Original article

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Prevalence of epilepsy in northeast Turkey

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ABSTRACT – The aim of this study was to determine the prevalence and clinical and socio-demographic characteristics of active epilepsy in the population, aged 15 and over, in the province of Trabzon in northern Turkey. We surveyed households and identified 34 epileptic patients (prevalence of 6/1,000), 28 of whom had active epilepsy (prevalence of 5/1,000). Only one case of hot water epilepsy was established among the 5,254 participants. Of the various seizure types, the most common were partial seizures (63%), over half of which were secondary generalised seizures. The largest syndromic category was that of localisation-related symptomatic cases (46%). Forty-six percent of cases were of unknown cause, and 16% were resistant to medication. The prevalence rate of active epilepsy in Trabzon is low compared to other parts of Turkey and other developing countries. This may be attributable to several factors, and particularly to variations among socio-economic factors. The population of Trabzon is regarded as relatively stable and homogenous, and socio-demographic and health data for the province of Trabzon are much better than those for the rest of the country.

Key words: neuroepidemiology, epilepsy, prevalence, Turkey

Although epilepsy is the most common serious neurological disorder worldwide, only a few studies have examined its prevalence in Turkey, and these have investigated relatively small populations. The reported rates range from 4.5/1,000 to 17.3/1,000 (Bilgin, 1980; Ozdemir, 1995; Aziz *et al.*, 1997; Karaağaç *et al.*, 1999; Topalkara *et al.*, 1999; Onal *et al.*, 2002; Çalişir *et al.*, 2006).

The prevalence of active epilepsy ranges from five to ten cases per 1000 in most developed countries (Gudmundsson, 1963; Osuntokun *et al.*, 1987a; Hauser and Hesdorffer, 1990; Hauser *et al.*, 1991; Wang *et al.*, 2003). In studies involving general populations in various geographic areas, however, including the United States, South America, Africa, Asia and Europe, the reported rates range from 2.5/1000 (rural Kashmir) to 57/1,000 (Changuinola on the Caribbean coast of Panama) (Granieri *et al.*, 1983; Koul *et al.*, 1988; Gracia *et al.*, 1990; Giuliani *et al.*, 1992; Rocca *et al.*, 2001).

This substantial variability in rate is partly due to geographical, medical and social differences, however, a considerable part of this variation may also be attributable to different case-finding techniques and inclusion criteria.

The aim of this study was to establish the prevalence and other characteristics of active epilepsy in the population, aged 15 and over, in the province of Trabzon and to compare our results with those of previous studies.

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Methods

Study area: population and geographical, socio-cultural and economic structure

Trabzon is a coastal city in the Black Sea region of northern Turkey. The total population of the province, including all its 17 outlying districts, is 975,137, according to the last census in 2000 (Turkish National Central Bureau of Census [TNCBC], 2000). Trabzon has 497 villages, mostly scattered on steep land. Due to the province's geographical position, almost the entire population lives in mountainous areas. Given the unfavourable logistical conditions in the villages in Trabzon, the city of Trabzon itself and its 17 district centres, excluding the villages, were selected for a population-based study of epilepsy. We divided Trabzon into two regions: central and peripheral. The central region included the city centre and the peripheral region included the 17 outlying district centres. Of these district centres, nine were located on the 114 km-long stretch of coast. The other eight districts lie along a highland and mountainous area running for almost 50 km from north to south *(figure 1)*.

There are some 578,954 inhabitants in Trabzon province, including the 17 district centres but excluding the villages. The study population, constituting 49.1% of the total population of the province, was comprised of the inhabitants of the central and peripheral regions, excluding the villages. Compared to the population of Turkey and the province of Trabzon as a whole (including the villages), the study population was not statistically different in terms of age or sex *(figure 2A, B)*.

Preventive health services in this area include 133 health centres, with 288 physicians and 277 nurses, and 577 health stations with 332 midwives. Treatment health services include 11 state hospitals run by the Ministry of Health, Karadeniz Technical University Hospital and a private hospital. Some health-related data from the province of Trabzon from 2003 are shown in *table 1*. The literacy rate is 81.13% among women and 95.88%

Figure 1. Map of Trabzon and outlying districts (the dots show the locations of Trabzon city centre and the 17 district centres).

