ORIGINAL ARTICLE

Childhood Epilepsy

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ABSTRACT

Objective: To determine the community-based prevalence of childhood epilepsy and its treatment gap in rural and urban population in Punjab, Pakistan.

Study Design: Cross-sectional study.

Place and Duration of Study: Gujranwala District, from March to June 2007.

Methodology: Ten out of 52 Union Councils of District Gujranwala, Pakistan, were randomly selected. Field officers, specifically trained for screening children with active epilepsy, performed a door-to-door survey in the selected Union Councils using area vaccinators as key informants. Final confirmation of active epilepsy and treatment details were ascertained by a qualified paediatrician and a paediatric neurologist, where required. Treatment gap was defined as relative (when treated inappropriately) and complete (complete lack of treatment).

Results: Among a total, under 16 years population of 92254, prevalence of childhood epilepsy was found to be 7.0/1000 (n=643) with similar distribution between urban and rural residents. Up to 66% (n=424) patients were being managed by an unqualified person including paramedics and faith healers. Treatment gap was found in 88% (n=566) patients.

Conclusion: Childhood epilepsy is common in both urban and rural areas of District Gujranwala. Area vaccinators may be incorporated into screening and referral program to bridge the treatment gap utilizing minimum available resources.

Key words: *Childhood epilepsy. Prevalence. Catch-recatch technique. Key informants. Children.*

INTRODUCTION

It has been estimated that the mean prevalence of active epilepsy worldwide is approximately 8% of the general population.[1] A high burden of this disease is found in developing countries where prevalence rates are between 10 and 40%.[2,3] The prevalence rate is higher in rural areas than in urban areas. The reason for this difference is not known.[4] The reason for wide disparity among the prevalence rate included the varying modes of case ascertainment and information chosen across the studies. The diagnosis of epilepsy is essentially clinical but there are difficulties in establishing and to peruse epidemiological statistics for a heterogeneous condition like epilepsy with its associated medical and social problems.[5]

Existing knowledge on the epidemiology and treatment of epilepsy has been derived mainly from studies conducted overseas. However, difference in ethnic composition, disease prevalence, and socioeconomic factors mean that findings from these studies may not be entirely applicable to the Pakistani communities. Local data are important in order to assess the magnitude of the problem and to target resources to patients and projects most in need. A successful control policy for developing countries has to be affordable, sustainable, acceptable and effective. This information would certainly be of prime importance as part of the efforts to fill what has been called the "treatment gap" in epilepsy, especially among the rural population.[6] WHO has recommended a strategy integrating epilepsy services at primary level.[7] Methods and thoroughness of case ascertainment is a prime determinant of the precision of epidemiological figures. Clearly culture specific assessment instrument must be developed to aid identification of childhood epilepsy disorders. The data of quality required to estimate the prevalence of epilepsy may not be available in the form of medical records.[8] Hence, a direct approach among members of the community is the best method to determine the rate of epilepsy in developing countries. Community surveys have the advantages of being more representative. They would include epileptic children and adolescents who do not attend school and those who don't have access to proper health facilities. Epileptic children are the most marginalized individuals in the community and voice of these minors is not sufficiently heard.

The aim of this epidemiological survey was to determine the local prevalence of childhood epilepsy and its treatment gap in urban, semi-urban and rural community.

METHODOLOGY

This cross-sectional randomized cluster sampling study was done in 10 out of 52 total Union Councils of the

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Gujranwala District. Rural, urban and semi-urban Union Councils were selected randomly, from 1st March to 30th June 2007. An epidemiological survey was conducted in a series of phases as follows;

Phase I was for training and developing research tools. A 3-day training workshop was conducted at the Sardar Family Hospital, Kangniwala in Gujranwala District under the supervision of the Paediatric Neurologist, trained in epidemiological surveys. A seven item questionnaire was adapted and modified from an extensively validated questionnaire used in Ecuador, translated into local Urdu and Punjabi languages in the form of specially designed proforma.[9] Another specially detailed proforma was adopted for the diagnosis and classification of childhood epilepsy according to International League Against Epilepsy (ILAE).[10] At the end of the workshop, competency of the research team, efficacy of the questionnaire and proforma was assessed. Continuous support and guidance was provided to the field of officers throughout the study period.

