

## Factors Associated with Utilisation of Services by Epilepsy Patients in Rural Areas - A Descriptive Study

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### Abstract

Epilepsy has been recognised as a major neurological public health problem through several epidemiological studies. The present report aims at understanding the profile and characteristics of persons with epilepsy in rural areas. Information from 1292 first contact epilepsy patient was collected from five extension service centres of NIMHANS in a prospective manner. The age and sex distribution revealed that epilepsy was predominant in the age group of <20 years and among males. The catchment area distribution indicated that people within a radius of <10 kms formed 52% of the total subjects. The duration of illness was >12 months in 45.7% of cases. Generalised convulsive epilepsy constituted 50% of diagnostic categories. The first contact drop out rate was 22.1% within this group. The present study discusses the importance of various socio-demographic and service utilisation factors in the care for epilepsy patients in rural areas.

Key words -

**Epilepsy,  
Epidemiology,  
Service utilisation,  
Socio demographic factors,  
Descriptive study**

Several neuro epidemiological surveys undertaken in India have brought to the forefront of health care delivery system [1], [2], [3]. Among the various neurological problems, epilepsy is the most common problem affecting all age groups and for whom services are provided by all categories of medical and allied professionals [4]. Even though the prevalence and incidence of this illness is low as compared to many infectious and nutritional problems, epilepsy still constitutes a major public health problem and is also found to occur in association with several other disorders.

Factors contributing to the utilisation of services have been reported earlier by some of the authors [5], [6], [7]. These characteristics are essential for understanding the nature of illness and also to develop appropriate programmes. The present report aims at identifying the characteristics of epilepsy patients seen in rural areas around Bangalore. The usefulness of such information for health care planning is also emphasized.

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## Materials and Method

Information from 1292 first contact epilepsy patients was collected from five extension service centres of NIMHANS namely Gunjur, Gouribidanur, Kanakapura, Maddur and Madhugiri. The description and operational characteristics of this approach has been presented in earlier reports [8], [9]. Two trained investigators collected the data from all epilepsy patients with the help of a pretested coded questionnaire. A pilot study was conducted to establish uniformity in data collection procedures. The information elicited focussed on sociodemographic characteristics, availability services, duration of illness and distance travelled to reach centres. The referral pattern and follow up aspects were studied in greater detail. Regularity of continuity in care and the self and family reported improvement were also documented.

All subjects diagnosed to be suffering from seizures were included for data collection purposes. The final diagnosis was made by the consulting team visiting these centres. The present report discusses in detail the characteristics of only epilepsy cases. Individuals diagnosed to be suffering from febrile convulsions, single seizures and epilepsy as a comorbid condition have been excluded from the present analysis. The diagnosis of epilepsy was established by the team of neurologists based on clinical history and eye witness description. None of the investigative procedures could be undertaken due to lack of facilities in rural areas. The classification of epilepsy was done in accordance with ICD-9 methods. The patients were also provided with necessary treatment and advice as part of the service programme.

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## Results

Information was collected from 1292 epilepsy subjects during the study period of 16 months from the five extension service centres. Epilepsy formed the major condition encountered in all these centres ranging from 85 to 412 in different centres (Table I). Seizure disorders constituted 30.2%, 56.4%, 40.9%, 45.7% and 35.8% at Gunjur, Gouribidnur, Maddur, Kanakapura and Madhugiri respectively out of the total patients. As mentioned above, only information from epilepsy cases has been included for this analysis. Epilepsy constituted 73.3%, 79.2%, 91.4%, 76.0% and 72.6% respectively among the total seizures in each of the centres mentioned earlier. The data from individual centres was examined separately and since the variation was minimal, information was pooled to develop a total profile of epilepsy subjects.

*Table I*

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Figures in parenthesis indicate percentages

***Table II - Socio-demographic characteristics of epilepsy patients (n=1292)***

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Table II shows the major sociodemographic characteristics of epilepsy patients seen in these centres. It was observed that about 66.9% of patients belonged to the age group of < 20 years. The sex differences revealed that males and females constituted 60.3% and 39.7% respectively. Majority of the patients were illiterates and only 15.3% had attained education beyond high school level. Among the various occupational categories about 30.8% were students and 17.1% were agriculturists. About 92.0% of subjects belonged to families with a per capita income of less than Rs.300 per month. Information on distance travelled, duration of illness and referral pattern is shown in Table III. About 52.1% of patients were from headquarters and neighbouring villages within a radius of < 10 kms. The representation of distant villages with a radius of > 20 kms constituted of 29.2%. The duration of epilepsy varied from 1 month to many months. The duration of epilepsy was less than 6 months in 30.8% of cases and more than 24 months in 41.9% of cases. The referral pattern observed among these cases revealed that neighbours and friends had referred 50% of patients. The local hospitals, health workers and the local practitioners had referred 3.7%, 11.8% and 18.2% of the patients respectively.