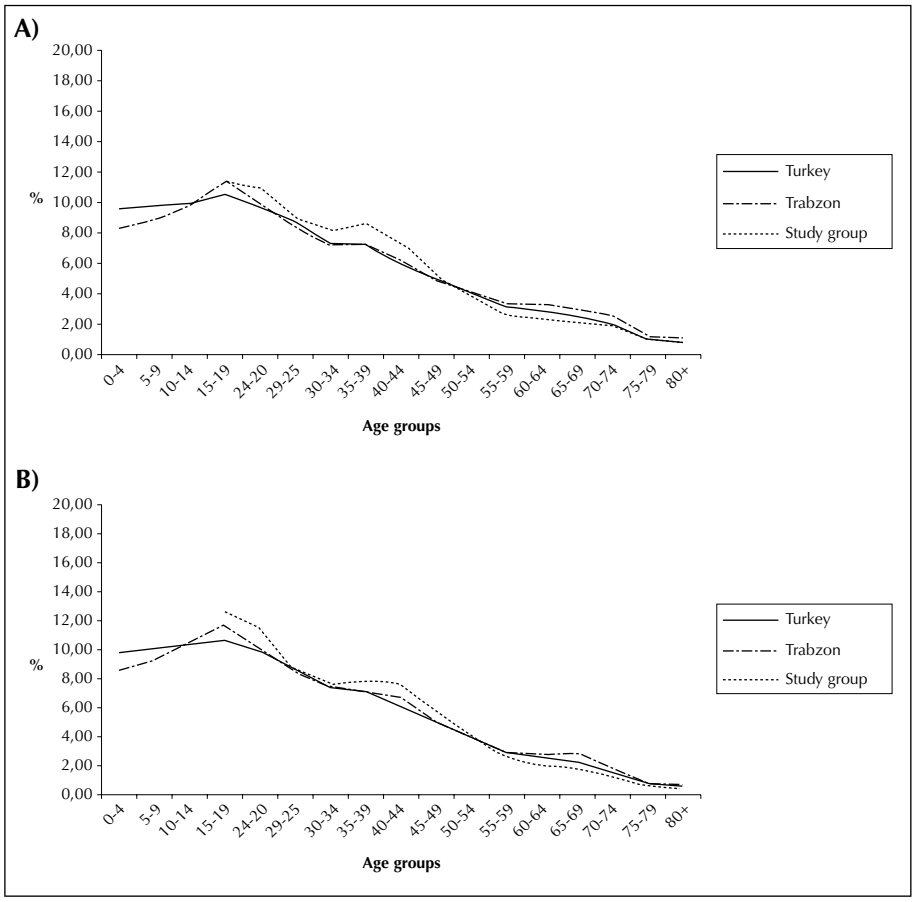

Figure 2. A) Comparison of female populations in the study group (Trabzon province excluding villages) *vs* the population of Trabzon (with villages) and Turkey. **B**) Comparison of male populations in the study group (Trabzon province excluding villages) *vs* the population of Trabzon (with villages) and Turkey.

Table 1. Demographic data of Trabzon province for 2003.

Demographical rates	Trabzon (in thousands)	Average in Turkey (in thousands)
Approximate birth rate	11.88	20.5
Approximate death rate	3.20	6.4
Rate of infant deaths	17.04	29
Normal population growth rate	8.68	15
Life expectancy at birth	? (unknown)	68.8*

* www.turkstat.gov.tr.

among men, according to the latest census (TNCBC, 2000). Official sources published annually by the Turkish National Central Bureau of Statistics (TNCBS) provided the population data (TNCBC, 2000; TNCBS, 2003).

Determination of the sampling magnitude

We carried out a survey of households. Given the highest safe prevalence rate (P) of 2.5 with a confidence level of 95% and an accepted sampling error boundary (d) of 0.5%, we calculated that 3,746 people would need to be recruited. Some 1,350 households would have to be included in order to achieve a population size of 3,746. However, due to possible recruiting problems, we planned a sample size of about 2,000 households; 800 from the city centre and 1,200 from the districts. The households to be recruited were determined using a systematic sampling method with family registration cards

obtained from the Trabzon Health Centre. As a result, 5,254 people from 1,976 households were enrolled. Twenty-four families refused to participate in the study.

Study plan

The study was performed in the Neurology Department of the Karadeniz Technical University Medical Faculty in cooperation with the Department of Public Health. It was considered by the Ethics Committee and approval was issued on 27th January 2004.

The questionnaire was administered by six volunteer interns, members of the Scientific Research Committee of the Karadeniz Technical University Medical Faculty and two research assistants who had been working for at least three years in the Department of Neurology. All attended three sessions with a 40-minute seminar on epilepsy by senior neurologists, epileptologists and epidemiologists from the departments of Neurology and Public Health. These seminars set out the objective of the study, with an introduction to epilepsy and instructions how to fill in the forms correctly. During this training, the volunteers were shown videos about epileptic seizures by an epileptologist.

The questionnaire was designed by considering the social, cultural and geographical structure of the local community, with the help of a questionnaire suggested by the World Health Organisation Protocol (1981) and screening tools designed by Karaağaç *et al.* (1999). Some questions on the Turkish synonyms for epilepsy (*e.g.*, "havale," "sara," and "maraz") were also included *(appendix 1)*. The purpose of the questionnaire was not only to identify epilepsy patients, if any, but also to obtain their demographic data, including type of seizure and epilepsy, family history, risk factors, probable aetiology, age at seizure onset, duration of epilepsy, treatment, compliance with treatment and seizure control. The first five questions were intended to disclose the presence of epilepsy. Questions six through to nine were intended to enhance the sensitivity of the first five questions and to reduce the possibility of denial. Question 10 to 16 were intended to determine family and personal history, risk factors, aetiology and treatment history. Another questionnaire was also administered to determine the prevalence of hot water epilepsy *(appendix 2)*. Patients suspected to have epilepsy were referred to the Department of Neurology at Karadeniz Technical University for evaluation by neurologists and epileptologists. The questionnaire's positive and negative predictive values were tested in a single-blind manner prior to the study, and sensitivity and specificity were determined at 100%.

Definitions

All concepts of epilepsy used in the study, including epileptic seizures, epilepsy, active epilepsy and epilepsy in remission with and without treatment, were identified according to the ILAE Guidelines for epidemiologic studies (ILAE, 1993). Seizures were classified according to the ILAE classification (ILAE, 1981). Epilepsy in remission was defined as a prevalent case of epilepsy with no seizures for at least five years, with or without AED treatment at the time of ascertainment. The success of treatment was defined by patients stating that they had benefited considerably from the treatment (they no longer suffered from seizures and had 50% fewer seizures). Resistance to treatment was defined according to patients reporting no change in the frequency of seizures, even under regular AED treatment (treatment-resistant patients).

The classification of epilepsies and epileptic syndromes was based on the criteria proposed by the ILAE (1989). We followed the instructions for the risk factors listed in a guide published by the ILAE in 1993 (ILAE, 1993). We recruited patients with active epilepsy living in Trabzon or its outlying districts, aged 15 years or older, and who had experienced at least two unprovoked seizures, separated by a minimum of 24 hours, with at least one seizure in the previous five years. Patients with only one seizure, seizures for exogenic or metabolic reasons, provoked seizures, acute or isolated febrile episodes, and alcohol and drug withdrawal were excluded from the study.

