

Epilepsy in India II: Impact, burden, and need for a multisectoral public health response

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Abstract

Epilepsy is a common neurological disorder whose consequences are influenced socially and culturally, especially in India. This review (second of the two part series) was carried out to understand the social impact and economic burden to develop comprehensive program for control and prevention of epilepsy. Epilepsy is known to have adverse effect on education, employment, marriage, and other essential social opportunities. Economic burden associated with epilepsy is very high with treatment and travel costs emerging as an important contributing factor. A vicious cycle between economic burden and poor disease outcome is clear. There is no significant change in the perception, stigma, and discrimination of epilepsy across the country despite improvement in educational and social parameters over the time. The huge treatment gap and poor quality of life is further worsened by the associated comorbidities and conditions. Thus, a multidisciplinary response is needed to address the burden and impact of epilepsy which calls for an integrated and multipronged approach for epilepsy care, prevention, and rehabilitation. Service delivery, capacity building, integration into the existing program, mobilizing public support, and increasing public awareness will be the hallmarks of such an integrated approach in a public health model.

Key Words

Care, economic burden, epilepsy, India, national programs, prevention, psychosocial impact, rehabilitation, stigma, treatment gap

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Introduction

The disability and psychosocial impact caused by epilepsy in socio-culturally determined traditional societies like India is phenomenal and impose huge economic burden to the individual and the society. Understanding the social and economic impact becomes critically important for effective control and prevention of epilepsy in resource-poor settings like India.

With this in background, an extensive literature review was undertaken to develop a comprehensive picture of epilepsy in India from a multidimensional perspective. Part 1 of the series

discussed the epidemiological profile and burden of epilepsy along with its association with major sociodemographic correlates and causative factors. The objectives of the present report is to examine the treatment gap and its implications, psychosocial and economic impact, and to broadly identify ongoing efforts for epilepsy control and care, setting out a road map for future activities in India.

Search Strategy and Selection Criteria

We searched PubMed (from 1950 to July 2014) for English language papers reporting psychosocial or economic consequences and service organization for epilepsy using the search terms "stigma", "quality of life", "education", "employment", "marriage", "disabilities", "psychosocial impact", "treatment gap", "cost of AEDs", "health care costs", "economic burden", "knowledge", "attitudes", "practice", "comorbidities", "organization of services", and "delivery of services". The above search terms were combined with the words "epilepsy" and "India", "South Asia", "developing countries", "tropical countries", "West Asia" using Boolean operator "AND" for retrieving articles related to epilepsy and India. Studies published in peer-reviewed journals, that

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used valid study instruments and methodology and that conducted in India were preferred for inclusion. Case reports were excluded. The initial search retrieved 1,376 records. After exclusion, 243 full text records and references from eight reviews were reviewed for relevance [Figure 1]. Previous review papers on epilepsy were examined carefully for relevant references, and papers known by the authors to be relevant to the topics were also included.

Cultural Interpretations of Epilepsy

Epilepsy is associated with substantial stigma and discrimination in the Indian subcontinent as in many other low- and middle-income countries (LMICs) where culture has a strong influence on life of people. "Stigma" means being devalued by individuals or communities on the basis of real or perceived health status, while "discrimination" refers to the legal, institutional, and procedural ways that people are denied access to their rights because of their real or perceived health status.^[1,2]

The word epilepsy originated from the Greek word which means "to take court, to grab, or to seize".^[3] There are many interpretations of the word epilepsy in different communities and even today it is referred as 'punishment for participation in a forbidden sacrifice' in some societies. Some common behavior observed among persons with epilepsy (PWE) has led people to believe that it is due to possession by evil spirits or sins of past life. Consequently, there are many cultural definitions and interpretations for the word epilepsy and societies follow different practices to manage the condition on their own understanding. Some of the harmful practices have resulted in stigma, poor health, and worst outcomes for PWE.

Treatment Gap in Epilepsy

Treatment gap is defined as the number of people with active epilepsy not on treatment or on inadequate treatment, expressed as a percentage of the total number of persons with active epilepsy.^[4] Epilepsy treatment gap is a useful indicator for accessibility and quality of epilepsy care and undoubtedly, a very high treatment gap would result in increased disease burden.

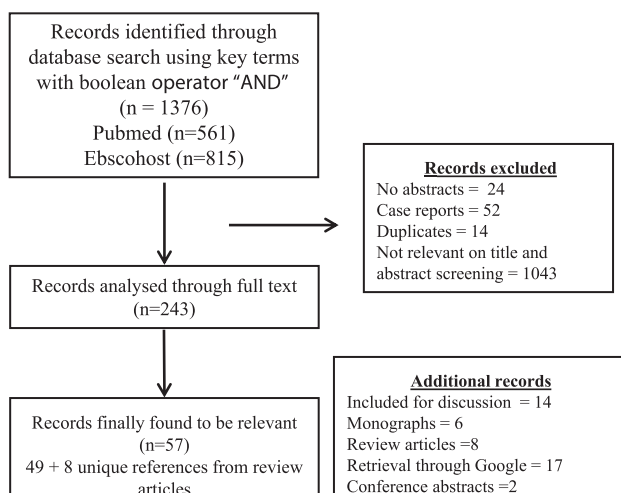


Figure 1: Flowchart of study selection

Even though more than 70% of patients on regular and systematic treatment achieve long-term remission usually within 2-5 years of diagnosis, huge disparities in treatment gap are observed both between and within countries and differently for urban-rural settings.^[5] A recent systematic review reported a treatment gap of over 75% in low-income countries, 50% in the lower middle- and upper middle-income countries, and less than 10% in high-income countries (HICs).^[6] The various causes of treatment gap expressed as median and range were cost of treatment (62%; 11-90%), non-availability of drugs (53%; 18-44%), belief in traditional treatment methods (44%; 6-82%), and superstitions and cultural beliefs (40%; 7-65%).^[7] Shortage of skilled manpower, low literacy rates, and long distance from a healthcare facility and other infrastructure problems were other factors responsible for treatment gap. In another systematic review among resource-poor countries, a treatment gap of 64% was reported for Asia with huge urban-rural variations.^[7,8]

Treatment gap in India were found to be comparable with other less industrialized countries (Brazil, China, Pakistan, and Togo).^[7] Studies from India have reported treatment gap between 22 and 95% [Table 1],^[9-22] with much higher gap in rural population and among women.^[23] A very high treatment gap of 95% was reported in tribal population of Jharkhand, while a treatment gap of 22% was reported in the highly literate affluent Parsi population in Mumbai [Table 1].^[9,21]

It is equally important to address the secondary treatment gap among those patients who discontinued the initiated treatment. Cost of antiepileptic drugs (AEDs), unemployment, frustration, and marital harmony were found to be the important causes for secondary treatment gap besides stigma. Das *et al.*, from Bengal reported a secondary treatment gap as high as 42.8%.^[24] A recent review of medical records from tertiary care hospitals in Karnataka has revealed polytherapy as major cause for non-compliance with AEDs.^[25]

Education

Epilepsy in early life has adverse impact on growth and development of the children. Children with epilepsy, especially in the rural settings often do not get into schools, have difficulties in coping abilities, exhibit drowsiness and behavioral problems, experience decreased attention, and have poor academic performance.^[26,27] Consequently, they experience discrimination in school environments, and few discontinue education. A multicentric, hospital-based study in India has observed adverse outcome of education because of epilepsy in 26.1% of urban patients and 38.3% of rural patients.^[28] Pal *et al.*, from Bengal have reported significant social deficits among children with epilepsy in the form of limited peer group activities.^[29] Lack of adequate knowledge among teachers and peer groups combined with parental attitudes worsens the condition further resulting in poor academic achievements and school dropouts.

