsi Hastalarının Yakınlarının Nöbet Sırasındaki Davranışları ve Bunun Epilepsi Hakkındaki Bilgileri ile İlişkisi

Öz

Amaç: Epilepsi hastalarının yakınları, epileptik nöbet sırasında hastalarına yardım etme niyetiyle müdahale etme eğilimindedir. Genellikle tıbbi bir bilgiye dayanmayan bu davranışlar, fayda sağlamaktan çok hastaya zarar verebilir. Bu çalışma, epilepsi hastalarını ve yakınlarını bilgilendirmek için bir temel oluşturmak için nöbete müdahale davranışlarını araştırmayı amaçlamıştır.

Gereç ve Yöntem: Bu çalışmada, dahil olma kriterlerini karşılayan hasta yakınlarına tarafımızca düzenlenen bir anket uygulanmıştır.

Bulgular: Katılımcıların 20'si kadın, 3'ü erkek olup ortalama yaş 42 idi. Olayın sara/epilepsi olduğunu düşünen 4 kişi vardı. Katılımcıların %47.8'i daha önce bir nöbet görmüş olduklarını belirtti. Yapılan işlemler hastaya veya çevreye müdahale olarak ayrıldığında, %52.2'si çevreye, %47.8'i hastaya müdahale etmeyi seçti. Katılımcıların yaklaşık yarısı "epilepsi bir beyin hastalığıdır" dedi ve hiçbiri epilepsiyi büyü veya doğaüstü bir güç ile ilişkilendirmedi.

Sonuç: Bizim çalışmamız nöbet tanıklığına ilişkin sorulara dayandığından "nöbet sırasında ne yaptınız" sorusuna yanıtlar arandı. Hasta yakınlarının yaklaşık yarısının (%47.8) hastasına müdahale etmeyi seçtiğini düşünürsek, yapılan müdahalelerin zarar verme potansiyeli olabileceği göz önüne alındığında toplumun bilgilendirilmesinin ne kadar önemli olduğu sonucu anlam kazanmaktadır.

Anahtar sözcükler: Epilepsi; nöbet; nöbete müdahale.

face fashion to the patients and their relatives who met the inclusion criteria, presenting to our outpatient clinic. Inclusion criteria for the study were having a history of clinical epileptic seizure for the patient and intervening to a seizure for the first time for the witness. The study was performed on voluntary basis after obtaining written consent from the participants. Ethics committee approval was obtained.

The questionnaire

- What did you think of this event?
- Have you ever seen any seizure of your patient before?
- Have you ever seen any seizure of any one before?
- What did you feel while your patient was having a seizure?
- What did you do while your patient was having a seizure?
- What was your aim in doing what you did during the seizure?
- Did your patient benefit from what you did during the seizure?
- What was your source of information about what you did during the seizure?
- What do you know about the epilepsy disease?

Results

Among those applied to the neurology clinic 23 participants who met inclusion criteria enrolled to the study. Mean age of the participants was 42 (range: 19–56 years), consisting of 20 females and three males.

Four of the witnesses declared that they thought the event to be epilepsy. The answers to this question are summarized in Table 1. The percentage of participants who had ever seen a seizure was 47.8%. All the witnesses stated that

they felt fear during the event. The interventions taken during the seizure was declared as following: "I spilt water," "I made her/him smell onion or garlic," "I put something to her/his mouth," "I poured cologne on her/his face," "I tried to make her/him drink sugared water," "I tried to give mouth-to-mouth resuscitation," "I gave painful stimulus," "I tried to make her/his body flat," "I moved surrounding items away," or "I opened the windows." The latter two were regarded as intervention to the surrounding area, and others were regarded as intervention to the patient. Near half of the participants (52.2%) were detected to prefer intervention to the surrounding, and the remaining 47.8% was found to prefer intervening to the patient. Some of the participants stated that they made several different interventions. The interventions made are summarized in Table 2.

The aim of the things done during the event was declared as "to make the patient recover consciousness" by some participants and as "to protect from possible injuries" by some others. Near one-third of the participants (30.4%) stated

Table1. What did you think of this event?

What did you think of this event?	Frequency	Percentage
Nothing	5	21.7
Epilepsy	4	17.4
Nothing	4	17.4
Stroke	3	13
Heart attack	3	13
Fall	2	8.7
Psychogen	2	8.7
Total	23	

Table 2. What did you do while your patient was having a seizure?