Collection and analysis of the data

The study was performed in two phases. In the first phase, 5,254 people from 800 households in the city centre and 1,176 from district centres were screened using the questionnaire. This was administered between 1st June 2004 and 1st May 2005, the prevalence day being taken as 1st June 2004. In the second phase, those whom the questionnaire suggested might have epilepsy were invited to the Neurology Clinic at Karadeniz Technical University. The participants were informed, and consent forms were signed by each subject. Each patient and/or one of his/her relatives was interviewed about individual or family medical history by one of the researchers, a neurologist. Epilepsy was diagnosed in patients admitted to the neurology clinic on the basis of the detailed history provided by them or their relatives and using complementary tests (*e.g.* MR, EEG, CT or routine blood tests). All cases were included in the prevalence data after confirmation of diagnosis by an epileptologist.

Statistics

Age- and sex-specific data were calculated using the population of Trabzon in 2000 as the denominator (TNCBC, 2000). Prevalence rates were age-adjusted on the basis of the direct method of standardization for international comparisons using the standard world population (DosSantos, 1999). For statistical analyses, a continuity correction of Fisher's exact probability test was used. Analyses were performed using SPSS version 12.0, and the reliability of the intervals in the results was calculated and confirmed.

Results

The study comprised 1,976 households containing 5,254 individuals: 51.5% male (n = 2,707) and 48.5% female (n = 2,547). The distribution of age groups and gender is representative of the general demographic characteristics of the total population in the province of Trabzon *(figure 2A, B)*. From the raw data collected with the questionnaire, 61 possible cases of epilepsy were identified *(figure 3)*. Two patients refused to participate in the study. After re-evaluation by neurologists, 28 patients (10 women and 18 men) were diagnosed with active epilepsy, and six were diagnosed as having epilepsy in remission without treatment. The diagnoses of the remaining 25 cases are presented in *figure 3*.

Prevalence

The crude prevalence of active epilepsy was 5.3/1,000 (95% confidence interval [CI]: 2.5-8.2) *(table 2)*. The prevalence, age-adjusted to the standard world population (Dos Santos, 1999), was 3.7 (95% CI: 3.3-4.0). If the six cases in remission without treatment had been included, the lifetime prevalence of epilepsy would have been 6/1,000 (age-adjusted to 4.5/1,000). The prevalence of inactive epilepsy was 1.14/1,000 (age-adjusted to 0.8/1,000).

Of the individuals with active epilepsy, 18 were male and 10 female, giving a prevalence of 7/1,000 and 4/1,000, respectively *(table 2)*. The prevalence of active epilepsy was higher in males compared to females, but the difference between the sexes was not statistically significant (p = 0.305). Age- and sex-specific prevalence rates are shown in *table 2*. The prevalence of epilepsy in the central region was 5/1,000 (95% CI: 4.8-5.3), compared to 6/1,000 (95% CI: 5.2-6.0) in the peripheral region. This difference was not statistically significant.

Only one case of hot water epilepsy was established among the 5,254 participants.

Seizure types

Altogether, 48 seizures were reported in the 28 patients with active epilepsy. We reported 30 cases (63%) of partial seizures (two simple, 14 secondary generalised simple