Employment

Employment is a marker of successful education and social opportunity. PWE are less likely to obtain a sustainable job or retain the existing job. Difficulties in workplace environments

Table 1: Treatment gap in epilepsy as observed in Indian studies

| Author | Year of publication | Place | Study setting | Study methodology | Study instrument | Operational definition for treatment gap | Treatment gap expressed as (%) |
|---|---------------------|--|--|---|--|--|--------------------------------|
| Nizamie <i>et al.</i> ^[9] | 2009 | Namkum block of Ranchi, Jharkhand | Rural tribal | 4-staged program with initial screening by voluntary health workers | WHO-SEARO questionnaire for major fits | % of cases diagnosed with epilepsy who are not currently on treatment by qualified practitioner | 95 |
| Banerjee <i>et al.</i> ^[10] | 2009 | Kolkata, West Bengal | Urban subjects < 20 years of age | Initial screening by field workers followed by neurologist confirmation | WHO modified questionnaire | % of active epilepsy who never received any antiepileptic drugs | 23.5 |
| Goel <i>et al.</i> ^[11] | 2009 | Chakrata block of Dehradun district, Uttarakhand | Rural | Initial screening by field workers followed by neurologist confirmation | Not mentioned | % of cases diagnosed with epilepsy who never used allopathic medicine | 71 |
| Sureka and Sureka ^[12] | 2007 | Churu Tehsil, Rajasthan | Rural | Initial screening by field workers and case finding by public address system followed by neurologist confirmation | Placencia's 9-item questionnaire | Study included only active epilepsy. But the data was insufficient to derive the definition of treatment gap | 40 |
| Saha <i>et al.</i> ^[13] | 2003 | Baruipur block, West Bengal | Rural | Initial screening by professionals followed by detailed examination in clinics | WHO protocol | Study focused on active epilepsy. The data could not be retrieved directly to derive the definition of treatment gap | 65 |
| Ray <i>et al.</i> ^[14] | 2002 | Review | – | – | – | % of patient populations not receiving the treatment | 73-78 |
| Radhakrishnan <i>et al.</i> ^[15] | 2000 | Kerala | Semiurban | Three-phased survey with initial screening by field workers followed by specialist confirmation | WHO modified questionnaire | % of active epilepsy patients who had not received any allopathic drugs for epilepsy before the prevalence day | 38 |
| Sridharan and Murthy ^[16] | 1999 | Meta-analysis | – | – | – | % of those with epilepsy who receive no or inadequate treatment | > 70% (rural areas) |
| Pal <i>et al.</i> ^[17] | 1998 | Bishnupur block, West Bengal | Rural | Two-stage survey and key informant interview | Placencia's 5-item questionnaire | % of those with active epilepsy not on treatment | 90.4 |
| Mani <i>et al.</i> ^[18] | 1998 | Yelandur, Karnataka | Rural | Initial screening by field workers followed by specialist team confirmation | ICBERG (International Community Based Epilepsy Research Group) questionnaire | % of patient with active epilepsy who did not receive any allopathic drugs | 78 |
| Bharucha <i>et al.</i> ^[19] | 1997 | Maharashtra | Semiurban | House-to-house survey, key informant, and self-referral | Information could not be retrieved | % of patient with epilepsy who did not receive any treatment (allopathic and nonallopathic) | 57 |
| Hackett <i>et al.</i> ^[20] | 1997 | Calicut, Kerala | Mixed population. Children aged 8-12 years | Initial screening by field workers followed by epileptologist confirmation | Modified Rose's screening questionnaires | % of children with active epilepsy who did not receive any treatment | 50 |
| Bharucha <i>et al.</i> ^[21] | 1988 | Bombay, Maharashtra | Urban | Initial screening by high school graduates, social workers, and medical students followed by neurologist confirmation | Modified WHO protocol | % of patient with epilepsy who did not receive any treatment on prevalence day | 22 |
| Koul <i>et al.</i> ^[22] | 1988 | Kuthar valley, Kashmir | Rural | Initial screening by Anganwadi workers followed by neurologist team confirmation | WHO protocol | % of active epilepsy cases who were receiving no specific treatment | 74.5 |

WHO = World Health Organization, SEARO = South-East Asia Regional Office

experienced by PWE ranged from non-availability of jobs, discrimination, poor performance, increased stress, frequent absenteeism, and finally loss of job. There is a strong reluctance to employ a PWE among employers. The situation worsens when a PWE had epileptic attacks in the workplace that results in social stigma and pushing one to low income assignments, sometimes even leading to job termination.

A survey conducted in Kerala revealed that 58% of people with epilepsy were unemployed, compared with 19% of the general population due to seizure-related falls in workplace, inadequate education, and AED-induced fatigue.^[30] An adverse work efficiency and prospectus was noticed among nearly one-fourth of PWE for more than 3 years.^[28] Das *et al.*, found that 20.6% of patients on AEDs were unemployed and 5.7% had lost the job with higher proportion among those who discontinued medication.^[24]

Driving and epilepsy has been critically reviewed by the legal sector and recently it has been argued that PWE should not be actively barred from undertaking any responsibilities.^[31] A recent review endorses that a seizure during driving is dangerous, but the risk is somewhat predictable and is not substantially higher than for those with other chronic medical conditions, such as heart disease, diabetes, or even for those who consume alcohol.^[32-34] This supports permitting patients with controlled seizures to drive at least personal vehicles and not public commercial vehicle once adequate seizure control is achieved.

Marriage

The stigma attached to epilepsy becomes more pronounced, especially when it comes for marriage; even though the word epilepsy has been removed from the Hindu Marriage Act 1955 and Special Marriage Act long ago.^[35] For females, the issues of child-bearing and child-rearing and for the male the issues of employment and income have become critical during the marriage. A study by Agarwal *et al.*, reported a lower marriage rate, delayed marriage especially among females, suspended marriage, and higher divorce rate in PWE as compared to general population.^[36] The disease status of PWE is usually not disclosed in most of India at the time of marriage due to fear of failure of marriage negotiations. Santosh *et al.*, observed that nearly 55% of people with epilepsy have concealed their disease status at the time of marriage.^[37] There was an increased demand for dowry or cancellation of engagements following disclosure.^[38]

Marital disharmony ensues when the presence of epilepsy becomes evident. Among those who concealed their epilepsy status at the time of marriage; 18% were divorced, 20% were separated, and 45% were disturbed.^[37] Das *et al.*, have reported adverse treatment outcome due to marital disharmony among the PWE.^[24] Pregnancy after marriage was discouraged due to fear of having a child with epilepsy or other abnormalities. Due to the long fought battle of Indian Epilepsy Association (IEA), the Indian judiciary has in recent times pronounced that epilepsy should not be equated to mental illness and the practice of divorce among married individuals due to epilepsy should be strongly discouraged.

Economic Impact

Epilepsy imposes a substantial economic burden to PWE and their families. People from lower socioeconomic status are more vulnerable due to their limited capacity to access good quality healthcare. Besides poor employment potentials, PWE have to spend on additional costs of transport and loss of wages to obtain medications due to interrupted supply of free AEDs in public-funded institutions.

The economic impact of epilepsy has not been studied extensively in the Indian context. The cost involved in epilepsy care can be broadly grouped into direct, indirect, and intangible costs.^[39,40] Direct cost includes medical costs related to prevention, diagnosis, treatment and rehabilitation, and non-medical cost related to travelling, housekeeping, etc. It encompasses outpatient treatment, investigation charges, radiological investigations, cost of AEDs, and others. The indirect costs include loss of time, productivity, and wages incurred by the individual and their family. The psychosocial pain, stigma, and suffering constitute the intangible costs that are still difficult to measure. Given the inherent difficulty in computing the indirect costs like time spent by the caregiver, lost productivity (due to disability and premature mortality), and lost opportunities (due to premature abandoning of school and employment); they are not included in majority of the studies. Similarly, cost due to pretreatment help seeking, cost of treating comorbid conditions, cost of side effects of AEDs and their management as a part of direct cost, and the intangible costs are also not included in most of the studies. Thus, the actual economic burden due to epilepsy is expected to be much higher than the available evidence.