For the screening purposes (phase II) , the field officers comprising of key informants, health visitors, medical students and volunteer community workers, under the supervision of medical officers, went door-to-door in the 10 randomly sampled Union Councils. All the field officers (minimum education ≥ Matric) were given a basic orientation on childhood epilepsy and survey work. One of the essential team members was key informant (KI) for each Union Council, usually a vaccinator working for more than 02 years who knew the community very well. The idea was to combine two methods (door-to-door and key informant) of survey together, to improve the validity of this survey. Help was sought from religious scholars, school teachers and political leaders to motivate the population to participate in this survey. Team members administered the questionnaire to mothers of children or older adults in the house hold, and enumerated all the children in the field area, aged ≤ 16 years. Any child having the possibility of any type of epilepsy was marked on the pre-designed proforma and was labeled as the "result". Probe question about associated fever or prior external stimulus was added to improve positive predictive value of the screening phase. These results (patients) were called at the nearest basic or primary health unit to be interviewed by the paediatricians under the supervision of paediatric neurologist. The field workers were motivated and monitored continuously.

Phase III comprised diagnostic confirmation, registration and data analysis. All the children, having suspicion of epilepsy (results) were called at nearest basic health unit (BHU) or primary health unit (PHU), they were interviewed and examined by qualified and trained paediatricians and paediatric neurologists. Missed case on one occasion were recalled (capture-recapture technique) for registration and diagnosis. Detailed history was obtained from both parents and witnesses. All those children who were diagnosed as epileptics were evaluated and registered on Proforma-II. Epileptic seizures were classified as generalized, focal and undetermined. The aims of this procedure were, to determine the true positive house for positive patients and increase the credibility and the reliability of the results, mainly in respect of classification of seizures, and cause of epilepsy, this procedure also has frequently been used by other authors.[9-10] Active epilepsy was defined as presence or absence of at least one unprovoked seizure over the last 2 years based on detailed history. Treatment gap was defined as absolute treatment gap when there was complete lack of treatment under untrained personnel. Relative treatment gap was defined as patient being under the care of a physician but treated inappropriately.

The data including age, gender, the type of seizures, frequency of seizures, duration since last seizure, treatment, medication, treating person and presence of treatment gap were recorded and analyzed through SPSS version 14. Mean and 95% CI was calculated for scale data including age. Frequencies were calculated for all mentioned nominal variables. Chi-square test was used as test of significance, considering $p < 0.05$ significant.

RESULTS

At the time of survey among the total (233371) population of 10 Union Councils of Gujranwala District, with 92254 (40%) aged ≤ 16 years. Among the study population, 27430 (30%) were urban residents, 20115 (22%) belonged to semi-urban population and 44709 (48%) were rural residents. The prevalence of childhood epilepsy was 7.0/1000, (n=643, rural population 6.8/1000, n=186/27430, semi-urban population 7/1000, n=140/20115 and urban population 7.1/1000, n=317/44709, p=0.9) Table I. Point prevalence of 6.7/1000 and 7/1000 was documented among the age groups of ≤ 5 years, and > 5 to ≤ 16 years respectively, (p=0.9).

Table I: Distribution of childhood epilepsy among different union councils (n=233371).