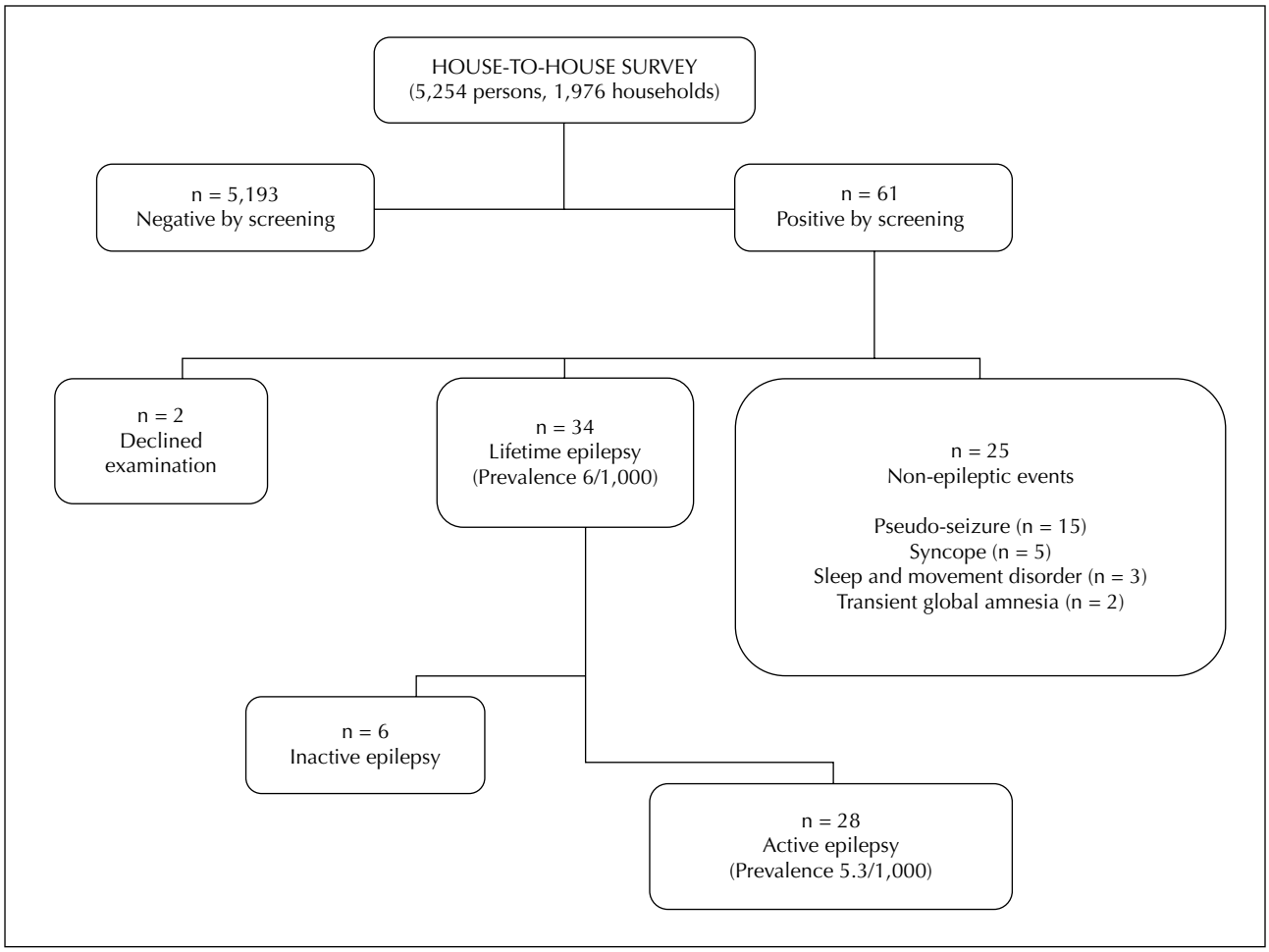

Figure 3. Flow chart of the study population.

Table 2. Age- and gender-specific prevalence.

Age	Women			Men			Total		
	Number	Epilepsy	Prevalence per 1,000	Number	Epilepsy	Prevalence per 1,000	Number	Epilepsy	Prevalence per 1,000
15-19	351	1	2.8	410	3	7.3	761	4	5.3
20-29	643	4	6.2	699	3	4.3	1,342	7	5.2
30-39	505	0	0.0	484	7	14.5	989	7	7.1
40-49	561	1	1.5	593	3	5.1	1,154	4	3.5
50-59	253	3	11.9	306	1	3.3	559	4	7.2
60-69	130	1	7.7	130	1	7.7	260	2	7.7
70 +	104	0	0.0	85	0	0.0	189	0	0.0 -
Total	2,547	10	3.9	2,707	18	6.6	5254	28	5.3
			(95% CI: 1.5-6.4)			(95% CI: 3.5-9.8)			(95% CI: 2.5-8.2)

partial, 12 complex partial and two secondary generalised complex partial), 13 cases (27.1%) of generalised seizures (12 tonic clonic and one myoclonic) and five cases (10.4%) of unclassifiable seizures. Sixteen (57%) of the patients had more than one seizure type, 12 (43%) had two types, and four (14%) had three types. The most common seizure type was partial seizure, the most common subtype being partial simple with secondary generalisation (29%), followed by partial complex (25%) and generalised tonic-clonic (25%).

Epilepsy syndrome

We determined a localisation-related epilepsy rate of 68%, 7% with generalised idiopathic epilepsy (one case with generalised tonic-clonic seizures and one with juvenile myoclonic epilepsy). The largest subgroups were localisation-related symptomatic and localisation-related cryptogenic syndromes *(table 3)*.

Age at seizure onset and duration of epilepsy

Mean age at the initial unprovoked seizure was 16.6 (SD ± 15) years (range: 1-50). Seizures began in the first decade of life in 39% of patients, and 68% were under 19 years old at seizure onset *(figure 4)*. The mean duration of disease was 19.2 (SD ± 13) years (range: 1-54 years; median: 19 years). Analysis of disease duration revealed that 50% (n = 14) had had the disease for more than 14 years, 32% (n = 9) for 0-9 years and 18% (n = 5) for 10-19 years *(figure 5)*.

Table 3. Epileptic syndromes.

	Case (%)	Rate (per 1,000)
Localization-related Epilepsy	19 (68)	3.6
- Symptomatic	13 (46)	2.5
- Cryptogenic	6 (21)	1.1
Generalized epilepsy	4 (14)	0.8
- Idiopathic	2 (7)	0,4
- Symptomatic	2 (7)	0,4
Undetermined	5 (18)	1
Total	28	5.3

Family history of epilepsy

A family history of epilepsy (including first and second degree relatives) was more likely in epileptic cases compared to non-epileptic subjects ($p < 0.005$) *(table 4)*.

Presumed aetiology

A presumed aetiological diagnosis could be established in 15 (53.6%) cases *(table 5)*.

Treatment, compliance with treatment and seizure control

Eighty-nine percent (n = 25) of the 28 patients with active epilepsy were on AEDs on the prevalence day. Although two patients (7%) had frequent seizures, they decided to stop taking AEDs because they believed they were not effective. One patient (4%) was not receiving treatment because active epilepsy was not diagnosed. This patient was further diagnosed using field screening, and treatment was commenced. Sixty-eight percent (n = 17) of the 25 cases received monotherapy, and 32% (n = 8) received polytherapy. Two AEDs were administered simultaneously in five cases (20% of those on medication), and three AEDs were administered simultaneously in three cases (12% of those on medication). Of the 25 cases, 11 (44%) stated that they benefited considerably from the treatment (those who no longer had any seizures or had 50% fewer seizures). Four patients (16%) reported no change in seizure frequency, although they had been taking AEDs regularly (treatment-resistant patients). While 56% of the patients stated that they took their medication regularly, 44% had some irregularities in terms of taking their medicine