Thomas *et al.*, in 2001 estimated annual economic burden of epilepsy in India as 88.2% of Gross National Product (GNP) per capita and 0.5% of the GNP which is to the tune of INR 68.75 billion (US\$1.72 billion).^[40] The direct and indirect costs constituted 27.1 and 72.9%, respectively.^[40] Similar to western studies, indirect costs exceeded the direct cost in most of the Indian studies [Table 2].^[40,44-46] A recent review estimated the indirect costs to range from 12 to 85% of the total costs.^[48] Pal *et al.*, have reported lack of continuity in treatment due to high indirect cost burden.^[49] Similar to the studies by Jacoby *et al.*, and Begley *et al.*, Krishnan *et al.*, have reported investigations, cost of drugs, and inpatient care as a major component of direct cost.^[44,50,51] In the same study direct treatment costs, travelling, and productivity loss accounted for 30, 6, and 64% of the costs respectively.^[44] Recently, Sinha and Bhaumik have estimated average direct treatment cost per month due to drugs, travel, and investigations as 219 INR (US\$3.64).^[52]

Thus, the costs of AEDs emerge as an important contributing factor to the economic burden of epilepsy, especially in LMICs like India. Thomas *et al.*, reported 57% share of the direct cost due to drugs alone.^[40] The cost due to AEDs was dependent on the type of therapy (mono- or polytherapy), type of drug, type of healthcare (public or private), and their duration. Radhakrishnan *et al.*, reported higher initial cost due to the use of polytherapy.^[47] Usage of polytherapy and, different treatment regimen among pediatric and elderly population and the differential titration of drug dosage should be considered

Table 2: Economic impact of epilepsy in India

| Author | Year of publication | Place of study | Sample | Costs measured | Annual direct cost per patient | Annual indirect costs per patient | Remarks |
|---|---------------------|---------------------------|--|--|--------------------------------|-----------------------------------|---|
| Haroon <i>et al.</i> ^[41] | 2012 | New Delhi | 134 epileptic patients | Direct medical (only drug and investigation cost) | - | - | Direct costs varied from INR 5942.7 with one AED to INR 10,683.4 with four AED. Higher monthly cost for the newer AEDs as compared with older drugs. Among the newer drugs, clobazam had the lowest cost |
| Murthy and Rajshekar ^[42] | 2007 | Hyderabad, Andhra Pradesh | 59 solitary cysticercosis granuloma (SCG) patients with new onset seizures | Direct medical, direct nonmedical, few indirect cost | INR 5,916 (81.8%) | INR 1,313 (18.2%) | Direct costs exceed the indirect cost because of the higher investigation cost involved in CT for SCG |
| Thomas <i>et al.</i> ^[43] | 2005 | Trivandrum, Kerala | 112 patients >16 years and >12 months of follow-up in the epilepsy clinic of tertiary center | Direct medical (only drug cost) | - | - | Cost of drug decreased for monotherapy and increased for polytherapy at the last follow-up. Monotherapy accounted for 8.8% and polytherapy accounted for 22.8% of per capita gross national income |
| Krishnan <i>et al.</i> ^[44] | 2004 | Ballabgarh, Haryana | 182 epilepsy cases registered in the epilepsy clinic | Direct medical, direct nonmedical, few indirect cost | USD 63.0 (35.9%) | USD 112.5 (64.1%) | The average annual drug cost per patient was US\$27.51. The annual drug cost was least for phenobarbitone (PB; U. S. \$11), and the maximum was for sodium valproate (VPA; US\$44.10) |
| Dhanaraj <i>et al.</i> ^[45] | 2003 | Chennai, Tamil Nadu | 183 patients newly registered in epilepsy clinic | Direct medical, direct nonmedical, few indirect cost | INR 1,378 (37.9%) | INR 2,254 (62.1%) | 90% of total direct cost was contributed by travelling expenses to collect drug |
| Thomas <i>et al.</i> ^[40] | 2001 | Multicenter study | 285 patients in 6 neurology referral centers | Direct medical, direct nonmedical, few indirect cost | INR 3,725 (27.2%) | INR 10,031 (72.9%) | The annual economic burden of epilepsy was estimated as 88.2% of GNP per capita and 0.5% of the GNP which was equivalent to INR 68.75 billion (US\$1.7 billion) |
| Thomas <i>et al.</i> ^[46] | 1999 | Multicenter study | 337 patients in 8 neurology referral centers | Direct medical, direct nonmedical, few indirect cost | INR 5,070 (45.7%) | INR 6,000 (55.2%) | Referral to the epileptologist was identified as extra economic burden to the family and there was a mean loss of 58 work days |
| Radhakrishnan <i>et al.</i> ^[47] | 1999 | Trivandrum, Kerala | 972 patients registered at epilepsy clinic in a tertiary center from 1993 to 1995 | Direct medical (only drug cost) | - | - | The average annual cost of AED treatment per patient was \$64.32 at entry and \$47.73 at last follow-up. Reduction in polytherapy resulted in the net annual saving of \$16,128 (\$16.59 per patient, or 5.4% GNP/capita) |

AED = Antiepileptic drug, CT = Computed tomography, GNP = Gross national product

while assessing the drug costs. Among the AEDs, Krishnan *et al.*, in 2004 have reported maximum annual drug cost for sodium valproate and minimum for phenobarbitone, while Haroon *et al.*, observed higher drug cost for newer AEDs such as lamotrigine, levetiracetam, and lacosamide as compared to standard drugs.^[41,44] Among the newer drugs, clobazam had the lowest cost. The cost for treating epilepsy was further increased when epilepsy was caused by neurocysticercosis (NCC). This was due to extra cost for additional drugs which constituted 3.6% of the total direct cost and 20.7% of AEDs cost.^[42]

The cost of treatment has deleterious effect on the drug adherence. Das *et al.*, reported a default rate of 42.8% with cost of the drug(s) as main factor for discontinuation.^[24] The discontinued group expended 40% of the total income, while the continued group expended only 18% of the total income for treatment highlighting the vulnerability of socioeconomically disadvantaged. The economic burden among the discontinued group was further worsened by the poor disease outcome

through positive vicious cycle. Interestingly, when the cost of the drugs was drastically reduced by the government subsidy, high travel expenditure emerged as a major contributor of direct cost.^[45] This highlights the critical role of accessibility and affordability of healthcare, further determined by the urban-rural disparity even among the population that uses public health sector in the absence of universal health assurance program.

It is estimated that India will have over 1 million people with medically refractory epilepsies with nearly half of them requiring surgery. But currently less than 500 epilepsy surgeries per year are undertaken in India, resulting in high surgical treatment gap and huge healthcare burden, as 80% of healthcare costs in epilepsy are accounted for by the patients with drug-resistant epilepsy.^[53]

Apart from the effects of epilepsy per se, there exists a complex relation between epilepsy, comorbidities, and treatment. The

burden of epilepsy is further complicated by its psychiatric and cognitive comorbidities. The early detection and management of these comorbidities is essential for effective prevention and control of epilepsy. Thus, the overall economic impact of epilepsy and the costs of medical care (where 80% of the healthcare provided by the private sector in India) are expected to be exceptionally high in India due to high treatment gap and associated comorbidities besides poor adherence to medication and lack of adequate services in the absence of universal health coverage.

Epilepsy and Comorbidities

Research across the globe has highlighted the association of epilepsy in children with behavioral and psychiatric problems. In India, majority of studies on comorbidity comes from clinical settings except for few population-based studies on children. Srivastava *et al.*, reported major depression and mixed anxiety depression as the most common neuropsychiatric manifestations in patients of NCC.^[54] The various comorbidities identified in the patients who attended a tertiary care hospital were migraine, anxiety, depression, sleep disturbances, neurocysticercosis, pulmonary tuberculosis, and extrapulmonary tuberculosis. Hypertension, diabetes, osteoarthritis, asthma, hypothyroidism, and acid-peptic disease were the other less common comorbidities that were reported.^[55]

Among the population-based studies, Datta *et al.*, reported behavioral problems in children with epilepsy, while Hackett *et al.*, documented the association of epilepsy with cognitive impairment.^[56,57] In a study from Bharwani district, epilepsy was found in 23.7% of the children with intellectual disability.^[58] Also, epilepsy in children with intellectual disability was associated with lower intelligent quotient score.^[58] Among the recent hospital-based studies, a higher frequency of psychiatric comorbidity was observed in children with longer duration of seizures, increased frequency of seizures, poor compliance with medications and especially, anticonvulsant polytherapy.^[59,60] Hence, it is important to differentiate comorbidities due to disease and drugs for proper management and should be one of the research priorities in the field of epilepsy in India.

For women with epilepsy (WWE), the data from Kerala Registry of Epilepsy and Pregnancy (KREP) reported higher frequency of anemia, ovarian cyst, fibroid uterus, spontaneous abortions, and congenital malformations.^[61,62] WWE are vulnerable for poor child rearing practice, which persisted even after intervention and studies have reported higher risk of children of WWE for developmental delay, low IQ, and low linguistic achievements.^[63-66]

Among the elderly, stroke is reported as the most common comorbidity with epilepsy.^[67] This might be due to rising burden of non-communicable diseases such as hypertension and diabetes and epilepsy among the increasing elderly population in recent years. Brain tumor, head injury, and Alzheimer's disease are the other major CNS disorders associated with epilepsy in the elderly. These comorbid conditions have the potential to alter the pharmacodynamics and pharmacokinetics of AEDs, thereby complicating the management of epilepsy in elderly.

