Seizure (2008) **17**, 646—650

ELSEVIER

SEIZURE

www.elsevier.com/locate/yseiz

SHORT COMMUNICATION

Epilepsy prevalence by individual interview in a Norwegian community

Eylert Brodtkorb [a,b,*], **Ottar Sjaastad** [a,b,c]

[a] *Department of Neuroscience, Norwegian University of Science and Technology, Trondheim, Norway*
[b] *Department of Neurology and Clinical Neurophysiology, St. Olav's University Hospital, Olav Kyrres Gate 17, 7006 Trondheim, Norway*
[c] *Vågå Communal Health Centre, Vågåmo, Norway*

Received 11 December 2007; received in revised form 23 February 2008; accepted 21 March 2008

KEYWORDS
Epilepsy;
Prevalence;
Case ascertainment;
Individual interview

Summary Incomplete case finding is a problem in epidemiological studies of epilepsy. We tried to optimize case ascertainment by combining information from individual interviews and medical records. During 2 years, 1838 inhabitants of Vågå, Norway, aged 18—65 (88.6% of the target population) were interviewed as part of an epidemiological study of headache. Individuals with learning disability, mental disorders and dementia were excluded. One question concerning epilepsy was presented to 1793 consecutive cases (mean age 35, males 49%): ''Have you ever had convulsions, epileptic fits or other epileptic symptoms?'' The medical records of the 133 subjects who acknowledged this possibility were reviewed, and telephone interviews were performed when needed. A diagnosis of epilepsy had been made in 41 subjects. Twenty-one were treated with antiepileptic drugs, of whom 12 had had seizures within the last 5 years. By this unique method of case ascertainment, the prevalence of epilepsy in adults (cases under treatment) was 1.2%, and of active cases 0.7%, despite the fact that high-risk groups for epilepsy, such as elderly people and individuals with cognitive deficits, were excluded. Although these findings were derived from a small population in a circumscribed rural area, they suggest that the true prevalence of epilepsy may be higher than reflected in many previous studies.

Introduction

Epilepsy is one of the most common chronic neurological disorders world-wide. The symptoms are limited to short-lasting attacks, which even in patients with intractable seizures occupy only minor parts of their total lives. The diagnosis is associated with prejudice and myths, and some victims endeavour to keep it secret. A large number of epidemiological studies have been undertaken to assess the population-based prevalence of epilepsy in various parts of the world (see[1—3]). However, a range of methodological shortcomings hamper these surveys. Study designs differ considerably. Diversities of sources for case identification, heterogeneity of

* Corresponding author. Tel.: +47 72575075; fax: +47 72575774.
E-mail address: eylert.brodtkorb@ntnu.no (E. Brodtkorb).

1059-1311/$ — see front matter
doi:10.1016/j.seizure.2008.03.005

clinical manifestations and differences regarding prognosis may influence the findings. Problems concerning definition and accurate diagnosis are often prevailing.[4] Cases are also missed because some sufferers conceal their condition and do not seek appropriate medical help or do not comply with treatment and follow-up.

We have tried to optimize case ascertainment by individual interviews in a population of a small, rural community in Norway.

Methods

The study was carried out as part of an epidemiological study of headache in the Vågå community in southern Norway. The design of this study has previously been described in detail.[5,6] A short version is given in this context.

During a 2-year period beginning in 1995, a total of 1838 inhabitants in the age range18—65 (males 49%) met for an individual examination by one single investigator (OS). The recruited individuals comprised 88.6% of the invited target population (n = 2075) at the start of the study. The examiner had been brought up in the parish and knows the local conditions well. Inhabitants with learning disability, mental disorders and dementia were excluded. The participants underwent a semi-structured interview concerning headache and a neurological/physical examination. In addition, one single question concerning epilepsy was presented to 1793 consecutive cases (mean age 35, males 49%): ''Have you ever had convulsions, epileptic fits or other epileptic symptoms?'' The Health Centre medical records of those who acknowledged possible epileptic symptoms were reviewed (by E.B.), and telephone interviews were performed when needed. The study area has a relatively stable, rural population. It is served by general practitioners with a basis in the national health care. Relevant medical reports from hospitals and specialists are usually available for all inhabitants at the communal health centre.