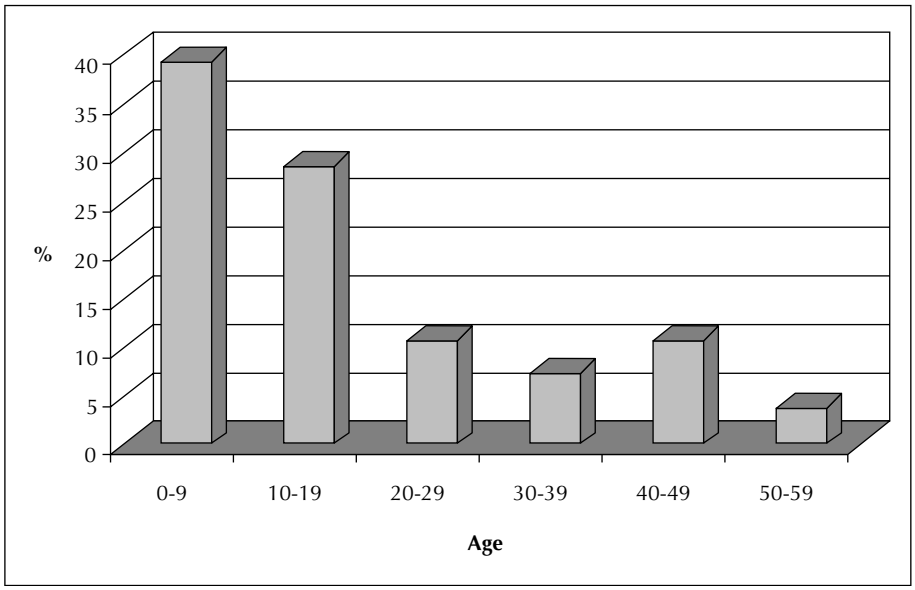

Figure 4. Age at seizure onset.

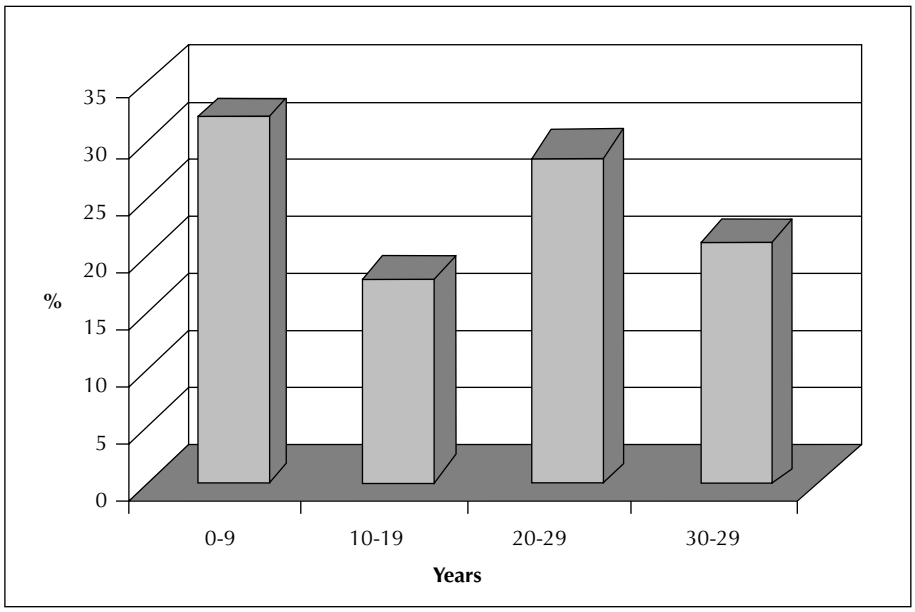

Figure 5. Duration of epilepsy from initial unprovoked seizure to prevalence day.

punctually. The most frequently prescribed drug was carbamazepine (CBZ), which was taken by 76% (n = 19) of all patients and used as monotherapy in 48% (n = 11) of cases. Use of more recent AEDs was limited *(table 6)*. We determined that six patients (21%) restarted daily AEDs due to recurrence of seizures after a minimum three and maximum five years of remission. No patients had more than one remission period. Of these six patients, two (33%) were diagnosed with idiopathic generalised epilepsy, and four (67%) with localisation-related symptomatic epilepsy.

Education levels and behavioural features of epilepsy patients

While 15 patients (54%) consulted a health centre at seizure onset, 13 (46%) consulted a "hodja," a devout Muslim respected for his knowledge of Islam. The group that consulted a "hodja" was made up of 11 elementary school graduates (84%), one university graduate (8%) and one illiterate person with no formal education (8%). Those who consulted a health centre appeared to be distributed

Table 4. Family history of epilepsy.

	Family history of epilepsy (%)		Total
	+	-	
People with epilepsy	4 (14,3%)	24	28
People without epilepsy	10 (0.2%)	5,216	5,226
Total	14 (0.3%)	5,240	5,254

Table 5. Putative etiology* in epilepsy in patients with active epilepsy.

	n	%
Remote symptomatic	14	50
- Pre/perinatal asphyxia	5	18
- CNS infection or infestation	4	14
- Head injury	2	7
- Prematurity/Birth trauma	2	7
- Stroke	1	4
Progressive symptomatic	1	4
- Neoplasms	1	4
Idiopathic	2	7
Cryptogenic	11	39
Total	28	100

* Etiology was classified according to the ILAE Guidelines for Epidemiologic Studies on Epilepsy.

Table 6. Antiepileptic drugs used by patients.

AED	Monotherapy n	Polytherapy n
Carbamazepine	11	8
Valproic acid	4	6
Phenytoin	2	2
Lamotrigine	0	2
Levetiracetam	0	1
Topiramat	0	1
Primidone	0	1

evenly in terms of education levels. Thirty percent of the participants who were residents of the city centre consulted a "hodja," compared to 56% of the participants living in the districts. Of the 15 patients who consulted a health centre, four (27%) were not diagnosed with epilepsy on their first visit. All these 15 patients were treated by a family practitioner or a physician who was not a neurologist.