Knowledge and Attitudes

The knowledge, attitudes, beliefs, and practices of individuals with epilepsy, their family, and the society have a major influence on recovery and quality of life of PWE. A poor knowledge and attitude towards epilepsy was observed among general public, school children, and teachers even though majority of them had heard or read about epilepsy [Table 3].^[12,15,63,68-77] Even among the primary healthcare doctors, overutilization of EEG, improper prescription of AEDs, and inadequate skills in the management of AED-resistant epilepsies have been reported.^[78] A significant number of general public in Kerala believed in other traditional medical practices for treating epilepsy.^[15] Among the PWE who attended a tertiary hospital, 7.7% reported the additional use of complementary and alternative medicine (CAM).^[79] Das *et al.*, found that significant number of patients in India had discontinued epilepsy treatment within 1 year because of poor knowledge regarding the outcomes after discontinuation.^[24] In the large population-based studies, Radhakrishnan *et al.*, in Kerala found that a considerable number of people still believed epilepsy as a form of insanity, while Sureka and Sureka in Rajasthan found that nearly one-fourth of the subjects thought epilepsy as disease of evil spirits.^[12,15]

Even though there has been a shift in the perceived knowledge and attitudes about epilepsy in HICs, the situation is far from satisfactory in many of the LMICs including India [Table 3]. There is a need for capacity strengthening of healthcare providers and creating awareness among students, teachers, and other educational institutions besides general community. A recent study evaluating the impact of comprehensive epilepsy education program for school teachers in Chandigarh has highlighted the need for regular workshops to improve and reinforce the knowledge and skills of the teachers about epilepsy.^[80]

Stigma and Quality of Life (QOL)

Numerous studies confirm the vulnerability of PWE to the pervasive stigmas in India [Tables 4 and 5].^[15,30,37,43,55,72-74,81-90] The nature, extent, and impact of stigma associated with epilepsy are very high and act as a significant barrier for delivery of effective epilepsy care and utilization of available services. The discriminating attitudes of the society not only affect education, employment, marriage, and social activities but also prevent PWE to come forward to receive and continue care. It interferes with the timely access to healthcare, adherence to treatment, and lifestyle recommendations influencing the overall health of the individual. Finally, stigma results in poor quality of life for the affected individuals and their families. This is because of the varying family response to epilepsy that range from overprotection, guilt, anxiety, sadness, worry, confusion, and depression to even avoidance resulting in major psychosocial consequences like loss of self-esteem, social withdrawal, isolation, and even occasional instances of suicide. The overall quality of life is also affected at times due to medication.

Researches on epilepsy-related stigma in India are relatively scarce when compared to developed countries. Earlier studies have attempted to study the stigma from the set of beliefs and perceptions using locally developed knowledge,

Table 3: Summary of knowledge and attitudes about epilepsy in India

| Author | Year of publication | Place | Sample | Salient findings |
|---|---------------------|---------------|---|---|
| Joshi <i>et al.</i> ^[68] | 2012 | Uttar Pradesh | 798 students of urban secondary school | 81.8% believed epilepsy as a psychiatric disorder and 71.6% as an inherited disease. Similarly, majority believed in lifelong treatment and separate school for epileptics |
| Sinha <i>et al.</i> ^[69] | 2012 | West Bengal | 315 epilepsy patients in hospital | Ignorance, faith in another system, rural residence, and monetary constraints were associated with initial nonallopathic care seeking. Rural population preferred general practitioner and urban preferred neurologist |
| Saramma <i>et al.</i> ^[63] | 2011 | Kerala | 88 cases and 88 healthy pregnant women | Women with epilepsy had poorer knowledge and skills in child rearing than women without epilepsy |
| Goel <i>et al.</i> ^[70] | 2011 | Uttarakhand | 219 class 12 students | Nearly 2/3 stated epilepsy as hindrance for marriage and occupation. 41% preferred to use onion or shoe during seizure attack. Ayurveda treatment was preferred over allopathic |
| Girotra <i>et al.</i> ^[71] | 2011 | Punjab | 109 NCC and 105 controls | Only 64.2% of NCC patient group and 19% of control had heard about NCC |
| Pal <i>et al.</i> ^[72] | 2008 | Punjab | 400 epileptic patients | Families have adopted some culturally prevalent methods to control seizures. Some families concurrently visited modern hospitals and occult healers seeking a cure for the disease |
| Thacker <i>et al.</i> ^[73] | 2008 | Uttarakhand | School teachers of primary and secondary levels | 97% were aware of epilepsy with majority including it as a brain disease, 38.2% were uncertain about relation of epilepsy and insanity, and only 16.3% provided appropriate first aid treatment |
| Sureka and Sureka ^[12] | 2007 | Rajasthan | 172,442 rural subjects | Nearly 1/4 th of the subjects thought epilepsy as disease of evil spirits |
| Pandian <i>et al.</i> ^[74] | 2006 | Kerala | 1,213 10 th grade students | Nearly 60% thought epilepsy as form of insanity. Half of the students considered epilepsy a hindrance to education, employment, and marriage. Some considered holding a bunch of keys to terminate epileptic attack |
| Radhakrishnan <i>et al.</i> ^[15] | 2000 | Kerala | 238,102 semiurban subjects | Nearly 30% believed that epilepsy was a hereditary disorder and a form of insanity. About 40% felt that individuals with epilepsy could not be properly educated or employed. 11% object to their children having contact with epileptic children |
| Desai <i>et al.</i> ^[75] | 1998 | Haryana | 80 epileptic patient attending OPD | More than half of them had tried alternative treatment methods. Few patients avoided taking medicines on days of religious fast and would stop the medicines if these were not given free of cost |

OPD = Outpatient department, NCC = Neurocysticercosis

attitude, and practices (KAP) questionnaires.^[91] Recently, there have been attempts to quantify stigma using standardized scales [Table 5].^[89,90] Culturally sensitive tools are required to understand the distribution, determinants, and impact of epilepsy-related stigma. Earlier, Radhakrishnan *et al.*, in Kerala found that negative attitude towards epilepsy was related to the age, gender, and education of PWE.^[15] Joseph *et al.*, in Mangalore found that stigmatization was related to the age and education, while Nehra *et al.*, in Delhi found that younger age was associated with more psychosocial consequences of epilepsy.^[89,92] However, strategies to mitigate epilepsy-related stigma and the cost of epilepsy-related stigma, which are critical from implementation point of view are yet to be investigated comprehensively in India.

Epilepsy and Disability

As discussed earlier, there are various studies in Indian settings that have shown the impact of epilepsy on various aspects of life among PWE. However, disability (defined as a physical or mental condition that limits a person's movements, senses, or activities) due to epilepsy in India is often overlooked and undervalued.^[93] Nehra *et al.*, in a recent study from a tertiary care center in New Delhi observed that 69.7% of the patients had disability with 23.08% of them having severe disability with

dysfunction in various physical and psychosocial domains. The disability was found to be increase with increasing stigma scores.^[89]

From Tables 3-5, it is evident that there is no significant improvement in the perception, stigma, and discrimination of epilepsy across the country despite improvement in educational and social parameters over the time. This highlights the need to increase the awareness of epilepsy among general public to reduce the stigma and disability due to epilepsy. Recently, Government of India has included chronic epilepsy in its draft bill of Rights of Persons with Disabilities.^[94]

Organization and Delivery of Services

Limited data from India clearly indicate that epilepsy is a major public health problem with huge burden and psychosocial impact. Undoubtedly, significant efforts are required towards prevention, care, and rehabilitation in India at a time when scientific knowledge exist that epilepsy is preventable and manageable. This emphasizes the need to take up epilepsy as a priority on a large scale. Existing services for PWE are largely urban-based, even though epilepsy care is getting expanded to rural areas; however, even available services are underutilized. The lack of awareness, extreme shortage of specialist or trained