Union Council	Total population	Children age ≤ 16 years	Epileptic children (age ≤ 16 years)	Per thousand (age ≤ 16 years)
Marali Wala (R)	21605	8851 (41%)	65	7.3
Mundyala Taingan (R)	21554	8656 (40%)	54	6.2
Ramkay Sindwan (R)	22835	9342 (41%)	66	7.1
Wando (R)	22777	8434 (37%)	54	7.0
Jurmama Shiram Singh (R)	23042	9426 (41%)	58	6.2
Kolu Wala (SU)	25735	10240 (40%)	74	7.2
Aimna Abad (SU)	25370	9875 (39%)	66	6.7
City UC No. 29	25870	9420 (36%)	58	7.2
City UC No. 10	23000	9450 (41%)	69	7.3
City UC No. 30	21583	8560 (40%)	60	7.0
Total	233371	92254 (40%)	639	7.0

R = Rural; SU = Semi-urban; City UC = Urban.

Table II: Distribution of childhood epilepsy among different age groups (n=233371).

Union Council	Children age ≤ 5 years			Children age > 5 years to ≤ 16 years		
	Total	Epileptic	Per thousand	Total	Epileptic	Per thousand
Marali Wala (R)	3673	28	7.6	5178	37	7.1
Mundyala Taingan (R)	3664	24	6.6	4992	30	6
Ramkay Sindwan (R)	3882	31	8	5460	35	6.4
Wando (R)	3872	24	6.2	4562	35	7.7
Jurmama Shiram Singh (R)	3917	29	7.4	5509	29	5.3
Kolu Wala SU	4375	28	6.4	5865	46	8
Aimna Abad SU	4313	26	6.0	5562	40	7.2
City UC No. 29	4398	26	6.0	5022	42	8.4
City UC No. 10	3910	23	6.0	5540	46	8.3
City UC No. 30	3669	29	8.0	4891	31	6.3
Total	39673 (17%)	268	6.7	52581 (23%)	371	7.07

R = Rural; SU = Semi-urban; City UC = Urban.

Table III: Distribution of different epileptic seizure among childhood epileptic population in the community (n=639).

Type of epileptic seizures	Children age ≤ 16 years	Percentage
Generalized tonic colonic	408	64
Absence	51	08
Myocolonic	26	04
Complex partial	96	15
Simple partial	32	05
Unclassified	26	04
Total	639	100

The point prevalence among the children of age group > 5 to ≤ 16 years ranged from 5.3/1000 (Jumama Shurm Singh Union Council) to 8.4/1000 (in City Union Council No. 29) (Table II). Over all, 76% patients had generalized epileptic seizures and 24% had partial epileptic seizures. Distribution of seizures is tabulated in Table III. Epilepsy was slightly more common in boys (54%) than in girls (46%, p=0.25). Electroencephalographic and neuroimaging data were often not available. Typically, there was great variability in case management of epilepsy from one Union Council to another. The epileptics were being managed as follows; 50% by paramedics, 20% by general practitioners, 10% by faith healers, 5% by neurosurgeons, 5% by paediatricians, 4% by psychiatrists and 6% by Hakims, Quacks and others. None of the epileptic children was being managed by an Epileptologist (Neurologist with special interest in epilepsy). Stigma of epilepsy was important in majority of the places and only 20% of the parents/ patients were hopeful about the useful life of the epileptics. Severe mental retardation was present among 18% of the epileptic patients and only 20% of the school going age epileptics were going regularly to their schools. The treatment gap was observed among the 88% (92% of rural and semi-urban population, and 78% of the urban population) of the total 643 epileptic children, whereas, overall absolute treatment gap was present among 27% of the epileptic children.