Discussion

The prevalence of epilepsy is reported to be four to six times higher in developing rather than developed countries (Aziz *et al.*, 1997; Birbeck and Kalichi, 2004). The lowest prevalence is in Japan, with 1.5 per 1,000, and the highest among Guaymi natives living in rural areas of Panama, with 57 per 1,000 (Sato, 1964; Gracia *et al.*, 1990). However, true differences of prevalence may be clouded by differences in study methods, differences in the causes of epilepsy, and variations in medical care, socio-economic status and geographical factors. In particular, comparisons between different studies carried out using different methodologies are a problematic issue. Case-finding methods vary among epidemiological studies and include chart reviews in hospitals, door-to-door surveys with medical examinations and ancillary tests, and comprehensive patient chart reviews. Case-finding methods have an impact on estimates of epilepsy frequency, and some methods are more precise than others. Data regarding the epidemiology of epilepsy in developing countries are not satisfactory from either a scientific or a geographical perspective. The current prevalence rate (5.3/1,000) of active epilepsy in Turkey is in the range reported for developed countries (Keranen *et al.*, 1989; Hauser and Hesdorffer, 1990; Hauser *et al.*, 1991; Forsgren, 1992; Boon *et al.*, 1995; Gekht *et al.*, 1999; Olafsson and Hauser, 1999; Wright *et al.*, 2000; Luengo *et al.*, 2001; Fong *et al.*, 2003; Forsgren *et al.*, 2005). Although Turkey is a developing country, our findings are comparable to those from developed countries. There is relatively less data on the frequency of epilepsy in Turkey, and prevalence studies mostly include rural areas (Bilgin, 1980; Ozdemir, 1995; Aziz *et al.*, 1997; Karaağaç *et al.*, 1999; Topalkara *et al.*, 1999; Onal *et al.*, 2002; Çalışır *et al.*, 2006). In these studies, with the exception of 17.3 per 1,000 reported in the rural Sivas region, prevalence has varied between 6 and 10 per 1,000. We also determined a lower prevalence compared to earlier epidemiological studies in Turkey. The population of Trabzon is regarded as relatively stable and homogeneous, and socio-demographic and health data for the province of Trabzon are much better than those for the rest of the country *(table 1)*. We believe that this may explain the epilepsy prevalence level being as low as that in developed countries. There are socio-demographic, socio-cultural and socioeconomic differences among Turkish provinces. Similarly, cultural differences leading to variations in self-reporting of illnesses could also play a role in these findings.

Most reports show slightly higher rates in male compared to female subjects (Gudmundsson, 1963; Annegers *et al.*, 1980; Granieri *et al.*, 1983; Haerer *et al.*, 1986; Hauser *et al.*, 1991; Rajeh *et al.*, 2001). In contrast, two studies reported lower self-reported epilepsy prevalence in men than in women (Centers for Disease Control, 1994; Kobau *et al.*, 2004). In our study, the prevalence rate was higher for males than females, but the difference between the sexes was not statistically significant.

The prevalence rates in different age groups (range, 5.2-7.7/1,000) were similar to those in most other countries (De la Court *et al.*, 1996; Sander and Shorvon, 1996; Olafsson and Hauser, 1999; Wiebe *et al.*, 1999; Luengo

et al., 2001; Sander, 2003; Tellez-Zenteno *et al.*, 2004). A high prevalence of epilepsy in older age groups is often determined (Cockerell *et al.*, 1995; De la Court *et al.*, 1996; Sander and Shorvon, 1996; Macdonald *et al.*, 2000; Heaney *et al.*, 2002; Sander, 2003). In our study, the significant high prevalence was not found in the older age group. Since there are few studies in the literature that refer to the age range in our study (15 and above), it was difficult to compare our data, and this imposed a restriction on discussion. Only a few studies are directly comparable and these include Keranen *et al.* (1989) in Finland, Oun *et al.* (2003) in Estonia, Forsgren (1992) in Sweden, and Sridharan *et al.* (1986) in Libya, with reported active epilepsy prevalences of 6.3/1,000, 5.3/1,000, 5.5/1,000, and 2.3/10,000, respectively. With the exception of the Libyan study, our data bear a close similarity to the prevalence values in these studies.

Seizure types

Partial seizures with or without secondary generalisation were the predominant pattern (63%) followed by generalised seizures (27%). This was in contrast to some previous reports (Rwiza *et al.*, 1992; Aziz *et al.*, 1994; Olafsson and Hauser, 1999; Rocca *et al.*, 2001) but in agreement with others (Hauser *et al.*, 1991; Forsgren, 1992; Karaağaç *et al.*, 1999; Nicoletti *et al.*, 1999; Oun *et al.*, 2003) as well as studies of meta analysis of incidence (Kotsopoulos *et al.*, 2002; Burneo *et al.*, 2005).

Epilepsy syndrome

The results of this study showed a high rate of localisation-related epilepsy (68%) and a low rate of generalised epilepsy (14%). Similar results have been found in other prevalence studies analyzing epileptic syndromes in adults (De la Court *et al.*, 1996; Olafsson and Hauser, 1999; Oun *et al.*, 2003). Several types of epileptic syndromes were not identified either in some population-based studies or in our study, since the number of patients participating was less than 200 (Sidenvall *et al.*, 1996; Shinnar *et al.*, 1999; Zarrelli *et al.*, 1999; Freitag *et al.*, 2001).

Age at onset

In our study, 68% of all cases reported an onset before the age of 20. Most patients in population studies with active epilepsy have an onset of seizures in the first two decades of life (Guvener *et al.*, 1995; Ozdemir, 1995; Karaağaç *et al.*, 1999; Onal *et al.*, 2002; Medina *et al.*, 2005; Velez and Eslava-Cobos, 2006).

Presumed aetiology

Presumed aetiology was known in 54% of our cases. The proportion of patients with symptomatic epilepsy and documented aetiology was higher than that in other studies (24%-39.6%) (Granieri *et al.*, 1983; Hauser *et al.*, 1991; Forsgren, 1992; Radhakrishnan *et al.*, 2000; Oun *et al.*, 2003; Gallitto *et al.*, 2005; Banerjee and Hauser, 2008). The reason for this high aetiology rate is probably because cases were brought to the hospital for a face-to-face interview and MRI diagnosis.

