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Are epilepsy patients bypassing primary care? A cross-sectional study from India

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ABSTRACT

Purpose: Lack of epilepsy primary and secondary care and an arbitrary referral system causes many epilepsy patients to seek tertiary care even when they may not need it. This causes overcrowding, increased waiting times and also compromises the quality of tertiary care. We conducted this study to identify what proportion of epilepsy patients presenting to tertiary care actually needed it.

Methods: To test appropriateness of candidacy for tertiary care, we formulated Modified NICE criteria (MNC) based on NICE criteria. Modified NICE criteria were used to dichotomize participants into two groups: a) those who needed tertiary care and b) those who did not need tertiary care. We also looked at agreement between MNC and original NICE criteria.

Results: Four hundred and twenty two patients were recruited. According to the MNC, 240 patients (57%) qualified for tertiary care while 182 (43%) did not. The agreement between MNC and original NICE criteria was 86.7%, kappa 0.73(95% CI 0.66–0.79, $p < 0.001$). The most frequently cited reason for seeking tertiary care was 'Unsatisfactory response to treatment', although; many of these patients were actually non-adherent to treatment. Amongst variables that predicted non-eligibility for tertiary care, the most important was not having been referred.

Conclusion: Many epilepsy patients seeking tertiary care do not need it. Access and quality of epilepsy care can be improved if there is a rational and need-based distribution of patients between primary, secondary and tertiary care. Referral systems also need to be developed and used to transition patients from one level of care to another.

1. Introduction

Epilepsy is an ancient disease and its treatment relatively effective and widely available. Of the seventy million epilepsy patients worldwide, 90% live in low and middle-income countries [1]. Approximately 10 million persons with active epilepsy live in India [2]. A treatment gap of up to 90% or more is reported from many parts of rural India [2]. There are multiple reasons for such a high epilepsy treatment gap: lack of an effective epilepsy primary and secondary care however, is often overlooked as being one of them. A system of care where many epilepsy patients have to present to a tertiary care center not because they *need* tertiary care but because *there is no credible primary or secondary care available to them*, is unlikely to be effective. Many patients remain untreated while others are unnecessarily burdened in terms of the time that they spend travelling to distant, tertiary care providing hospitals and also the increased direct and indirect cost of such care [3,4]. From the tertiary care providers' perspective, this avoidable increase in patient load leads to overcrowding, reduced efficiency and an inordinate delay for those patients who may genuinely need tertiary care. Many epilepsy patients treated at tertiary centers have complex problems necessitating specialized care. However, there are also many others who are relatively straightforward in their presentation and do not seem to need the expertise or facilities available in tertiary care.

While untreated epilepsy finds a mention occasionally [5], we are still a long way from making any significant gains in eliminating or even significantly reducing it. In populous countries like India where rural and semi-rural communities constitute up to 70% or more of the population [6], and tertiary care providers are only available in a handful of big metropolitan cities, epilepsy primary and secondary care need to be developed and made widely available. One way of assessing the strength of epilepsy primary and secondary care and the rigour of the referral system would be to look at epilepsy patients who are

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seeking tertiary care and making a determination if they justifiably need it.

To the best of our knowledge, there has not been any such study where the appropriateness of triaging of epilepsy patients to tertiary level care has been audited. We therefore conducted this study with an aim of evaluating epilepsy patients presenting to a tertiary care center to estimate what proportion of them actually needed tertiary care. The study was designed in compliance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement ([7].

2. Methods

2.1. Standard protocol approvals, registrations and patient consents

This single center, cross-sectional study was conducted at the All India Institute of Medical Sciences (AIIMS), which is a tertiary care teaching hospital that provides comprehensive epilepsy care including epilepsy surgery in New Delhi, India. Consecutive epilepsy patients presenting to the Neurology outpatient clinic for the first time were enrolled. All patients or their legal representatives (for minor and disabled patients) gave a written informed consent and the institutional ethics review board approved the study.

2.2. Sample size

With no published literature evaluating appropriateness of patients availing epilepsy tertiary care, we were guided by estimates drawn from our own clinical experience. In our opinion, of the new epilepsy cases presenting to our Neurology outpatient department, 50–60% seem appropriate candidates for tertiary level of epilepsy care. The remaining 40–50% could very well have been managed in primary or secondary care. To estimate such a proportion in a two-sided 95% confidence interval with an absolute error margin of 5% we needed to recruit 385 consecutive new epilepsy patients.

2.3. Definitions and criteria

In this study we followed the practical clinical definition of epilepsy accepted by ILAE in 2014 [8]. Epilepsy was diagnosed if a patient had at least two unprovoked seizures occurring more than 24 h apart or even one unprovoked seizure with a high probability of further seizures. Acute symptomatic seizures were diagnosed as per Beghi et al. [9]. Non-epileptic seizures were diagnosed if the patient's description of seizure semiology made non-epileptic seizures likely.

