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Epilepsy and treatment gap in urban and rural areas of the Southern Kazakhstan in adults

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ABSTRACT

Purpose: There are no data in the English literature about the epidemiology of epilepsy in the large countries in the Asian region of the former Soviet Union. This paper presents the results of epidemiological studies of active epilepsy in the population 14 years of age and older in the Province of South Kazakhstan.
Methods: The study population consisted of 306.44 thousand persons: 139.42 in the urban Enbekshinskiy district of the city of Shymkent and 167.02 in the rural Sairam district. To collect patient's data, multiple medical sources were used. For each person with epilepsy (PWE), a questionnaire was completed by members of the research team. Clinical profiles, seizure type, clinical syndrome, etiology, seizure frequency, therapy, educational level, and social status were abstracted.
Results: Overall, 1351 PWE were identified: 459 in the urban district and 892 in the rural district. The age-adjusted prevalence of epilepsy was 3.14/1000 (CI95%: 2.86–3.45) in the urban district and 4.95/1000 (CI95%: 4.62–5.30) in the rural district. Prevalence for men was higher than for women. Focal seizures predominated in both regions. Traumatic brain injury was the most frequently identified cause of epilepsy. The other important antecedents were pre/perinatal disorders, CNS infection, and cerebrovascular disease.
Half of PWE experienced more than 12 seizures per year. Substantial social impacts of epilepsy were observed: 44% of PWE received disability pensions from the government; only 15.5% were employed. About a quarter of all PWE were not taking AEDs at the time of the record review. For those on treatment, regimens were frequently suboptimal.
Conclusion: In the first study performed according to the guidelines for epidemiologic studies on epilepsy of ILAE in the Asian part of the former Soviet Union, poor seizure control and a substantial treatment gap were identified. The need for improvement of epilepsy care was highlighted, especially in the rural regions.

1. Introduction

Epilepsy is a neurological disorder linked to substantial burden on physical and mental health. Despite the numerous studies of the epidemiology of epilepsy from different regions of the world, publications on epidemiology of epilepsy from the former Soviet Union countries are scarce [1–3].

There are no data in the English literature on the epidemiology of epilepsy in the large countries in the Asian region of the former Soviet Union. A few papers were published in Russian and Kazakh journals [4] that are not retrievable by routine literature search; further, these studies did not use current guidelines for epidemiologic studies on epilepsy [5,6].

The paper presents the results of an epidemiological study of active epilepsy in the population 14 years old (y.o.) and older in the urban (Enbekshinskiy district of the city of Shymkent) and rural (Sairam district) areas in the Province of South Kazakhstan; both regions were evaluated according to the same protocol. The prevalence of epilepsy, clinical profile, seizure type, clinical syndrome, etiology, seizure frequency, therapy, educational level, and social status were investigated. The data were collected in 2009–2011 in accordance with the protocol previously used in a Russian study of epilepsy prevalence [2]. This protocol was based upon the guidelines for epidemiologic studies on epilepsy and used definitions recommended by the International League against Epilepsy (ILAE) [5]; people with epilepsy (PWE) aged 14 y.o.

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and older were included to ensure comparability with the data obtained in Russia.

South Kazakhstan Province of the Republic of Kazakhstan has a population of 2429 thousand (as of January 1, 2010) and a land area of 117.3 thousand km^2 [7]. South Kazakhstan Province is one of the fastest growing and the most densely populated regions of the Republic of Kazakhstan because of its relatively comfortable climate with moderately hot summers and mild winters, and a good irrigation infrastructure because of the Syr Darya River with its tributaries. The population of Southern Kazakhstan consists predominantly of Kazakhs (about 70% of the population). Uzbeks make up the second largest population subgroup (about 18%). The proportion of the Russian population was about 6% at the time of the study, significantly diminished compared with the Soviet period (23% in 1980). There is also a small proportion of Tajiks, Koreans, and Kurds [7].

Shymkent is the capital of the South Kazakhstan Province with a total population of 539,600 people. The largest proportion of the city population is Kazakhs (58.1%), followed by Russians (18.4%), Uzbeks (14.9%), Tatars (2.1%), Azeri (2.0%), Koreans (1.2%), and Ukrainians (1.0%).

Enbekshinskiy district is representative of the whole city of Shymkent in terms of infrastructure and population. The total population (as of 01.01.2010) of the Enbekshinskiy district was 193.2 thousand. The study population included all the inhabitants of this region 14 y.o. and older (adolescents and adults): 139.42 thousand (64,053 men and 75,367 women).

Sairam district is the rural area of Southern Kazakhstan with a territory of 1.7 thousand km^2, total population of 262.7 thousand people (Uzbeks – 64.8%, Kazakhs – 26.9%, Turks – 3.0%, Russians – 1.8%, Azeri – 1.1%). The study population included 167,021 people (82,943 men and 84,078 women) – all the inhabitants 14 y.o. and older.