We conclude that people with epilepsy have a greater likelihood of having a relative with epilepsy (including first and second-degree relatives). A history of epilepsy in relatives has been reported in 5.2% to 17% of patients (Koul *et al.*, 1988; Sridharan and Murthy, 1999; Gallitto *et al.*, 2005).

Antiepileptic treatment, psychosocial approaches to treatment and prognosis

Eighty-nine percent of active epilepsy patients were receiving AED treatment and regularly taking AEDs on the assessment day. Twenty-eight percent of patients living in urban areas of Pakistan, 2% of patients living in rural areas of Pakistan and 31% of patients in Guatemala are reported to take AEDs (Mendibazal and Salguero, 1996; Khatri *et al.*, 2003). The proportion of subjects with medical treatment on the prevalence day was comparable to that reported in the majority of surveys from Western Europe (Forsgren, 1992; Rutgers, 1986; Olafsson and Hauser, 1999). Compared to two previous studies from Turkey (44.9% in Silivri [1994] and 34.6% in Bursa [1995]), the percentage of patients receiving AEDs was higher in Trabzon (Karaağaç *et al.*, 1999; Çalişir *at al.*, 2006). The difference between the studies in terms of patients' compliance with treatment might represent the impact of socio-economic and educational developments in Turkey over recent years. The high rate of treatment compliance in this study also shows that the city of Trabzon and its outlying districts are comparably developed. The data regarding the type and number of AEDs used are available for all patients. Most patients received only one AED, the most common being CBZ. In our study, the use of older AEDs was more common than more recent alternatives, suggesting that new AEDs were used as an add-on treatment. In many developing countries, CBZ and VPA appear to be the drugs of choice (Jallon, 1997). In many countries, the cost of more recent drugs is disproportionately high because the market for them remains small and, therefore, no economies of scale apply.

Many factors, such as the availability of health services, the management of communication facilities, education and the population's mystical or dogmatic beliefs concerning epilepsy, can change attitudes towards the disease. In developing countries, these attitudes vary according to region, and patients usually deny or under-report the disease and look for paramedical cures (Osuntokun *et al.*, 1987b; Koul *et al.*, 1988; Shorvon and Farmer, 1988; Senanayake and Roman, 1993). Forty-six percent of the patients in our study visited a "hodja" at the onset of their disease. Most of our patients (84%) who consulted a "hodja" had a low education level, and the number of patients residing in districts who consulted a "hodja" (56%) was greater than the number of patients residing

in the city centre. The other two studies conducted in Turkey (Ankara and Silivri/Istanbul) reported higher rates (71% and 65%, respectively) of "hodja" visits (Aziz *et al.*, 1997; Karaağaç *et al.*, 1999).

Among our epilepsy patients, the recurrence rate was 21%, most of these cases (67%) being localisation-related symptomatic epilepsy. The MRC trial on AED withdrawal reported 22% recurrence with AED treatment and 41% recurrence without, after two years (Antiepileptic Drug Withdrawal Study Group, 1991). Furthermore, we determined a rate of resistance to treatment of 16% and a treatment success rate of 44%. Previous studies reported that, despite their compliance with proper treatment, 20% of epilepsy patients still suffered seizures. Nevertheless, 50%-70% of patients had an excellent prognosis, with a high probability of spontaneous remission (20%-30%), or a good prognosis (30%-40%) with easy pharmacological control and the possibility of spontaneous remission (Jallon, 1997; Waaler *et al.*, 2000; Gallitto *et al.*, 2005; Beghi and Sander, 2008).

In this study, 27% of patients who consulted the health centre were not diagnosed with epilepsy on their first visit, since on that occasion all of them were treated by a physician who was not a neurologist. The rate of misdiagnosis is reported to be in the range of 5% to 23% in community-based studies (McCluggage *et al.*, 1984; Scheepers *et al.*, 1998). The relative rate of misdiagnosis by neurologists is 6%, while that for non-specialists is 19% (Leach *et al.*, 2005).

Hot water epilepsy seems to be very scarce in Western countries. There are several descriptions of patients with hot water epilepsy from India and Turkey (Satishchandra *et al.*, 1988; Bebek *et al.*, 2001; Yalçın *et al.*, 2006). We determined only one case of hot water epilepsy. Çalişir *et al.* (2006) identified two cases of hot water epilepsy in a study carried out in the Turkish province of Bursa. We hope that further scientific research will add to these findings. □

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Appendix 1

English version of the questionnaire used in the study

Name of the interviewer:
Address:
Tel:
Name and surname of the participant: ……

Name and surname of the family members	Age	Sex M / F	Occupation	Social security a) Government b) Emekli Sandığı* c) Bağ-Kur* d) SSK* e) Government assistance f) Private g) none *Various government retirement agencies

1– Have you, or any other person living with you, ever lost consciousness for a short time or been unaware of what was going on (such as not hearing or not seeing) even for a short length of time?
□ – Yes (once) (Who experienced that?: .....)
□ – Yes (more than once)
□ – No
□ – Not sure
□ – No answer

2 – If yes:

A – Have you/she/he ever had any whole body muscle spasms, an episode of staring at one spot, being tongue-tied, froth from saliva forming in the mouth, urinate, or any injuries during this loss of consciousness?
□ – Yes (once) If yes, .. (Who experienced one of these?)
(…….. had a complaint of …….)
□ – Yes (more than once) (it was ……ago when I (she/he) last experienced it.)
□ – No
□ – Not sure
□ – No answer

Age at onset : ……
Duration of unconsciousness : .....
How many times : .....
Precipitating factors : (sleep, sleep loss, stress, febrile diseases, TV, light.....)