What did you do while your patient was having a seizure?	Frequency	Intervention
I spilt water	9	Intervening to the patient
I made her/him smell onion or garlic	1	
I put something to her/his mouth	1	
I poured cologne on her/his face	3	
I tried to make her/him drink sugared water	1	
I tried to give mouth-to-mouth resuscitation	1	
I gave painful stimulus	1	
I tried to make her/his body flat	1	
I moved surrounding items away	6	Intervening to surrounding area
I opened the windows	5	

that their patients benefited from their actions performed during the seizure. While 47.8% of patients responded to the question about “what is epilepsy disease” as a brain disease, the remaining (52.2%) participants did not have any idea.

Discussion

There have been numerous studies evaluating viewpoints and stigmas regarding epilepsy. With the aim of gaining insights about the public opinion about epilepsy, these studies consisted of questioning various populations about the knowledge of epilepsy, things that would be done during a seizure, and attitudes and behaviors toward epileptic patients. In this study, we collected participants’ responses about the things they did during the seizure, the aim and the source of information of these actions and compared them with the findings of the similar studies.

Familiarity with epilepsy– A study performed with 587 students in Health Sciences of Manipal University and evaluating attitudes regarding epilepsy reported that 92.5% of students were aware of epilepsy and 41.6% declared to see an epileptic seizure.^[11] In another study performed in USA with Chinese and Vietnamese adults, 58% of participants stated that they either witnessed or saw seizure on TV.^[12] In the study performed in Batibo region of Cameroon, 87.7% of 350 participants declared that they witnessed a seizure. Since Batibo is a small area with a high prevalence of epilepsy, study authors attributed this high rate to the fact that many of these people may recognize or see the same epileptic patients.^[13] A study in Ebolowa and Sangmelima regions of Cameroon reported that 75% of 456 participants ever saw a seizure.^[14] The study performed with basic and clinical medicine students in Nigeria reported that 46.8% of students were familiar with someone with epilepsy.^[15] A 2007 study in Isparta reported 53% of 582 participants to

ever see a seizure.^[16] Another study performed in Malaysia in 2010 reported that 62.9% of 615 participants witnessed a seizure.^[17] In the study by Aydemir, 30.7% of participants never heard of epilepsy and 68.4% either were not familiar with an epileptic person or did not read something about epilepsy.^[18] In our study, the percentage of participants who ever saw epileptic seizure was 47.8%. There were four people who thought that the event they witnessed was epilepsy; the reason for this opinion was that they previously saw someone suffering a seizure.

Intervening in the seizure– In the study in Manipal, 51% of participants declared that they would move the objects that the sufferer may hit away, 65.4% to move the victim to a safer place, and 20% to put a hard object into the mouth of the patient. In fact, the latter originates from the belief that sharp objects would repel demonic souls and resolve the seizure.^[11]

The US study reported that 75% of participants found it appropriate to put a hard object into the mouth of a person suffering a seizure.^[12] In a study performed in Yuksekova and consisting of 130 epileptic patients, 130 patient’s relatives, and 130 control subjects, 76 relatives stated that they would call ambulance if their patient had experienced a seizure, and 83 relatives declared that they would move the victim to a safer place. The number of participants declaring that they would spill water on the patient’s face was similar in control and relative groups (28 and 22 participants, respectively).^[19]

In a study performed in Kutahya and Yuksekova, while the percentage of participants who would make her/his seizing patient to smell something was 32.4% and 8.5%, respectively; those declaring that they would spill water on the sufferer’s face was 19.4% and 21.5%, respectively.^[20] The study by Atakli et al.^[21] reported that the percentages of advocates of

making the patient smell onion and putting a spoon on the sufferer's mouth was 17% and 9.1%, respectively.

Almost half of the epileptic patients claimed that putting an object to the mouth was wrong, as reported by a Korean study in 2006.^[22] In the study by Long et al.,^[23] 41% of epileptic patients advocated the idea of putting an object to the mouth. The study by Aydemir reported that the percentages of people who thought it was wrong to make the epileptic patient smelling onion and to spill water on the face were 59.3% and 36.5%, respectively.^[18]

Since our study was based on the questions regarding witnessing of the seizure, we looked for what the witnesses did during the seizure. The percentage of patients who stated that they spilled water onto the sufferer's face was 39.1. While most of participants told that they did it to recover the patient's consciousness, one participant stated to previously see the behavior of spilling water on the face and to associate this behavior with a feeling of patient's relief. No relative declared to move the patient into another place. A participant (4.3%) stated that s/he tried to put an object into the sufferer's mouth, where the aim was to prevent the patient from biting his/her own tongue, though s/he had no source for this knowledge.