Table 1 Diagnoses in 133 subjects who acknowledged a possible ''history of convulsions, epileptic fits or other epileptic symptoms'' (numbers)

Epilepsy ever (41)
Active (12)
In remission with treatment (9)
In remission, treatment withdrawn (18)
In remission, never treated (2)
Single unprovoked seizures (4)
Situation-related seizures (20)
Febrile seizures in childhood (14)
Alcohol related (3)
Hypoglycemia in diabetes (2)
Other (1)
Psychogenic non-epileptic seizures (1)
Apparent syncopes (35)
Miscellaneous (32)
Probably hyperventilation induced (5)
Transitory ischemic attacks (5)
Migraine aura (1)
Unclear and other episodes (21)

The following definitions were adopted from the International League against epilepsy.[4] Active epilepsy means fulfilment of the criteria for epilepsy and a minimum of one seizure in the previous 5 years. Cases under treatment are individuals with the correct diagnosis of epilepsy receiving antiepileptic drugs (AEDs), regardless of seizure control.

Informed consent was given by all patients. The study was as a whole recommended by the Regional Committee for Ethics in Medical Research and by the Norwegian Data Inspectorate.

Table 2 Patients with active epilepsy in Vågå

Patient number	Sex	Age	Onset age	Seizure types	Epilepsy syndrome	Etiology
1	F	49	0	CP, GTC	Partial	Cryptogenic
2	F	36	7	SP, GTC	Partial	Cryptogenic
3	M	19	15	CP	Partial	Cryptogenic
4	M	36	19	SP, GTC	Partial	Encephalitis
5	F	24	20	CP, GTC	Partial	Cryptogenic
6	M	38	25	CP, GTC	Partial	Cryptogenic
7	M	31	26	GTC	Partial	Cryptogenic
8	M	37	28	GTC	Partial	Cryptogenic
9	M	36	33	GTC	Partial	Post-traumatic
10	M	60	43	GTC	Unclassified	Unknown
11	F	61	45	CP, GTC	Partial	Post-traumatic
12	F	54	51	GTC	Partial	Post-traumatic

F, female; M, male; CP, complex partial; GTC, generalized tonic-clonic; SP, simple partial.

Table 3 Patients with epilepsy in remission with treatment in Vågå

Patient number	Sex	Age	Onset age	Age of last seizure	Seizure types	Epilepsy syndrome	Etiology
1	F	57	11	40[a]	GTC	Partial	Cryptogenic
2	M	22	14	16	GTC	Generalized	Idiopathic
3	M	56	15	19	SP, GTC	Partial	Post-traumatic
4	F	49	16	31	GTC	Generalized	Idiopathic
5	M	46	18	36[a]	GTC	Generalized	Idiopathic
6	M	38	33	33	SP, GTC	Partial	Cryptogenic
7	M	41	35	36	GTC	Partial	Cryptogenic
8	M	59	36	39	GTC	Partial	Post-traumatic
9	F	47	41	42	GTC	Partial	Cryptogenic

F, female; M, male; GTC, generalized tonic-clonic; SP, simple partial.
[a] Recurrence after AED withdrawal.

Results

As many as 133 inhabitants confirmed that a history of convulsions, epileptic fits or other epileptic symptoms could not be excluded. Nevertheless, only 41 (mean age 42, males 51%) were diagnosed as ever having had epilepsy (2.3%) on the basis of medical records, supported by telephone interviews in 30 patients. The remaining subjects were categorized with a range of other diagnoses (Table 1).

A total of 21 individuals were treated with AEDs (mean age 43, males 62%), of whom 12 had active epilepsy (mean age 40, males 58%) with seizures within the last 5 years (Tables 2 and 3). The crude prevalence of definite epilepsy (cases under treatment) was estimated to be 11.7/1000 in the investigated population. Prevalence of active epilepsy was 6.7/1000. Twenty patients in remission were not treated at the time of examination; two individuals with nocturnal seizures limited to early school-years had never received AEDs (Table 1).