For assessment of psychiatric co-morbidity, M.I.N.I., English version 5.0.0 was used for patients who were 18 years or older. For patients who were 4–13 years old, the Parent-completed version (PSC) was used and for patients older than 13 but younger than 18 years of age, the youth self-report Pediatric Symptom Check list (Y-PSC) was used. Common Terminology Criteria for Adverse Events (CTCAE), Version 4.0 grading was used to record the severity of adverse drug events. Based upon the permanent residence of the patient and the distance of living from our hospital in New Delhi, patients were categorized as those belonging to Delhi NCR (National capital region) or from outside of Delhi NCR. To determine per capita income, the income of the patient and his/her household was considered and this was categorized in to five categories according to revised Kuppuswamy and B G Prasad socio-economic scales [10]. For treatment adherence, we relied on the patient's statement. Adherence was defined as good for patients reporting taking medication regularly (an occasional miss was accepted), fair for taking medication at least 80% of the time and non-adherent if neither of the above categories were fulfilled [11]. Seizures were defined as frequent if ≥ 1 seizure occurred per month and infrequent if there was < 1 seizure per month. If a patient cited 'Unsatisfactory response to treatment' as a reason for seeking tertiary care, then appropriateness of his seeking tertiary care was decided based on seizure frequency, treatment duration and drug adherence: [a] In patients with frequent seizures: If seizures were uncontrolled even after 3 months of starting antiepileptic drugs (AEDs) with good to fair treatment adherence and [b] In patients with infrequent seizure: If seizures were uncontrolled even after 2 years of starting AEDs with good to fair treatment adherence [12–14]; then the patient was considered to have had an unsatisfactory response to treatment.

Table 1
Modified NICE criteria.[a]

S. No	Various reasons for seeking tertiary care (as cited by patients or primary/secondary care providers)	Need tertiary care (According to Investigators)
1.	Unsatisfactory response to treatment	
	a) Fulfilled definition	Yes
	• Did not fulfill definition	No
2.	AED[b] adverse event (CTCAE Grade 2 or more)[c]	Yes
3.	Diagnostic uncertainty	Yes
4.	Psychological or psychiatric co-morbidity	Yes
5.	Inter-departmental referral within AIIMS	Yes
6.	To start treatment (treatment naïve)	
	a) Entitled for treatment – employee etc.	Yes
	• Living on or close to hospital campus	Yes
	• Others	No
7.	Looking for a reduction in cost of treatment	No
8.	Seeking epilepsy-related information	No
9.	Social issues related to education, employment, marriage etc	No
10.	Looking for good quality of care	No
11.	Acquaintance of hospital staff with expectation of favor in treatment	No

If answer of any of the above was Yes = > Patient included in '**Needs tertiary care**' group

If answer of all of the above was No = > Patient included in '**Does not need tertiary care**' group

[a] Each participant gave one or more reason for seeking tertiary care.
[b] AED: Antiepileptic drug.
[c] CTCAE: Common terminology criteria for adverse event.

2.4. Modified NICE criteria: formulation and validation

As there are no validated guidelines that define the need for epilepsy tertiary care in India, we used a modification of the NICE criteria laid down for this purpose [15]. Investigators developed modified NICE criteria based on their own clinical experience and feasibility in the Indian context (Table 1). Some referral items of the NICE criteria were excluded and few new ones added. Two NICE criteria pertaining to number of AEDs used in the past and duration of prior treatment were combined into one criterion that was used to test patients reporting 'Unsatisfactory response to treatment'. As the setting of this study was an adult neurology service, the NICE criteria recommending referral of children less than 2 years of age was not relevant and was excluded. Most patients presenting toour tertiary care hospital have not been adequately imaged for structural causes. Therefore, the NICE criterion recommending referral of patients with aunilateral structural lesion had to be excluded. Many of these patients we assumed would get included through other criteria such as 'Unsatisfactory response to treatment' or unacceptable AED adverse effects. Criteria not in NICE that we acceptedwere including patients who had entitlement for treatment at AIIMS (for example hospital employees), patients who were for some reason living on the hospital campus and epilepsy patients who were referred from some other department within AIIMS. Patients belonging to these three categories were not disqualified from seeking tertiary care even if they might not have actually needed it. The modified NICE criteria were validated in the first 100 patients who were enrolled to the study by ascertaining agreement between candidacy for tertiary care using Modified NICE and the original NICE criteria. There was an 84% agreement with a kappa of 0.67 (95% CI 0.53 to 0.82, p-value <