Causes of epilepsy– Many studies reported that there were misbeliefs about the association of epileptic seizures with mystic events or supernatural powers. In fact, people tend to use several methods such as consulting hodja, wearing amulets, or attending some religious ceremonies.^[24–26]

The study in Manipal reported that 41% of participants associated epilepsy with brain tumor, and 12.4% had no idea.^[11] The US study showed that 42% of participants regarded the epilepsy as a mental disease.^[12] The percentage of participants who selected the reason for epilepsy as the brain disease was 27% in study performed in Batibo. Around one-third of the patients (34.4%) associated the disease with magic, which, in fact, was the most common belief for the cause of epilepsy.^[13] The study in Ebolowa and Sangmelima of Cameroon reported that 43% of participants associated the disease with a brain disorder. The percentage of participants who indicated magic as the causing factor was 13.7. The misbelief of magic was more prevalent in studies performed in Batibo and Ghana, which was attributed to the differences in cultural beliefs.^[14]

The study performed in Isparta showed the percentage of answers of reason for epilepsy as brain disease and mental disease as 42% and 16%, respectively.^[16]

While most of the patient's relatives in the study performed in Yuksekova in 2010 declared that the reason for epilepsy was brain disorder, the percentage of those having no idea was similar between epileptic patients, patient's relatives, and control group.^[19]

The study in Yuksekova and Kutahya reported that the percentage of statement of the cause of epilepsy as brain disorder was 78.5 and 52.2, respectively. In Yuksekova, all participants declared that they would also try alternative methods apart from medical therapy.^[20] The need for seeking alternative advices suggests high prevalence of the misbelief of the causality to the religious factors regarding epilepsy.

In our study, the answer of brain disorder as the causing factor was 47.8%. As we did not question education level of our patient, we could not determine its association to this finding. Although our result was similar to the study in Isparta, the answer of mental disease was 16% in that study, which was null in our study.^[16]

In Laos, where the epilepsy is known as "mad pig disease," 25–42% of the population thought that the disease originated from supernatural powers, and 10–21% thought that it was transmitted through the habit of eating pork meat.^[27]

In fact, no participant in our study declared the belief of reasoning the disease to originate from mental disease or magic. This may be due to face-to-face setting of the survey. Indeed, collecting written data would be more likely to reflect actual opinions.

Conclusion– The percentage of witnessing a seizure before was 47.8% in our study, which was similar to that in studies in Manipal and Nigeria. This was 53% in the study performed in Isparta. High percentages of witnessing above 75% reported by the studies in Cameroon, Batibo, and Sangmelima were explained by the fact that these regions were small and had high prevalence of epilepsy.

The percentage of those having the knowledge that epilepsy is a brain disease was 41%, 27%, 43%, 42%, 78.5%, and 52.2% in Manipal, Batibo, Cameroon, Isparta, Yuksekova, and Kutahya, respectively; which could be regarded as similar to that of our study.

Most important aspect of our study was that it included questions regarding interventions and their aims during witnessing the seizures. While more than 25% of medical students in Nigerian study declared that they would put

an object into the sufferer's mouth,^[15] this was 9.2% in the study by Atakli et al.^[21] and 4.3% in our study.

Spilling water onto the patient's face during the seizure was declared by 19.4 and 21.5% of participants in Kutahya and Yuksekova, respectively.^[20] On the other hand, those thinking that spilling water would be wrong constituted 36.5%.^[18] Spilling water on the patient's face during the seizure was declared by 39.1% of our participants, which was determined as higher compared to other studies. One participant (4.3%) stated that s/he would make the patient smell onion. Making the patient smelling something was declared by 32.4% and 8.5% of participants in Kutahya and Yuksekova, respectively.^[20] The participants having the opinion that making the patient smelling onion during the seizure is wrong constituted 59.3% in the study by Aydemir.^[18]

None of our participants associated epilepsy with magic or supernatural powers, which was considered as pleasing and promising in terms of the tendency of the public toward more educational activities.

Study Limitations– The low number of participants is the limitation of our study. The approach during epileptic seizures in our society may be demonstrated more clearly with studies more participants.

Improper intervention to a seizure can be harmful. Raising awareness on this issue is another responsibility of health-care professionals.

Informed Consent– Written informed consent was obtained from the patients for the publication of the this study and the accompanying images.

Ethics Committee Approval– This study was approved by the Ankara University Faculty of Medicine Clinical Research Ethics Committee (Approval No: 25.05.2009/152-4770).

Peer-review– Externally peer-reviewed.

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