

Pathway to care of epilepsy patients: Exploratory study from an urban slum in Northern India

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Abstract

Introduction: Epilepsy is a chronic neurological disorder with major psychosocial correlates. Most epilepsy patients in developing countries are untreated or inadequately treated. It is essential to understand the pathway, to care taken by epilepsy patients in a community, to be able to target appropriate services to them. **Materials and Methods:** A community based study was conducted on all epilepsy patients in an urban slum in Northern India to study their pathways to care. A list of persons suffering from epilepsy was generated by house to house visits, snowballing, and key informant contacts. In-depth interview and Medical Record Review were used to document their pathway to care. **Results:** Thirteen of the twenty two patients had contacted a health-care provider for their first episode. The most common first link of care for the patients was secondary level Government hospitals. The next common was private practitioners, followed by Tertiary Care Hospitals, and registered medical practitioners. Eleven out of twenty two patients had to contact a Tertiary Level Center for seeking care. The number of health-care facilities consulted before arriving at their latest point of care ranged from 0 to 5. Traditional or faith healers were consulted at some point of time for cure. **Conclusion:** There is a need to focus on strengthening and capacity building of the primary care settings for managing epilepsy to enable their better utilization. This shall prevent unnecessary referrals and hence the load on the already burdened higher facilities.

Key Words

Care seeking, epilepsy, pathway to care, primary level care

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Introduction

Epilepsy is a chronic neurological disorder, that has major psychosocial correlates.^[1,2] Developing nations are home to more than 85% of the epilepsy cases in the world where most of them are untreated.^[3,4] Over 70% of the epilepsy patients are not on any kind of treatment or are receiving inadequate treatment in India.^[5] The diagnosis of epilepsy is associated with social problems like discrimination, stigma, difficulty in interpersonal relationships etc.^[6] Hence, even among the few receiving appropriate treatment, their psychosocial needs are often overlooked in the absence of obvious disability.^[7] Besides these psychosocial barriers, supply side issues like poor health-care infrastructure or manpower deficit and demand

side issues like poor affordability and lack of awareness factors have been identified as potential barriers to access health-care for epilepsy. Over all, epilepsy patients suffer from poor quality of life as an effect of the type and frequency of seizures, the therapy for epilepsy, social discrimination, etc.^[3]

The need for research in developing countries on their indigenous problems related to epilepsy and epilepsy care has been emphasized.^[8] Hospital based studies on epilepsy, patients suffer from the shortcoming of missing out on those who never come in contact with Formal Health Care providers at any point of health-care. Hence, it is essential to trace the pathway to care for the patients identified from the community. It shall help us identify target links at which delay usually occurs. The present community based study was conducted with the objective to understand the pathway to health care for epilepsy patients in an urban resettlement colony in Northern India.

Materials and Methods

The study area is an urban resettlement colony in Chandigarh Union Territory, Northern India with a population of 22,357.

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The health-care services to this area are provided through an Urban Health Training Center (UHTC) by four multi-purpose health workers, two resident doctors (MD Community Medicine) and one faculty-in-charge. Two secondary level health-care centers are situated within two kilometers and a third one at about 8 km distance from the colony. A tertiary care referral center is situated at about 10 km distance from this area.

A list of epilepsy patients was generated by the health workers from their respective field areas. We included only permanent residents of the colony as the occupants of rented houses were migrants who changed their accommodation frequently, thus, difficult to trace. The initial list comprised of 19 epileptic patients. Epilepsy being a disorder with enormous social stigma attached, people hesitate to disclose the fact. We added more patients to the list by snowballing and enquiry from local Registered Medical Practitioners (RMPs) and alternative medicine practitioners. Our final list had 22 patients and each of these patients were visited at their home and interviewed in-depth using an interview guide prepared for this purpose. The focus was to understand the various links in their pathway to accessing care and the nodes of potential delay. We probed into the reasons for delay, if any, at each of these points. The interview transcripts were recorded on paper. Textual analysis of the data was performed. A flow chart was created for each patient tracing their pathway to care from the onset of the onset of the first symptom.

Results

A total of 22 patients were studied of whom 13 (56.5%) were males. The average age of the patients studied was 20.13 years. The mean age of onset of first episode of seizures was 15.7 years and ranged from 1 year to 46 years of age. Thirteen of the 22 patients had contacted a health-care provider immediately after the first episode of seizures. Six patients had accessed care between 1 day to 1 week and one of them had accessed health-care only after 10 days. The most common first link of care for the patients was secondary level Government hospitals of Chandigarh and Panchkula. The next common were private practitioners ($n = 6$) followed by tertiary care hospitals in Chandigarh ($n = 4$) and RMPs ($n = 3$). Only one of the four patients who consulted a Tertiary Care Hospital first needed to seek a second link for care, while the others had their diagnosis made and treatment schedule finalized at the first link itself. In contrast, all those who had other health-care providers as their first link had consulted a second link.