***Table III - Service utilisation factors associated with epilepsy***

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The predominant type of epilepsy was generalised convulsive epilepsy in 49.6% of cases (Table IV). Partial epilepsy with and without impairment of consciousness and unspecified epilepsy constituted 19.5% and 31.0% of total cases respectively. A total number of 929 (71.9%) subjects had taken treatment earlier before reaching the centres. Further investigation into the source of treatment revealed that it was predominantly local doctors (23.2%) and local hospitals (17.3%) at or near to their place of residence. The other source of care was mainly local traditional healers (5.0%) and over the counter self medication in 28% of cases. About 6.4% of patients from this earlier treated group had been previously hospitalised in local hospitals or nursing homes, but had not noticed any significant improvement.

***Table IV - Distribution of epilepsy in diagnostic categories (n=1292)***

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In order to maintain continuity of care, these patients were informed to return for follow up examination and continuation of medication. About 62% of patients were regular in visits, 15.9% were irregular and 22.1% were first contact dropouts. Among those on follow up, about 64% had noticed total improvement based on the reduction in frequency of seizures as reported by them and their family members. Partial improvement (25-50% reduction) was reported by 15% and 20.0% did not notice any significant improvement (less than 25% reduction) at the end of the study period.

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## **Discussion**

Several epidemiological studies conducted in India and other developing countries by different groups

of researchers have shown epilepsy to be a major public health problem. The prevalence of epilepsy ranges from 2-10 per 1000 across different studies [2], [10], [11], [12]. The incidence of epilepsy from a recent review is estimated to be 20-50 per 1,00,000 population [4]. Even with the lowest estimates there would be more than 5,000,000 individuals in India suffering from epilepsy and requiring immediate intervention. The present report is an attempt at examining a profile of epilepsy patients and also to delineate various factors associated with utilisation of services in rural areas.

The age-sex distribution of epilepsy cases in the present series has shown preponderance of males and high representation in younger age groups. This phenomenon has been observed by other authors as well [8], [13]. The ICMR collaborative study on epilepsy observed that about 57.5% of patients presented before the age of 20 years [14]. The high occurrence of epilepsy in this age group could be attributed to the possible ethiological association to the presence of known risk factors like birth trauma, head trauma and nervous system infections in younger age groups from India.

It was also observed that a high proportion of epileptics in this series were associated with lower levels of education (42.6%), agricultural communities (agriculturists and agricultural labourers 33.3%) and from families with lower per capita income (92.0%). This reflects the existing situation in rural areas in terms of sociodemographic factors. In a recent review on the association of socioeconomic factors with epilepsy, it has been observed that these factors are significantly associated with occurrence and prognosis of epilepsy in developing countries [4]. These factors also play a predominant role in awareness, help seeking pattern and drug compliance which are essential in developing countries. Considering the important social and economic aspects of providing care for economic aspects of providing care for patients with epilepsy, it is essential to investigate these aspects in detail.

About 52% of patients were from within a radius of 10 kms and only 29% were from a distance of more than 20 kms. Moily et al observed that 77% of patients were from within a radius of <10 kms in a study done at Sakalwara [8]. This information on catchment areas is an important aspect in planning services as decentralisation and primary health care are gaining momentum in the country by making services available nearer to the place of residence in the community. The provision of services in future rests on strengthening the PHC services in the country. The duration of illness at the time of first contact was < 12 months in 45.7% of the patients (< 6 months -31%) with 42% being >24 months.

It was interesting to note that the local medical and paramedical professionals had referred a total of 33.7% of cases, while, the commonest mode of referral was neighbours and friends in 49.6% of cases. The source of treatment prior to reaching the extension centre was once again found to be local doctors and hospitals. Surprisingly, contact with traditional healers was noticed in a small group and self medication was recorded in 28% of patients. This signifies the importance of health education in rural areas as this practice of self medication can be extremely harmful. Seeking help for epilepsy in the community is influenced by the existing awareness and also the burden experienced by the family along with the availability of services.

Information on the type of epilepsy indicates that generalised convulsive epilepsy was the predominant type in 50% of the cases. Partial seizures constituted 19.5% cases. Moily et al noticed that generalised seizures and partial seizures constituted 62% and 37% respectively [8]. The present findings about the type of epilepsy are also in accordance with the earlier reports [14]. We also observed an increased occurrence of hot water epilepsy in two centres which has been reported earlier [15]. In these settings, epilepsy is primarily a clinical diagnosis substantiated by history and eye witness description by the patient or his family members. As sophisticated investigations are not possible in rural areas, a large

number of cases had to be classified as epilepsy N O S (31%).