Table 4: Quality of life among persons with epilepsy

| Author | Year of publication | Place | Sample | Salient findings |
|--|---------------------|----------------------|---|---|
| Arya <i>et al.</i> ^[81] | 2014 | Haryana | Children with epilepsy 2-14 years with comprehensive epilepsy evaluation | Overall QOL was more affected in terms of low self-esteem and physical restrictions, whereas cognitive functions and social activities were less affected. Parental education, socioeconomic status, and frequency/type of seizure did not significantly affect the QOL |
| Ashwin <i>et al.</i> ^[82] | 2013 | Karnataka | PWE >18 years attending outpatient department of secondary hospital | The QOL was lower in the psychological domain. Age >30 years, female, and being married were associated with poor QOL scores |
| Rakesh <i>et al.</i> ^[83] | 2012 | Tamil Nadu | Adult epilepsy patients from 20 randomly selected villages | The presence of anxiety, lack of primary education, being single, separated or widowed, increasing age, low per capita income, and having a seizure episode in the past year are associated with lower QOL among people with epilepsy |
| Shetty <i>et al.</i> ^[84] | 2011 | Bangalore, Karnataka | 60 patients >18 years with epilepsy attending OPD | Older patients, female patients, and married people had poor quality of life |
| Aggarwal <i>et al.</i> ^[85] | 2011 | New Delhi | 108 epileptic children (6-15 years) in hospital | Overall quality of life was affected by age, type of epilepsy, seizure frequency, and maternal education. Energy levels, language, and attention were better in older children |
| Nadkarni <i>et al.</i> ^[86] | 2011 | Madhya Pradesh | Parents of 102 children with epilepsy aged 5-15 years in hospital setting | QOL was compromised more in older, poorer, and rural children. Better QOL was observed in children of literate mothers |
| Babu <i>et al.</i> ^[55] | 2009 | Bangalore, Karnataka | 250 PWE and 250 controls in hospital | Comorbid conditions like migraine, anxiety, depression, sleep disturbances, neurocysticercosis, pulmonary tuberculosis, etc., was noted in 60.8% cases and among them, 24.8% had ≥ 2 comorbidities |
| Sachin <i>et al.</i> ^[87] | 2008 | New Delhi | 100 women with epilepsy, 50 with migraine, and 100 healthy pregnant women in hospital | Quality of life was least, and the burden experienced by the caregiver was significantly more in patients with epilepsy |
| Malhi and Singhi ^[88] | 2005 | Chandigarh | Children aged 4-15 years with epilepsy in hospital | Incontinence during a seizure, the ill-effects of antiepileptics, and longer duration of treatment had poor QOL. Nearly 40% of the children had significant psychopathology |
| Thomas <i>et al.</i> ^[43] | 2005 | Kerala | PWE >16 years and >12 months follow-up in hospital setting | Frequent seizures and use of polytherapy were associated with poor QOL |

PWE = Persons living with epilepsy, QOL = Quality of life, OPD = Outpatient department

manpower, and inadequate skills of healthcare providers in managing epilepsy poses a major challenge in organizing services for PWE. The stigma and its subsequent impact on employment, education, and marriage emphasize the importance of counseling and vocational rehabilitation besides the need to promote awareness and upscale the capacity of various cadres of health providers. Thus, there is a need to conceptualize a comprehensive preventive, promotive, curative, and rehabilitative healthcare delivery model to reduce the treatment gap in epilepsy; most importantly implementing the same and it is indeed a challenge.

Integrated Approaches for Epilepsy Prevention, Care, and Rehabilitation

Focus on prevention

A significant proportion of epilepsy in India occur due to adverse perinatal events and neonatal infections and majority of the infections that cause epilepsy in developing countries are preventable through improved obstetric and neonatal care, immunization, vector control measures, and improved food hygiene. Thus, active disease surveillance becomes critical for planning appropriate preventive/control measures. Besides several new initiatives in the areas of maternal and child

health, control and prevention of childhood infectious diseases, prevention of communicable diseases like malaria and others, many effective solutions to prevent road traffic injuries, work place injuries, and other injuries can significantly contribute for epilepsy prevention. The entire National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases And Stroke (NPCDCS) program can address epilepsy secondary to some metabolic conditions if prevention becomes central focus. Sensitization/orientation of administrators and professionals in various national programs for prevention and management of epilepsy would go a long way in control of epilepsy during the days to come.

Emphasis on care

With shortage of specialist manpower and health facilities for epilepsy, there is a need to organize services based on a public health approach model by using existing healthcare facilities.^[95] The immediate focus should be on capacity building of various healthcare providers, applying appropriate technology for diagnosis, ensuring uninterrupted drug supply, and creating awareness. In recent years, there is a strong thrust to develop a national epilepsy control program and it is envisaged that India would have a national epilepsy control program in the coming years to close the wide treatment gap.^[96]

Table 5: Stigma and epilepsy

| Author | Year of publication | Place of study | Sample | Stigma assessment | Salient findings |
|---|---------------------|-------------------|---|--|--|
| Nehra <i>et al.</i> ^[89] | 2014 | New Delhi | 208 PWE of epilepsy clinic | The Stigma Scale for Epilepsy (SSE), The Locke-Wallace Marital Adjustment Test (MAT) for marital satisfaction, and Rosenberg's Self-Esteem Scale | High prevalence of stigma, and its role in decreasing QOL and causing disability in PWEs. Frequent discrimination of PWE in occupational, social, emotional, and married life |
| Kumari <i>et al.</i> ^[90] | 2009 | Ranchi, Jharkhand | 45 patients in hospital | SSE | Stigma was higher, while quality of life was poorer for new cases when compared to old cases |
| Pal <i>et al.</i> ^[72] | 2008 | Chandigarh | 400 patients of epilepsy clinic | The questionnaire-cum-interview schedule on sociocultural and psychosocial factors | There was difficulty in getting a spouse when disease was disclosed. But well-being and safety of the patient override the stigma burden factor |
| Thacker <i>et al.</i> ^[73] | 2008 | Uttar Pradesh | 568 primary and secondary school teachers | 15-item self-administered questionnaire related to awareness and attitudes towards epilepsy | 31.7% felt epileptics to be of below average intelligence and 86.8% had an overwhelming no for marriage with an epileptic |
| Santosh <i>et al.</i> ^[37] | 2007 | Kerala | 82 married women of the epilepsy clinic | 10-item close-ended questions related to concealment/disclosure of the history of epilepsy and its consequences on the married life of women with epilepsy | At the time of marriage, 55% concealed the history of epilepsy. Fear of breakup of marriage negotiations was one of the main reasons for concealment |
| Varma <i>et al.</i> ^[30] | 2007 | Kerala | 202 epilepsy outpatient clinic patients | Questionnaire developed <i>de novo</i> through a series of semistructured interviews | 15.8% of unemployed were denied job because of epilepsy. Of the 38 who disclosed their status to their employer, 8 (11.1%) had been dismissed from their job and 8 (11.1%) had to repeatedly change jobs because of epilepsy |
| Pandian <i>et al.</i> ^[74] | 2006 | Kerala | 1,213 10 th grade students of Kerala | Modified 24-item survey questionnaire developed by authors on knowledge, attitude, and practice towards epilepsy | 13% of the students were found reluctant to sit adjacent to or play alongside a child with epilepsy in the classroom. 45% of the students believed that society discriminated against PWE |
| Radhakrishnan <i>et al.</i> ^[15] | 2000 | Kerala | 238,102 semiurban subjects by H-H survey | 24-item survey questionnaire developed by authors on knowledge, attitude, and practice towards epilepsy | About 40% of the respondents felt that individuals with epilepsy could not be properly educated or employed and 11% object to their children having contact with epileptic children |

PWE = Persons with epilepsy, QOL = Quality of life, H-H = House-to-house

Various approaches have been attempted by India and other developing countries to deliver epilepsy services in the community with need-based specialized diagnostic techniques and surgical facilities.^[97] Some of the notable approaches are fixed satellite clinic model of apex institutions,^[98] camp approach (specialists or trained physicians engaging in rural camps),^[99] mobile clinic approach (single visit by neurologist),^[100] rural approach (integrating epilepsy care in primary healthcare),^[101] general practitioners approach (training general practitioners in epilepsy care),^[102] key informant approach (availing services from school teachers and other key leaders of community in identification and education of PWE and their families),^[103,104] community health worker approach (for identification, referral, and follow-up),^[12] and community-based rehabilitation model.^[4]

The community-based rehabilitation model of care had resistance due to categorization of PWE as having disabilities, while the camp approach and satellite clinic model had inherent problems of stigma, difficulty in follow-up, and the failure to ensure uninterrupted supply of drugs. These initial problems can be overcome with community involvement. Though these models could be cost-effective and complementing, no large-scale replication and evaluation studies have been reported till date to examine its cost effectiveness in India.

To circumvent these challenges, a decentralized model of epilepsy care at the district level with two essential parallel and complementary approaches, namely "center to periphery"

and second, "periphery to center" was proposed.^[95] This model had envisaged the district medical officer as the core person, neurologist as a nodal person, and the primary health center medical officer as the delivery agent. In line with this, Tripathi *et al.*, have highlighted the complementary bottom up training and case finding model with top down information, education, and communication (IEC) delivery model.^[96] National epilepsy network and national epilepsy surgery support activity was proposed to provide proper guidance and support for managing difficult cases and reduce the surgical treatment gap in India.^[53,105]

Strengthening and capacity building of primary care settings for managing epilepsy,^[106] implementation of telemedicine facilities in managing complicated cases of epilepsy, expanding the scope of surgical interventions and therapeutic drug monitoring, and provision of emergency kits in different settings for management of status epilepticus were suggested for prevention of unnecessary referrals and better utilization of services.