The secondary level Government Hospitals were the most sought after even as second or third links in care. This could be either due to the reason that after initial first aid and management at lower centers, the cases are referred to these hospitals for regular treatment. Else, after investigation, diagnosis and stabilization on a drug schedule from a tertiary care center the cases are sent back to these hospitals to procure their drugs which are available free of cost and are closer to their residence. Eleven out twenty two patients had to contact a tertiary level center for seeking care. The others were diagnosed and treated at primary and secondary level health care centers itself.

While traditional or faith healers were not reported as the first point of care sought, 8 of the 22 patients had resorted to them at some point of time for cure. The average number of health care facilities consulted before arriving at their latest point of care seeking was two with a minimum of 0 and a maximum of five links in the pathway to care. Eight patients had contacted two links and five of them three links before reaching their final point of care seeking. Five of them had accessed only one point while two others had accessed four links of care. There was no significant difference in the pathway to care by sex, age at first symptom or current age of the patient. The pathways to care taken by 22 patients are presented in Figure 1.

Seventeen patients are currently on medication of whom 10 claim to be compliant while the remaining seven are non-compliant. Two patients had successfully completed their treatment and two had prematurely stopped their treatment without medical advice. Among the 22 patients, eight are currently symptomatic while the remaining 14 are asymptomatic.

Discussion

Epilepsy is a disorder associated with increased levels of psychological morbidity, including, anxiety and depression, low self-esteem, and a reduced sense of mastery. Our study identified a prevalence of epilepsy of 1 per 1000 in an urban slum, which is low compared to the national estimates.^[6] However, under reporting of epilepsy is a quite common phenomenon worldwide especially in developing countries.^[9] Scanty evidence is available in developing countries regarding epilepsy and its impact.

People with epilepsy experience problems with education, marriage, social isolation, and employment. Hermann and Whitman designed a conceptual framework constructed using three alternative list of variables that explain the impact of epilepsy namely psychosocial variables, neuro-epilepsy variables and medication variables. The medication variables include the number of medication, the type and its serum levels. Each of these three variables impact the care seeking pattern

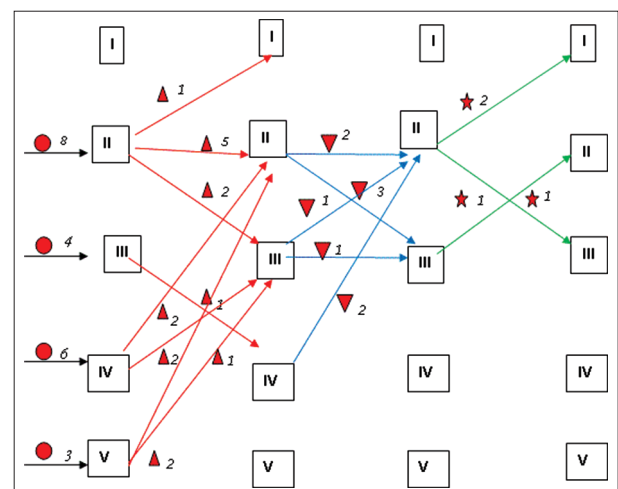


Figure 1: Pathways to health-care for the 22 patients from Indira Colony, Chandigarh, India. I- Primary level Government Facility, II- Secondary level Government Facility, III-Tertiary level Government Facility, IV-Private Practitioners, V-registered medical practitioners
 ● - First link, ▲ - Second Link, ▼ - Third Link, ★ - Fourth link

of epilepsy patients and contributes variably to the impact of epilepsy on the life of patients in developed and developing countries.^[10]

The care seeking pattern for diseases varies among different communities in terms type of health care facility or providers sought, time taken to seek formal health care and compliance with the prescribed treatment schedule. A thorough understanding of this pattern is vital to identifying weak points in health-care, delivery to patients that provide scope for improvement, and strengthening. By defining the various types of care sought and the reason for the choice, one should be able to decide how to channelize resources to strengthen the key nodes of care provision to these patients. The ultimate aim shall be that of making scientifically sound, acceptable, and affordable care accessible to patients. Various attempts have been made to study the pathway to care for dementia, alcohol use disorders,^[11] psychiatric morbidity^[12] acute renal colic,^[13] post-natal depression,^[14] Attention Deficit Hyperactivity Disorder (ADHD)^[15] etc.

Drebing *et al.*^[16] attempt to establish the validity of the three most commonly used methods to study dementia care namely questionnaire, structured interview, and medical record review. We used snowballing and key informant contacts to trace epilepsy patients in the community. To understand their care seeking patterns, we had adopted a combination of in-depth interviews and Medical Record Review wherever available given the strong psychosocial correlates of epilepsy and the stigma attached to the condition.