Discussion

By this unique method of case ascertainment, the prevalence rate of definite epilepsy (cases under treatment) was 1.2% in the present population sample. Although these findings were derived from a limited number of individuals, they highlight problems in case definitions and ascertainment which may hamper the comparison between various studies. In Forsgren's multisource, population-based study from a Swedish county,[7] the prevalence in adults was less than half as high (5.5/1000). This figure was also based on at least one unprovoked seizure during the last 5 years or treatment with AEDs for epilepsy during the preceding year. The figure from rural Iceland was similar (5.5/1000 above age 25), although slightly different criteria were used.[8] In a recent county-based survey from the same part of Norway as the present study, the mean prevalence was 8.2/1000 in selected age-groups from 31 to 76 years.[9] However, information collected by questionnaires could only partly be medically confirmed. Lower rates have been found in Southern Italy, the lowest in the Aeolian Islands.[10] Active epilepsy was identified in 3.1/1000 (3.5/1000 when including cases in remission with treatment). The low figures have been interpreted as partly due to concealment of the diagnosis causing under-ascertainment. Accordingly, our findings suggest that the prevalence of epilepsy may be higher than reflected in various other studies.

The present investigation does not comprise the entire population of the Vågå community. It aims at assessing the prevalence of epilepsy in a segment of the inhabitants characterized by a relatively stable and low risk for epilepsy. High-risk groups for epilepsy, such as elderly people and individuals with cognitive deficits, were excluded from this survey, which was based on self-reporting. Non-participation might possibly be associated with milder degrees of brain dysfunction than learning disability or dementia, which may have been related to epilepsy. The fact that participants were invited for an epidemiological study of headache, is a potential bias, as studies have shown an association between headaches and epilepsy, particularly between migraine and epilepsy.[11–13] A lower prevalence of headaches as well as seizures in individuals who did not show interest in the study is possible. However, an essential influence on the results is improbable since the participation of the target population was extremely high (88.6%).

Most epidemiological studies of epilepsy are based on multiple sources, first of all on patients attending special clinics or other treatment or diagnostic facilities. Studies based on less specialized levels may comprise larger parts of the population,

but may be less suitable due to a lower yield. The most direct method is the individual interview or door-to-door survey. This approach can seldom be employed due to the large patient number needed, the time consumption and costs required, as well as problems concerning the definition of the target population[14] and the medical verification of the diagnosis. The strength of the present study design is that many of these problems largely were overcome. We believe that the health care system of rural Norway provides a suitable background for this kind of investigation. Vågå has a relatively stable population and is served by one single government-run primary health care centre. The only neurological service for the area is provided by the County Hospital in Lillehammer. Relevant medical background information was available or could be collected for all subjects who had been examined for possible epileptic seizures. However, several weaknesses are apparent. A random error due to the small sample size is possible and the representativeness of the area in relation to the entire country may be questioned, as people with handicaps such as epilepsy may tend to accumulate in their rural home communities.

Nevertheless, the present survey calls attention to some problematic issues in epidemiological studies in epilepsy. Which patients should be included in estimates of epilepsy prevalence? This has differed in the past,[1] a fact which makes it difficult to compare various studies.[8,9] "Active epilepsy"[4] is an ambiguous term. It is evident that the number of patients with a 5-year remission is influenced by the quality of health care and by patient compliance. Active epilepsy does not include all patients with an enduring epileptic condition. E.g., patients with a history of an unsuccessful discontinuation of AEDs more than 5 years ago are left out from the prevalence of active epilepsy (patients 1 and 5, Table 3). It also excludes most patients with idiopathic generalized epilepsy of more than 5 years duration (patients 2, 4 and 5, Table 3), including juvenile myoclonic epilepsy, in spite of the fact that many of these patients usually need life-long treatment to avoid recurrence.[15] The great majority of patients with idiopathic generalized epilepsy achieve seizure freedom with appropriate treatment.[16] Thus, only adult patients with relatively new onset idiopathic generalized epilepsy are usually included as cases of active epilepsy. Many patients with idiopathic generalized epilepsy harbour a persistent inherent predisposition to seizures, but no such subjects were represented among our active cases (Table 2). In contrast, in a recent study from Tanzania, seizures were categorized as generalized in 70%, although the epilepsy syndromes could not be accurately classified due to limited access to diagnostic tools.[14]