A recent study by Dash *et al.*, has demonstrated the effectiveness of health education in improving drug adherence and self-management skills of PWE with low educational background.^[107] This highlighted the importance of including educational program in providing holistic management of PWE, irrespective of their educational status.

While the need for an independent epilepsy control program has been articulated by professionals, there is urgent

need for integrating epilepsy prevention, early diagnosis, management, and rehabilitation in the existing programs. As neurological diseases are considered in the larger spectrum of non-communicable diseases and there is a growing elderly population, integrating epilepsy care with the upcoming National Program for Health Care of Elderly (NPHCE) and NPCDCS and in trauma care appears to be some promising strategies in effective reduction of epilepsy burden.^[108,109]

Need for Rehabilitation

Psychosocial and vocational rehabilitation is one of the immediate needs of PWE to improve their employment opportunities through a skill-based approach in a non-stigmatizing environment. Increasing awareness about epilepsy through audio-visual communication channels, street play models, and exhibition models, especially in schools, workplaces settings, and community provides immense scope for improving the life of PWE. An integrated team of psychologist, social workers, health workers, and primary care doctors along with neurologist trained in epilepsy care are urgently required. A greater involvement of non-governmental organizations (NGOs) is required to facilitate the larger integration of PWE into the mainstream society. Thus, addressing both demand and supply side becomes essential to inform, educate, and motivate people and professionals from varied background through multidisciplinary approach.^[110] Diploma in epilepsy care, a correspondence course initiated by IEA would be a step in this direction to increase the capacity.^[111]

Summary and Conclusion

Even though epilepsy is an eminently preventable and treatable condition, it still remains a major public health problem due to high stigma, wide socioeconomic inequity, huge treatment gap, and the poor epilepsy healthcare delivery system in India. Thus, besides considering the epidemiological aspects, the psychosocial and economic impact of epilepsy becomes more crucial while addressing the problem of epilepsy. It is clearly evident that epilepsy is a complex public health problem that requires integrated multidisciplinary approach. Time has been lost and rather than focusing on pilot projects, a sustainable, cost effective, and comprehensive public health response is required to address the challenge of epilepsy in India. Neurologists, public health professionals, psychiatrists, psychiatric social worker, psychiatric nurse, and program managers need to join hands for prevention, improved care, and rehabilitation of PWE in India.

References

1. Definition of "stigma", no. 2. The oxford english dictionary. 2nd ed. Oxford: Oxford University Press; 1989. Cited by Gruskin S, Ferguson L. Using indicators to determine the contribution of human rights to public health efforts. *Bull World Health Organ* 2009 ;87:714-9.
2. Definition of "discrimination", no. 1. The oxford english dictionary. 2nd ed. Oxford: Oxford University Press; 1989. Cited by Gruskin S, Ferguson L. Using indicators to determine the contribution of human rights to public health efforts. *Bull World Health Organ* 2009;87:714-9..
3. Karceski S, Morell M. Principle in epilepsy: Diagnosis and pharmacotherapy. In: Noseworthy JH, (editor). *Neurological therapeutics-principles and practice*, 1st ed, Volume 1. London: Martin Ounitz Taylor and Francis group; 2003. p. 286-96.
4. Meinardi H, Scott RA, Reis R, Sander JW, ILAE Commission on the Developing World. The treatment gap in epilepsy: The current situation and ways forward. *Epilepsia* 2001;42:136-49.
5. de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav* 2008;12:540-6.
6. Meyer AC, Dua T, Ma J, Saxena S, Birbeck G. Global disparities in the epilepsy treatment gap: A systematic review. *Bull World Health Organ* 2010;88:260-6.
7. Mbuba CK, Ngugi AK, Newton CR, Carter JA. The epilepsy treatment gap in developing countries: A systematic review of the magnitude, causes, and intervention strategies. *Epilepsia* 2008;49:1491-503.
8. Neligan A, Sander JW. The treatment gap in epilepsy: A global perspective. *Epileptology* [Internet]; Available from: <http://www.sciencedirect.com/science/article/pii/S2212822012000063>. [Last accessed on 2013 Mar 31].
9. Nizamie SH, Akthar S, Banerjee I, Goyal N. Health care delivery model in epilepsy to reduce treatment gap: World Health Organization study from a rural tribal population of India. *Epilepsy Res* 2009;84:146-52.
10. Banerjee TK, Hazra A, Biswas A, Ray J, Roy T, Raut DK, *et al.* Neurological disorders in children and adolescents. *Indian J Pediatr* 2009;76:139-46.
11. Goel D, Agarwal A, Dhanai JS, Semval VD, Mehrotra V, Saxena V, *et al.* Comprehensive rural epilepsy surveillance programme in Uttarakhand state of India. *Neurol India* 2009;57:355-6.
12. Sureka RK, Sureka R. Prevalence of epilepsy in rural Rajasthan — a door-to-door survey. *J Assoc Physicians India* 2007;55:741-2.
13. Saha SP, Bhattacharya S, Das SK, Maity B, Roy T, Raut DK. Epidemiological study of neurological disorders in a rural population of Eastern India. *J Indian Med Assoc* 2003;101:299-300, 302-4.
14. Ray BK, Bhattacharya S, Kundu TN, Saha SP, Das SK. Epidemiology of epilepsy—Indian perspective. *J Indian Med Assoc* 2002;100:322-6.
15. Radhakrishnan K, Pandian JD, Santhoshkumar T, Thomas SV, Deetha TD, Sarma PS, *et al.* Prevalence, knowledge, attitude, and practice of epilepsy in Kerala, South India. *Epilepsia* 2000;41:1027-35.
16. Sridharan R, Murthy BN. Prevalence and pattern of epilepsy in India. *Epilepsia* 1999;40:631-6.
17. Pal DK, Das T, Sengupta S. Comparison of key informant and survey methods for ascertainment of childhood epilepsy in West Bengal, India. *Int J Epidemiol* 1998;27:672-6.
18. Mani KS, Rangan G, Srinivas HV, Kalyanasundaram S, Narendran S, Reddy AK. The Yelandur study: A community-based approach to epilepsy in rural South India — epidemiological aspects. *Seizure* 1998;7:281-8.
19. Bharucha NE, Weiss MG, Bharucha EP, Jadhav SS, Raven RH, Rajole BK. Sociocultural aspects of epilepsy in developing countries. In: *Proceedings of the 22nd International Epilepsy Congress, Dublin, Ireland, June 29-July 4, 1997. Abstracts.* *Epilepsia* 1997;38(Suppl 3):166.
20. Hackett RJ, Hackett L, Bhakta P. The prevalence and associated factors of epilepsy in children in Calicut District, Kerala, India. *Acta Paediatr* 1997;86:1257-60.
21. Bharucha NE, Bharucha EP, Bharucha AE, Bhise AV, Schoenberg BS. Prevalence of epilepsy in the Parsi community of Bombay. *Epilepsia* 1988;29:111-5.
22. Koul R, Razdan S, Motta A. Prevalence and pattern of epilepsy (Lath/Mirgi/Laran) in rural Kashmir, India. *Epilepsia* 1988;29:116-22.
23. Thomas SV, Deetha TD, Nair P, Sarma SP. Fewer women receive tertiary care for epilepsy in Kerala State, India. *Epileptic Disord* 2006;8:184-9.