Among the 22 epilepsy patients studied, the secondary level Government Health Care facilities (Community Health Centre (CHC)/district hospital) were the most commonly chosen as first or second links for health-care. One reason could be the proximity of these facilities, approximately 2 km and 4 km respectively, from the study area and the availability of basic medication for epilepsy treatment. The pathways to care were defined in terms of type of facility contacted first, average number of facilities contacted and seeking care from traditional healers. Primary level care (sub center/UHTC) was the most under-utilized and was being solely used as an outlet to procure medicines that have been prescribed at higher institutions. Similar findings have been observed for alcohol use disorders where Commander *et al.*, have identified primary care as the main filter before accessing specialist services and the need to develop strategies that would improve identification and treatment of alcohol use disorders at primary care level.^[11]

The National Mental Health Program in India sets standards for the manpower, logistics, and funds to be available for care at various levels of care for psychiatric and neurological disorders including, epilepsy. However, the program is plagued by issues like lack of awareness, cultural beliefs, inadequate professionals and lack of comprehensive services.^[17] There is also a need for the orientation and capacity building of ground level health-care workforce on mental health. The health workers, who share a good rapport with the community shall act as change agents and encourage the epilepsy patients to seek appropriate care in a timely manner.

Tools have been developed by the WHO to guide the management of priority conditions like depression, psychosis, bipolar disorders, epilepsy, developmental and behavioral disorders in children and adolescents, dementia, alcohol use disorders, drug use disorders, self-harm/suicide and other significant emotional or medically unexplained complaints in non-specialized health settings.^[18] However, the fact that the primary health care is still bypassed or largely under-utilized points to the fact that there is a need to adapt these guidelines for our country settings. Preparation of a clear action plan and its effective country wide implementation is also recommended.

Thus, our study findings highlight the need to focus on strengthening the primary care settings for epilepsy. This shall prevent unnecessary referrals and hence the load on the already burdened secondary and tertiary care facilities. Availability of trained service providers at primary and secondary levels coupled with awareness building exercises in the community shall go a long way in shortening the pathway to appropriate care for epilepsy patients. Our study is limited by its sample size restricting the use of extensive statistical analysis to establish associations and causations. Larger studies that integrate community based and hospital based data are essential to analyze differences in the patterns of care seeking among various sub groups of the population.

References

- Gaitatzis A, Trimble MR, Sander JW. The psychiatric comorbidity of epilepsy. *Acta Neurol Scand* 2004;110:207-20.
- Gilliam F, Hecimovic H, Sheline Y. Psychiatric comorbidity, health, and function in epilepsy. *Epilepsy Behav* 2003;4:S26-30.
- Thomas SV, Koshy S, Nair CR, Sarma SP. Frequent seizures and polytherapy can impair quality of life in persons with epilepsy. *Neurol India* 2005;53:46-50.
- de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav* 2008;12:540-6.
- Sridharan R, Murthy BN. Prevalence and pattern of epilepsy in India. *Epilepsia* 1999;40:631-6.
- Cyriac N, Sureshkumar PN, Kunhikoyam AM, Girija AS. Social factors and psychopathology in epilepsy. *Neurol India* 2002;50:153-7.
- Pal DK, Chaudhury G, Sengupta S, Das T. Social integration of children with epilepsy in rural India. *Soc Sci Med* 2002;54:1867-74.
- Krishnamoorthy ES, Satishchandra P, Sander JW. Research in epilepsy: Development priorities for developing nations. *Epilepsia* 2003;44:5-8.
- Yemadje LP, Houinato D, Quet F, Druet-Cabanac M, Preux PM. Understanding the differences in prevalence of epilepsy in tropical regions. *Epilepsia* 2011;52:1376-81.
- Baker GA. The psychosocial burden of epilepsy. *Epilepsia* 2002;43:26-30.
- Commander MJ, Odell SO, Williams KJ, Sashidharan SP, Surtees PG. Pathways to care for alcohol use disorders. *J Public Health Med* 1999;21:65-9.
- Temmingh HS, Oosthuizen PP. Pathways to care and treatment delays in first and multi episode psychosis. Findings from a developing country. *Soc Psychiatry Psychiatr Epidemiol* 2008;43:727-35.
- Wright PJ, English PJ, Hungin AP, Marsden SN. Managing acute renal colic across the primary-secondary care interface: A pathway of care based on evidence and consensus. *BMJ* 2002;325:1408-12.
- Whitton A, Warner R, Appleby L. The pathway to care in post-natal depression: Women's attitudes to post-natal depression and its treatment. *Br J Gen Pract* 1996;46:427-8.

15. Sayal K, Taylor E, Beecham J, Byrne P. Pathways to care in children at risk of attention-deficit hyperactivity disorder. *Br J Psychiatry* 2002;181:43-8.
16. Drebing C, Movitz R, Lyon P, Harden T, McCarty E, Herz L. Documenting pathways to dementia care: Relative validity of questionnaire, interview, and medical record formats. *Am J Alzheimers Dis Other Demen* 2004;19:187-97.
17. Murthy RS. Mental health initiatives in India (1947-2010). *Natl Med J India* 2011;24:98-107.
18. mhGAP intervention guide for mental, neurological and

substance use disorders in non-specialised settings. Geneva: WHO; 2010.

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