DISCUSSION

Data on the epidemiology of epilepsy in a rural/semi-urban/urban community in a developing country would be of value in planning a decentralized management of this malady in its early stages to commensurate with available local resources. Approximately 50% of the cases of epilepsy begin in childhood or adolescent.[11] There is a lack of data on the epidemiology of childhood epilepsy in Pakistan; even though epilepsy is the most common serious chronic neurological condition in this age group. The crude prevalence rate of epilepsy, of 9.98/1000 population of all age groups, has been reported in Pakistan and among these, 74% were aged ≤ 18 years.[12] Whereas this percentage varies from country to country in Asia. The medium lifetime prevalence of epilepsy is estimated at 6/1000 persons in Asia.[13] Aziz *et al.* had highlighted the need to conduct a truly community-based point prevalence study of childhood (≤ 16 years age) epilepsy in Pakistan.[14]

This cross-sectional randomized cluster sampling study was done over a 4 months period. In general, the use of the questionnaire was well accepted in the presence of key informants in house to house survey and refusal was minimal. More than 98% of the target population attended the camping sites; this high attendance rate was due to combination of door-to-door survey in the presence of key informants and catch-recatch technique. Better positive predictive value of epidemiological surveys in childhood epilepsy by combination of different survey methods in childhood epilepsy has been documented in other studies.[13,15]

The combination of different survey methods confirm that the prevalence of epilepsy can be quite variable even in the same country.[16] In contrast to this study, the point prevalence rate of 4.5/1000 children has been reported from Hong Kong.[13] In this study the highest (8.4/1000) prevalence rate was found among the children age > 5 years to < 16 years in city union council (CUC) and the lowest (5.3/1000) point prevalence was documented in Jumama Shurum Singh. At the moment we could not ascertain the etiology of this significant variability. Kandil *et al*. reported the highest frequency rate (48%) at the time of interview was during childhood (2-11 years) followed by in infancy (15.8%).[16] Kramer

et al. from Israel found that 18% of the seizures began in infancy, 64% in 2-10 years of age and 18% in adolescents (11-18 years), whereas Cowan *et al.* reported that seizures began before the age of one year in 32% of cases.[17,18] In the study by Shawki *et al.* 78% of the cases of epilepsy developed their first seizure before the age of 12 years.[19]

It was found that higher incidence of epilepsy with higher incidence of seizures was reported among rural population, but in this study this could not be confirmed. No etiology (idiopathic, cryptogenic or symptomatic) was identified, at the time of registration. These aspects would be explored later on.

The frequency distribution of epileptic seizure in this study was the highest for generalize seizures followed by partial seizures and unclassified seizures. Because partial seizure is difficult to document in infants and children, the frequency of its association with complex partial seizure may have been underestimated. The generalized tonic clonic seizure, on the other hand is hardly ever underdiagnosed because of its florid clinical symptomatology. Shakya *et al.* from Katmandu have reported generalized seizures among 78% of the epileptic children.[20] In Asia, the range of patients with generalized epilepsy is 50-69% and 31-50% has partial seizures, which is slightly different to the present observations.[21,22] The treatment status of childhood epilepsy was found to be very poor, with only 22% of urban and 8% of rural epileptic children receiving anti-epileptic drugs in proper dosage and with proper compliance. Aziz *et al.* documented 98% treatment gap in all age groups in Pakistan, which is defined as the percentage of person with active epilepsy who are not receiving treatment.[14] Overall treatment gap in this study was 88%, having higher percentage (92%) in rural and semi-urban population and having lower percentage (78%) in urban population. In this study, we documented absolute treatment gap among 27% and relative treatment gap among 61% of the epileptic children. Overall, 60% treatment gap was due to poverty and non-availability of antiepileptic medicines. Other epidemiological studies in developing countries suggest that between 80-94% of the patients with active epilepsy, having higher percentages in the rural populations, are not receiving antiepileptic drugs.[21-23] The cost is one of the major reasons of high treatment gap for epileptic patients in these countries and this is higher in rural populations.[20]

CONCLUSION

We conclude that childhood epilepsy is under-resourced and undertreated having a large treatment gap in Pakistan. Local vaccinators could be of immense importance in gathering data about stigmatized diseases. The education of health workers, patients and the wider community is, therefore, essential. Government should give high priority to the development of childhood epilepsy centres at the district level, where free or subsidized antiepileptic drugs should be available.

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