Hence, reported prevalence rates of active epilepsy are not only determined by the underlying epileptic disorder. Seizure control in subjects with epilepsy is dependent on geographical, socio-economic and cultural differences. The patients' level of knowledge about their disorder and its management is essential for treatment compliance and behaviour in relation to seizure precipitants. The standard of care and the access to treatment facilities are crucial. In addition, traditions and costs are factors which influence the duration of treatment in patients in remission. The Norwegian reimbursement practice of AEDs may increase the number of patients with epilepsy under treatment, as an economical motivation for patients to stop treatment is negligible. The term, prevalence, should always be clearly delineated in relation to epilepsy. The present two-staged method with an initial screening interview and a subsequent detailed epileptological evaluation of subjects who acknowledged possible epileptic seizures, warrants a high sensitivity and specificity. The fact that more than 50% of subjects who acknowledged the possibility of epileptic manifestations, appeared to have had other episodic symptoms, may reflect a low level of knowledge about epilepsy in the society. Surveillances exclusively relying on self-reporting may be seriously biased by low specificity.

In conclusion, our findings indicate that the prevalence of definite epilepsy (cases under treatment) exceeds 1.2% in a small community in rural Norway. Further analyses will be undertaken to explore the association between migraine and seizure disorders in this population.

References

[1] Forsgren L, Beghi E, Oun A, Sillanpää M. The epidemiology of epilepsy in Europe. *Eur J Neurol* 2005;**12**:245—53.
[2] Theodore WH, Spencer SS, Wiebe S, Langfitt JT, Ali A, Shafer PO, et al. Epilepsy in North America: a report prepared under the auspices of the global campaign against epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization. *Epilepsia* 2006;**47**:1700—22.
[3] Mac TL, Tran DS, Quet F, Odermatt P, Preux PM, Tan CT. Epidemiology, aetiology, and clinical management of epilepsy in Asia: a systematic review. *Lancet Neurol* 2007;**6**:533—43.
[4] Commission on epidemiology and prognosis of the International League Against Epilepsy. Guidelines for epidemiological studies on epilepsy. *Epilepsia* 1993;**30**:389—99.
[5] Sjaastad O. The Vågå Study: an outline of the design. *Cephalalgia* 1999;**19**(Suppl. 25):24—30.

[6] Sjaastad O, Pettersen H, Bakketeig LS. The Vågå study; epidemiology of headache I: the prevalence of ultrashort paroxysms. *Cephalalgia* 2001;**21**:207—15.
[7] Forsgren L. Prevalence of epilepsy in adults in Northern Sweden. *Epilepsia* 1992;**33**:450—8.
[8] Olafsson E, Hauser WA. Prevalence of epilepsy in rural Iceland: a population-based study. *Epilepsia* 1999;**49**:129—34.
[9] Svendsen T, Lossius M, Nakken KO. Age-specific prevalence of epilepsy in Oppland County, Norway. *Acta Neurol Scand* 2007;**116**:307—11.
[10] Gallitto G, Serra S, La Spina P, Postorino P, Lagana A, Tripodi F, et al. Prevalence and characteristics of epilepsy in the Aeolian islands. *Epilepsia* 2005;**46**:1828—35.
[11] Leniger T, von den Driesch S, Isbruch K, Diener HC, Hufnagel A. Clinical characteristics of patients with comorbidity of migraine and epilepsy. *Headache* 2003;**43**:672—7.
[12] Yankovsky AE, Andermann F, Bernasconi A. Characteristics of headache associated with intractable partial epilepsy. *Epilepsia* 2005;**46**:1241—5.
[13] Syvertsen M, Helde G, Stovner LJ, Brodtkorb E. Headaches add to the burden of epilepsy. *J Headache Pain* 2007;**8**:224—30.
[14] Dent W, Helbok R, Matuja WB, Scheunemann S, Schmutzhard E. Prevalence of active epilepsy in a rural area in South Tanzania: a door-to-door survey. *Epilepsia* 2005;**46**:1963—9.
[15] Kwan P, Sander JW. The natural history of epilepsy: an epidemiological view. *J Neurol Neurosurg Psychiatry* 2004;**75**:1376—81.
[16] Osservatorio Regionale per L'Epilessia (OREp), Lombardy. ILAE classification of epilepsies: its applicability and practical value of different diagnostic categories. *Epilepsia* 1996;**37**:1051—9.