About 62% of the patients were on regular follow up and 64% had reported improvements as noticed by their self reporting. About 22% of patients had discontinued services and 20% did not observe any positive changes. The present study has an inherent limitation as the period of follow up was only 14 months based on consecutive visits. It was observed by Kulhara et al [16] that 50% of the subjects with epilepsy dropped out after first contact, while Sriram et al [9] noticed that 41% dropped out after first contact which are much higher than the findings of the present study. Parthasarathy et al [17] in another study at Sakalwara found the first contact drop out rate to be 61%. The ICMR Collaborative Multicentric Study based on hospital subjects reported a follow up rate of 71% with 64% being seizure free at the end of the 4th year. This study also highlighted that age of the patient, place of residence, educational background, nature of work and per capital income were important factors influencing follow up pattern among epilepsy patients [14]. Undoubtedly, there is need for more longitudinal studies from India to determine long term continuity and course of illness.

The present study has described the profile and service utilisation characteristics of a largest series of epilepsy patients from rural areas. These observations are likely to be different in urban areas due to changes in availability and acceptability of services. Further studies are required on long term follow up of epilepsy patients factors contributing to continuity and discontinuity of care, remission and relapse nature and natural course of epilepsy in rural areas. Future epidemiological studies could focus on these factors for better understanding of epilepsy in its various facets.

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1. Gourie-Devi M, Can India afford neuroepidemiology?

*Neurology India* Page: 35: 125-127, 1987

2. Gourie-Devi M, Rao V N & Prakash R, Epidemiological study in semiurban and rural areas in South India. Pattern of neurological disorders including motor neurone disease

*In: Gourie-Devi M (Ed) Motor Neurone Disease: Global Clinical Patterns and International Research.* Page: 11-21, 1985

3. Kapoor S K & Banerjee A K, Prevalence of common neurological diseases in a rural community of India:

*Indian Journal of Community Medicine* Page: 14(4): 171-176, 1989

4. Zielinsky J J, Epidemiology, In: Laidlaw J, Richens A & Orkey J (Eds)

*A Text-book of Epilepsy, Edinburgh, Churchill Livingstone* Page: 21-48, 1988

5. Sundar Moily, Kishore Kumar K V, Uday Kumar G S et al, [Epilepsy in Primary Care: 1. Inception of a programme and patient characteristics]

*NIMHANS Journal* Page: 8(2): 127-132, 1990

6. Sriram T G, Chandrashekar C R, Sundar Moily et al, [Epilepsy in Primary Care: 2 A study of follow up

profile and response to treatment]

*NIMHANS Journal* Page: 8(2): 133-137, 1990

7. Gururaj G, Narayana Reddy G N & Subbakrishna D K, [Service utilisation pattern in extension services of NIMHANS]

*NIMHANS Journal* Page: 6(2): 85-91, 1988

8. Narayana Reddy G N, [Innovations in neuropsychiatric services]

*NIMHANS Journal* Page: 1(1): 1-14, 1983

9. Narayana Reddy G N, Channabasavanna S M, Gourie-Devi M et al, [Extension of mental health services by satellite clinics as a model]

*NIMHANS Journal* Page: 4(2): 71-75, 1986

10. Issac M K, *Collaborative study of severe mental morbidity. Indian Council of Medical Research and Department of Science & Technology, New Delhi* 1987

11. Roshan Koul, Razdan S & Anil Motta, Prevalence and pattern of epilepsy (Lath/Mirgi/Laran) in rural Kashmir, *Intra*

*Epilepsy* Page: 29(2): 116-122, 1988

12. Shorovon S D, The epidemiology of epilepsy

*Neurology India* Page: 35: 271-274, 1984

13. Mathai V K, Epilepsy - Some epidemiological, experimental and surgical aspects

*Neurology India* Page: 34: 299-314, 1986

14. Tandon P N, *Epilepsy in India. Indian Council of Medical Research, New Delhi* Page: 8-12, 1989

15. Gururaj G & Satishchandra P, Correlates of hot water epilepsy in rural South India: A descriptive study

*Neuroepidemiology* Page: 11: 173-179, 1992

16. Kulhara P, Chandiramani K, Muttoo S K et al, Pattern of follow up visits in rural psychiatric clinic

*Indian Journal of Psychiatry* Page: 29: 189-195, 1987

17. Parthasarathy R, Chandrashekar C R, Mohan K Issac et al, A profile of the follow up the rural mentally ill

*Indian Journal of Psychiatry* Page: 23: 139-141, 1981

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