24. Das K, Banerjee M, Mondal GP, Devi LG, Singh OP, Mukherjee BB. Evaluation of socio-economic factors causing discontinuation of epilepsy treatment resulting in seizure recurrence: A study in an urban epilepsy clinic in India. *Seizure* 2007;16:601-7.
25. Joseph N, Kumar GS, Nelliyanil M. Pattern of seizure cases in tertiary care hospitals in Karnataka state of India. *Ann Indian Acad Neurol* 2013;16:347-51.
26. Satishchandra P, Gururaj G, Mohammed QD, Senanayake N, Silpakit O. *Epilepsy: Out of the shadows: From prejudice to hope*. New Delhi: World Health Organisation, Regional Office for South East Asia; 2001; p. 42.
27. Singh H, Aneja S, Unni KE, Seth A, Kumar V. A study of educational underachievement in Indian children with epilepsy. *Brain Dev* 2012;34:504-10.
28. Tandon PN. *Epilepsy in India (Report based on a multicentric study on epidemiology of epilepsy carried out as a PL480 funded project of the Indian Council of Medical Research)*; 1989.
29. Pal DK, Chaudhury G, Sengupta S, Das T. Social integration of children with epilepsy in rural India. *Soc Sci Med* 2002;54:1867-74.
30. Varma NP, Sylaja PN, George L, Sankara Sarma P, Radhakrishnan K. Employment concerns of people with epilepsy in Kerala, south India. *Epilepsy Behav* 2007;10:250-4.
31. Jain V. *Epilepsy and driving: Fit to drive*: [Internet]. India Together 2008. Available from: <http://indiatogether.org/epilepsy-laws>. [Last accessed on 2015 Feb 21].
32. Sheth SG, Krauss G, Krumholz A, Li G. Mortality in epilepsy: Driving fatalities vs other causes of death in patients with epilepsy. *Neurology* 2004;63:1002-7.
33. Taylor J, Chadwick D, Johnson T. Risk of accidents in drivers with epilepsy. *J Neurol Neurosurg Psychiatry* 1996;60:621-7.
34. Hansotia P, Broste SK. The effect of epilepsy or diabetes mellitus on the risk of automobile accidents. *N Engl J Med* 1991;324:22-6.
35. D'Souza C. Epilepsy and discrimination in India. *Neurol Asia* 2004;9:53-4.
36. Agarwal P, Mehndiratta MM, Antony AR, Kumar N, Dwivedi RN, Sharma P, *et al.* Epilepsy in India: Nuptiality behaviour and fertility. *Seizure* 2006;15:409-15.
37. Santosh D, Kumar TS, Sarma PS, Radhakrishnan K. Women with onset of epilepsy prior to marriage: Disclose or conceal? *Epilepsia* 2007;48:1007-10.
38. Nag D. Gender and epilepsy : A Clinician's experience. *Neurol India* 2000;48:99-104.
39. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. *Methods for the Economic Evaluation of Health Care Programmes*, 3rd ed. Oxford: Oxford University Press; 2005. p. 24.
40. Thomas SV, Sarma PS, Alexander M, Pandit L, Shekhar L, Trivedi C, *et al.* Economic burden of epilepsy in India. *Epilepsia* 2001;42:1052-60.
41. Haroon A, Tripathi M, Khanam R, Vohora D. Antiepileptic drugs prescription utilization behavior and direct costs of treatment in a national hospital of India. *Ann Indian Acad Neurol* 2012;15:289-93.
42. Murthy JM, Rajshekar G. Economic evaluation of seizures associated with solitary cysticercus granuloma. *Neurol India* 2007;55:42-5.
43. 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.
44. Krishnan A, Sahariah SU, Kapoor SK. Cost of epilepsy in patients attending a secondary-level hospital in India. *Epilepsia* 2004;45:289-91.
45. Dhanaraj M, Kannan S, Jayavelu A, Amalraj E, Dutta M. Cost of epilepsy treatment in a state government hospital: A preliminary study. *Ann Indian Acad Neurol* 2003;6:7.
46. Thomas SV, Abraham PA, Alexander M, Pandit L, Shekhar L, Sarma PS, *et al.* Utilization of services for epilepsy and its economic burden in India: A multi-center study; 1999. Available from: <http://dspace.sctimst.ac.in/xmlui/handle/123456789/1270>. [Last accessed on 2013 Mar 31].
47. Radhakrishnan K, Nayak SD, Kumar SP, Sarma PS. Profile of antiepileptic pharmacotherapy in a tertiary referral center in South India: A pharmacoepidemiologic and pharmacoeconomic study. *Epilepsia* 1999;40:179-85.
48. Strzelczyk A, Reese JP, Dodel R, Hamer HM. Cost of epilepsy: A systematic review. *Pharmacoeconomics* 2008;26:463-76.
49. Pal DK, Das T, Sengupta S, Chaudhury G. Help-seeking patterns for children with epilepsy in rural India: Implications for service delivery. *Epilepsia* 2002;43:904-11.
50. Jacoby A, Buck D, Baker G, McNamee P, Graham-Jones S, Chadwick D. Uptake and costs of care for epilepsy: Findings from a U. K. regional study. *Epilepsia* 1998;39:776-86.
51. Begley CE, Famulari M, Annegers JF, Lairson DR, Reynolds TF, Coan S, *et al.* The cost of epilepsy in the United States: An estimate from population-based clinical and survey data. *Epilepsia* 2000;41:342-51.
52. Sinha A, Bhaumik DK. Treatment expenditure pattern of epileptic patients: A study from a tertiary care hospital, Kolkata, India. *Neurol Res Int* 2014;2014:869572. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3953574/>. [Last accessed on 2014 Jul 22].
53. Radhakrishnan K, Rathore C, Rao MB. National epilepsy surgery support activity. *Ann Indian Acad Neurol* 2014;17:S132-3.
54. Srivastava S, Chadda RK, Bala K, Majumdar P. A study of neuropsychiatric manifestations in patients of neurocysticercosis. *Indian J Psychiatry* 2013;55:264-7.
55. Babu CS, Satishchandra P, Sinha S, Subbakrishna DK. Co-morbidities in people living with epilepsy: Hospital based case-control study from a resource-poor setting. *Epilepsy Res* 2009;86:146-52.
56. Datta SS, Premkumar TS, Chandy S, Kumar S, Kirubakaran C, Gnanamuthu C, *et al.* Behaviour problems in children and adolescents with seizure disorder: Associations and risk factors. *Seizure* 2005;14:190-7.
57. Hackett R, Hackett L, Bhakta P. Psychiatric disorder and cognitive function in children with epilepsy in Kerala, South India. *Seizure* 1998;7:321-4.
58. Lakhan R. The coexistence of psychiatric disorders and intellectual disability in children aged 3-18 years in the barwani district, India. *ISRN Psychiatry* 2013;2013:875873.
59. Amruth G, Praveen-Kumar S, Nataraju B, Kasturi P. Study of psychiatric comorbidities in epilepsy by using the Mini International Neuropsychiatric Interview. *Epilepsy Behav* 2014;33:94-100.
60. Choudhary A, Gulati S, Sagar R, Kabra M, Sapra S. Behavioral comorbidity in children and adolescents with epilepsy. *J Clin Neurosci* 2014;21:1337-40.
61. Thomas SV, Indrani L, Devi GC, Jacob S, Beegum J, Jacob PP, *et al.* Pregnancy in women with epilepsy: Preliminary results of Kerala registry of epilepsy and pregnancy. *Neurol India* 2001;49:60-6.
62. Thomas SV, Sindhu K, Ajaykumar B, Sulekha Devi PB, Sujamol J. Maternal and obstetric outcome of women with epilepsy. *Seizure* 2009;18:163-6.
63. Saramma PP, Sarma PS, Thomas SV. Women with epilepsy have poorer knowledge and skills in child rearing than women without epilepsy. *Seizure* 2011;20:575-9.
64. Saramma PP, Sarma PS, Thomas SV. Effect of a self-instructional module on the child rearing knowledge and practice of women with epilepsy. *Seizure* 2014;23:424-8.
65. Thomas SV, Sukumaran S, Lukose N, George A, Sarma PS. Intellectual and language functions in children of mothers with epilepsy. *Epilepsia* 2007;48:2234-40.
66. Thomas SV, Ajaykumar B, Sindhu K, Nair MK, George B, Sarma PS. Motor and mental development of infants exposed to antiepileptic drugs in utero. *Epilepsy Behav* 2008;13:229-36.
67. Ng SK, Hauser WA, Brust JC, Susser M. Hypertension and the risk of new-onset unprovoked seizures. *Neurology* 1993;43:425-8.