B – Have you/she/he ever experienced behavioral changes, such as brushing your-/her-/himself off with your/her/his hands, pulling at your/her/his clothes, looking for something aimlessly, playing with objects or smacking your/her/his lips during loss of consciousness?
□ – Yes (once) If yes, .. (Who experienced which one of these?)
(…….. had a complaint of …….)
□ – Yes (more than once) (it was ……ago… when I/he/she last experienced it.)
□ – Not sure
□ – No answer

Age at onset :
Duration of unconsciousness :
How many times :
Precipitating factors : (sleep, sleep loss, stress, febrile diseases, TV, light.....)

3 – Have you, or any other person living with you, ever remained motionless for a short time, or become lost in thought such as staring at one spot, or stopped doing whatever you/she/he were doing at that moment, such as stopping eating, hesitation in speaking, stopping cycling for a few minutes, or being unable to answer when called on or being unaware of your/their surroundings for 5–10 seconds?

□ – Yes (once) If yes, .. (Who experienced which one of these?)
(…….. had a complaint of …….)
□ – Yes (more than once) (it was on ……when I/he/she last experienced it.)
□ – Not sure
□ – No answer

Age at onset :
Duration of unconsciousness :
How many times :
Precipitating factors :

4 – Have you, or any other person living with you, ever had any twitches in your/her/his arms, shoulders or whole body

□ – Yes (once) If yes, .. (Who experienced which one of these?)
(…….. had a complaint of …….)
□ – Yes (more than once) (it was on …… when I/he/she last had it.)
□ – No
□ – Not sure
□ – No answer

While falling asleep :
Towards morning :
Duration :
Age at onset :
How many times :
Precipitating factors :

5 – Have you, or any other person living with you, ever had any complaints – without loss of consciousness - of muscle spasms in your/her/his arms or legs, or spasms in any part of your/her/his face lasting for 1 or 2 minutes at most?

□ – Yes (once) If yes, .. (Who experienced which one of these?)
(…….. had a complaint of …….)
□ – Yes (more than once) (it was on …… when I/he/she last had it.)
□ – No
□ – Not sure
□ – No answer

6 – Do you, or any other person living with you, sometimes urinate while sleeping?

□ – Yes (once)
If yes,
Who experienced that?: (……. experienced it)
□ – Yes (more than once)
□ – No
□ – Don't know
□ – No answer

7 – Have you, or any other person living with you, ever had muscle spasms in your/her/his limbs or bitten your/their from time to time in your/her/his sleep?
- □ – Yes (once)
  - If yes, ..
  - Who experienced that?: (……. experienced it.)
- □ – Yes (more than once) (it was on …… when I/he/she last had it.)
- □ – No
- □ – Not sure
- □ – No answer

8 – Have you, or any other person living with, you ever experienced a "havale", or "sara", or "maraz"?
- □ – Yes (once)
  - If yes, ..
  - Who experienced that?: (……. had it.)
- □ – Yes (more than once) (it was on …… when I/he/she last had it.)
- □ – No
- □ – Not sure
- □ – No answer

9 – Have you, or any other person living with you, ever had any EEG test (an electroencephalogram test, with electrodes attached to the patient's head, that produces a written map of brain waves)?
- □ – Yes (Who underwent that?:.....)
- □ – No
- □ – Not sure
- □ – No answer

10 – Has anyone in the family ever had epilepsy (uncle, aunt, their children or grandchildren, grandmothers or grandfathers)?
- □ – Yes
- □ – No
- □ – Not sure/don't know
- □ – No answer

If yes :
Who had it? :……..

When the interviewer considers that the person has had an epileptic seizure(s) after questions 1-10, s/he must continue with questions 11-16.

11 – Did you have any other health problems during this seizure?
- □ – Yes
- □ – No
- □ – Not sure
- □ – No answer

If yes :
- □ – After or during head trauma?
- □ – During pregnancy?
- □ – Other problems? (name of the disease, if known:.....)

12 – Have you ever had a febrile seizure(s)?
- □ – Yes (once)
- □ – Yes (more than once)
- □ – No
- □ – Not sure
- □ – No answer

13 – Has anyone in the family ever had a febrile seizure(s) during childhood?
- □ – Yes (once)
- □ – Yes (more than once)
- □ – No
- □ – Not sure/don't know
- □ – No answer

If yes :
Who had it? ……..

14 – Have you ever had ……:
- □ – Head trauma? (..... year(s))
- □ – Stroke? (..... year(s))
- □ – Meningitis? (..... year(s))
- □ – Diabetes mellitus? (..... year(s))
- □ – High blood pressure (Hypertension)? (..... year(s))
- □ – Kidney disease ? (..... year(s))
- □ – Other diseases?……. (..... year(s))

15 – Have you ever been treated for these diseases?
- □ – Yes (Name of drugs taken: .....)
- □ – No

16 – Have you ever had any treatment for epilepsy or "havale" or febrile convulsion?
- □ – Yes (once)
- □ – No
- □ – Not sure
- □ – No answer
- □ – I have never seen a doctor about this illness

If yes

What drugs have you taken and in what dosages?:
For how long have you been taking it if you are still using it?
How long did you take it, if you are not taking it any more?
Was the treatment successful? : □ Yes □ No
Are you taking your medicine(s) regularly?

Appendix 2

1. Is there anything that attracts your attention or concerns you when you or anyone in your household is having a bath?
2. Have you, or anyone in your household, ever felt dizzy, stopped moving, fainted, smacked your lips, gulped, blushed, had a pale face or a spasm while having a bath?
3. Have you, or anyone in your household, ever had a dream-like experience, a revival of past memories, or a feeling of a change of environment while having a bath?
4. Have you, or anyone in your household, experienced epilepsy seizure/"havale" while having a bath?