2. Methods

To collect patient-related information multiple data sources were used including medical records from hospitals, outpatient departments and clinics (including non-governmental), and intensive care units. The medical records for people with diagnostic codes of G40, G41, and R56 (ICD 10) were screened to identify people with active epilepsy. Screening of medical records in the outpatient departments was our primary source of information, since medical information was stored there for the substantial part of the population. There are 3 outpatient multidisciplinary facilities ("Poliklinika") in the urban area, which represent the only source of the outpatient medical care. In these "polyclinics", general practitioners (GPs) and neurologists offices are located in the same facility; 5 neurologists were working in these "polyclinics".

People are assigned to specific clinics ("Poliklinika") in their region and would be referred back to the assigned clinic if they attempted to be seen elsewhere. If they were seen elsewhere for emergency care all records would be forwarded to the facility of record. People with seizures were seen by a neurologist without a visit to or referral from the GP. If a patient with seizures initially approached the GP, he would be referred directly to a neurologist on the same day.

In the rural (Sairam) area, there is one "Poliklinika", where three neurologists and GPs are located in the same facility; in addition there are 5 other smaller facilities, staffed only by GPs. To verify that all the patients were identified, in addition to review of records from the rural outpatient multidisciplinary "polyclinica", we also reviewed records from the smaller clinics of GPs.

In Kazakhstan, all PWE are referred to a neurologist for the confirmation of the diagnosis and treatment. There is an advantage for PWE to being identified to the state institution even if they are also being seen by private doctors, as all the examinations (including magnetic resonance imaging) and approved antiepileptic drugs (AEDs) are available free of charge if they are prescribed by the neurologists from the state hospitals or outpatient clinics.

There was one facility in which people with intellectual handicaps received care. All PWE in that facility would also have been referred to the neurologist and the records reviewed.

We reviewed, and, when appropriate, abstracted medical records of people with a diagnostic code for seizures from all neurologists (5 in the Enbekshinskiy region and 3 in the Sairam region), working in the state outpatient clinics in these regions, as well as from all (3) neurologists in the private clinics serving both regions. Access to all the information was feasible as one of the study team members (N.Zh.) was the chief neurologist of the region. In this position, she supervised the work of all neurologists in the South Kazakhstan Province, and was ultimately responsible for all neurologic care including provision of care to all the identified PWE.

Patients were classified as having epilepsy based upon clinical evaluation and EEG findings; EEG was performed on all patients. Imaging investigations were performed in 542 patients (40.1%): computed tomography in 109 patients (8.1%), 0.3 T and 1.5 T magnetic resonance imaging in 162 (12.0%) and 271 patients (20.1%), respectively.

Study neurologists reviewed the medical history of all patients with the designated diagnostic codes to identify those with active epilepsy. For each eligible subject, abstraction forms were completed, including demographic data, possible exposure to etiologic factors, clinical pattern of epilepsy, results of neurological examination, EEG, and other investigations, therapy, and seizure frequency. Information was obtained about educational level and social status.

According to the standards for epidemiologic studies and surveillance of epilepsy [6], epilepsy was defined as two or more unprovoked seizures occurring at least 24 h apart. A person who was either on current treatment for epilepsy or who had experienced a seizure within the past 5 years was considered to have active epilepsy [5,6].

All cases were classified according to the ILAE classification of epileptic seizures and the classification of epilepsies and epileptic syndromes [8,9]. Etiology was considered as presumed and was determined on the basis of history, clinical data, and available routine neuroimaging studies [10].

We categorized people by etiology based upon the guidelines for epidemiologic studies on epilepsy [5]. Whenever possible, standards for epidemiologic studies and surveillance of epilepsy [6] were applied in terms of etiology, and seizure and syndromic classification. Age-standardized (direct standardization with European Standard Population 1976) [11] prevalence of the active epilepsy with its' 95% confidence intervals for total population [12] and age- and gender-specific prevalence were calculated. The prevalence was standardized to the same standard population as in an earlier study of prevalence in Russia to which we intended to make comparisons [2]. Treatment gap was defined as the proportion of PWE who require but do not receive treatment [13,14].

The mean ± SD or median (25, 75 percentile) were calculated for continuous variables; the proportion and 95% confidence interval (CI95%) (by Wilson's method) were determined for categorical variables. Normally distributed continuous variables were compared by the Student's t-test, otherwise Mann–Whitney U test was used. Two proportions were compared with Z-test. Categorical variables were compared by Chi-squared test or Fisher's exact test.

The study was approved by the Local Ethics Committee of the South-Kazakhstan State Pharmaceutical Academy.

3. Results

3.1. The study population and prevalence of epilepsy

The total study population was 306.44 thousand inhabitants (on Jan.1, 2010): 139.42 thousand in the urban Enbekshinskiy district and 167.02 thousand in rural Sairam district. A total of 1351 PWE (aged 14 and above) were identified: 459 in the urban district and 892 in the rural district (Table 1). All the PWE in the urban district