68. Joshi HS, Mahmood SE, Bamel A, Agarwal AK, Shaifali I. Perception of epilepsy among the urban secondary school children of Bareilly district. *Ann Indian Acad Neurol* 2012;15:125-7.
69. Sinha A, Mallik S, Sanyal D, Sengupta P, Dasgupta S. Healthcare-seeking behavior of patients with epileptic seizure disorders attending a tertiary care hospital, Kolkata. *Indian J Community Med* 2012;37:25-9.
70. Goel D, Dhanai JS, Agarwal A, Mehlotra V, Saxena V. Knowledge, attitude and practice of epilepsy in Uttarakhand, India. *Ann Indian Acad Neurol* 2011;14:116-9.
71. Girotra M, Gera C, Abraham RR, Gauba R, Bansal T, Kaur P, *et al.* Awareness of neurocysticercosis: A study from northwest India. *Ann Indian Acad Neurol* 2011;14:27-30.
72. Pal SK, Sharma K, Prabhakar S, Pathak A. Psychosocial, demographic, and treatment-seeking strategic behavior, including faith healing practices, among patients with epilepsy in northwest India. *Epilepsy Behav* 2008;13:323-32.
73. Thacker AK, Verma AM, Ji R, Thacker P, Mishra P. Knowledge awareness and attitude about epilepsy among schoolteachers in India. *Seizure* 2008;17:684-90.
74. Pandian JD, Santosh D, Kumar TS, Sarma PS, Radhakrishnan K. High school students' knowledge, attitude, and practice with respect to epilepsy in Kerala, southern India. *Epilepsy Behav* 2006;9:492-7.
75. Desai P, Padma MV, Jain S, Maheshwari MC. Knowledge, attitudes and practice of epilepsy: Experience at a comprehensive rural health services project. *Seizure* 1998;7:133-8.
76. Seshadri V, Thomas J, Murthy JMK, Verma MA, Raju CR. Knowledge, attitude, and practice of epilepsy in rural Andhra Pradesh, South India. In: *Proceedings of the 4th Joint Annual Conference of the Indian Epilepsy Association & Indian Epilepsy Society, Vishakapatnam, Andhra Pradesh, 2003. Abstract Book* 2003. p. 4.
77. Goel S, Singh N, Lal V, Singh A. Knowledge, attitude and practices of students about first aid epilepsy seizures management in a Northern Indian City. *Ann Indian Acad Neurol* 2013;16:538-43.
78. Iyer RS, Rekha M, Kumar TS, Sarma PS, Radhakrishnan K. Primary care doctors' management behavior with respect to epilepsy in Kerala, southern India. *Epilepsy Behav* 2011;21:137-42.
79. Bhalerao MS, Bolshete PM, Swar BD, Bangera TA, Kolhe VR, Tambe MJ, *et al.* Use of and satisfaction with complementary and alternative medicine in four chronic diseases: A cross-sectional study from India. *Natl Med J India* 2013;26:75-8.
80. Goel S, Singh N, Lal V, Singh A. Evaluating the impact of comprehensive epilepsy education programme for school teachers in Chandigarh city, India. *Seizure* 2014;23:41-6.
81. Arya V, Gehlawat VK, Kaushik JS, Gathwala G. Assessment of parent reported quality of life in children with epilepsy from Northern India: A cross-sectional study. *J Pediatr Neurosci* 2014;9:17-20.
82. Ashwin M, Rakesh P, Pricilla RA, Manjunath K, Jacob K, Prasad J. Determinants of quality of life among people with epilepsy attending a secondary care rural hospital in south India. *J Neurosci Rural Pract* 2013;4:S62-6.
83. S RP, Ramesh R, Rachel P, Chanda R, Satish N, Mohan VR, *et al.* Quality of life among people with epilepsy: A cross-sectional study from rural southern India. *Natl Med J India* 2012;25:261-4.
84. Shetty PH, Naik RK, Saroja A, Punith K. Quality of life in patients with epilepsy in India. *J Neurosci Rural Pract* 2011;2:33-8.
85. Aggarwal A, Datta V, Thakur LC. Quality of life in children with epilepsy. *Indian Pediatr* 2011;48:893-6.
86. Nadkarni J, Jain A, Dwivedi R. Quality of life in children with epilepsy. *Ann Indian Acad Neurol* 2011;14:279-82.
87. Sachin S, Padma MV, Bhatia R, Prasad K, Gureshkumar C, Tripathi M. Psychosocial impact of epilepsy in women of childbearing age in India. *Epileptic Disord* 2008;10:282-9.
88. Malhi P, Singhi P. Correlates of quality of life with epilepsy. *Indian J Pediatr* 2005;72:131-5.
89. Nehra A, Singla S, Bajpai S, Malviya S, Padma V, Tripathi M. Inverse relationship between stigma and quality of life in India: Is epilepsy a disabling neurological condition? *Epilepsy Behav* 2014;39:116-25.
90. Kumari P, Ram D, Haque Nizamie S, Goyal N. Stigma and quality of life in individuals with epilepsy: A preliminary report. *Epilepsy Behav* 2009;15:358-61.
91. Thomas SV, Nair A. Confronting the stigma of epilepsy. *Ann Indian Acad Neurol* 2011;14:158-63.
92. Joseph N, Ray A, Reshma BK, Bhat S, Herady M, Kumar A, *et al.* Assessment of quality of life, stigma associated and self-management practices among patients suffering from epileptic seizures: A cross sectional study. *J Neurosci Behav Health* 2011;3:91-8.
93. Disability — definition of disability in English from the Oxford dictionary [Internet]. Available from: <http://www.oxforddictionaries.com/definition/english/disability>. [Last accessed on 2015 Feb 26].
94. The draft Rights of Persons with Disabilities Bill Ministry of Social Justice and Empowerment, Government of India Department of Disability Affairs; 2012. [Internet] Available from: <http://socialjustice.nic.in/pdf/draftpwd12.pdf>. [Last accessed on 2015 Feb 26].
95. Gourie-Devi M, Satishchandra P, Gururaj G. Epilepsy control program in India: A district model. *Epilepsia* 2003;44:58-62.
96. Tripathi M, Jain DC, Devi MG, Jain S, Saxena V, Chandra PS, *et al.* Need for a national epilepsy control program. *Ann Indian Acad Neurol* 2012;15:89-93.
97. Jain S, Chandra PS. Delivery of health care and socioeconomic issues -India. In: Engel J Jr, Pedley TA, editors. *Epilepsy: A Comprehensive Textbook*. 2nd ed. Philadelphia: Lippincott-Raven; 2008;2:2885-9.
98. Reddy GN, Channabasavanna SM, Gourie-Devi M, Das BS, Prabhu GG, Shariff IA, *et al.* Extension of the mental health services by satellite clinics as a model. *NIMHANS J* 1986;4:71-5.
99. Kapur RL, Chandrashekar CR, Shamasundar C, Isaac MK, Parthasarathy R, Shetty S. Extension of mental health service through psychiatric camps: A new approach. *Indian J Psychiatry* 1982;24:237-41.
100. Bigelow J, Singh V, Singh M. Medication adherence in patients with epilepsy after a single neurologist visit in rural India. *Epilepsy Behav* 2013;29:412-5.
101. Mani KS, Rangan G, Srinivas HV, Srinidharan VS, Subbakrishna DK. Epilepsy control with phenobarbital or phenytoin in rural south India: The Yelandur study. *Lancet* 2001;357:1316-20.
102. Averis AK. Epilepsy management: The general practitioner's perspective. *Seizure* 1997;6:81-5.
103. Feksi AT, Kaamugisha J, Gatiti S, Sander JW, Shorvon SD. A comprehensive community epilepsy programme: The Nakuru project. *Epilepsy Res* 1991;8:252-9.
104. Feksi AT, Kaamugisha J, Sander JW, Gatiti S, Shorvon SD. Comprehensive primary health care antiepileptic drug treatment programme in rural and semi-urban Kenya. ICBERG (International Community-based Epilepsy Research Group). *Lancet* 1991;337:406-9.
105. Rathore C, Rao MB, Radhakrishnan K. National epilepsy surgery program: Realistic goals and pragmatic solutions. *Neurol India* 2014;62:124-9.
106. Jeyashree K, Sinha S, Patro BK. Pathway to care of epilepsy patients: Exploratory study from an urban slum in Northern India. *Ann Indian Acad Neurol* 2013;16:357-60.
107. Dash D, Sebastian TM, Aggarwal M, Tripathi M. Impact of health education on drug adherence and self-care in people with epilepsy with low education. *Epilepsy Behav* 2015;44:213-7.
108. National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) | National Health Portal [Internet]. Available from: <http://www.nhp.gov.in/npcdcs>. [Last accessed on 2014 Jul 12].

109. Operational Guidelines for NPHCE : Ministry of Health and Family Welfare [Internet]. Available from: <http://mohfw.nic.in/showfile.php?lid=1403>. [Last accessed on 2014 Jul 12].
110. Amudhan S, Mani K, Rai SK, Pandav CS, Krishnan A. Effectiveness of demand and supply side interventions in promoting institutional deliveries — A quasi-experimental trial from rural north India. *Int J Epidemiol* 2013;42:769-80.
111. Welcome to EpilepsyIndia.org - one-stop destination for general and medical information on Epilepsy [Internet]. Available from:

http://www.epilepsyindia.org/announcements_iea.html. [Last accessed on 2014 Dec 18].

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