



BARRIERS OF EPILEPSY SURGERY: A SURVEY AMONG INDIAN NEUROLOGISTS

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ABSTRACT **PURPOSE:** Epilepsy surgery is safe and effective treatment for medically refractory epilepsy. However, only a minority of such cases are referred for surgical evaluation. We investigated Indian neurologists' views on drug refractory epilepsy, factors determining referral for surgery and their experience of epilepsy surgery.
MATERIALS AND METHODS: We surveyed 100 practicing neurologists gathered to attend a national level neurology conference in India. The survey questionnaire consisted of three parts: (1) Demographic data (2) Their perception of medically refractory epilepsy and important factors deciding referral for pre-surgical evaluation (3) Knowledge and experience of epilepsy surgery.
RESULTS: Among 100 neurologist 78% have treated >20 patients of epilepsy per month. Frequency of seizures (92%), knowledge of epileptogenic foci (91%), type of seizure (82%), desire of the patient to undergo surgery (81%) and duration of epilepsy (80%) were among the most important factors to consider before referral to pre surgical evaluation. Most neurologists consider at least 2 yr duration of epilepsy (83%) and frequency of at least one seizure per month (88%) before referring for surgery. Survey revealed Various factors considered important or very important by Neurologists who have referred patients for epilepsy surgery, included serious complications after surgery (90%), communication from referral centre (84%), seizure free outcome (82%) and follow up of patient after surgery (82%).
CONCLUSION: Uncertainties about definition of refractory epilepsy, incomplete knowledge of postsurgical outcomes and complications, poor communication from epilepsy centres and fear of loss of follow up of patient after surgery contribute to the underutilization of epilepsy surgery.

KEYWORDS : Epilepsy surgery, barriers, survey, India, neurologist

INTRODUCTION

Epilepsy is a common disorder affecting approximately 1% of the population. Around 50 million people have epilepsy worldwide 85% of who live in developing countries¹. In spite of availability of more than 20 antiepileptic drugs 30% of patients with epilepsy do not respond to medical therapy.² Drug refractory epilepsy is a significant challenge for both patients and neurologists. Refractory epilepsy is not only associated with increased probability of premature death³ but cognitive and psychosocial dysfunctions which often persist even after control of seizures.⁴

Epilepsy surgery has been demonstrated to be a safe and effective treatment for refractory epilepsy and, when compared with medical therapy, has been associated with significantly higher rates of seizure freedom.⁵ Early intervention reduces the deleterious effects of seizures on the developing brain among children with intractable epilepsy. Epilepsy surgery is considered the last treatment option for epilepsy by physicians, including many neurologists.

Despite class I evidence of superiority of surgery over pharmacologic treatment⁵ and subsequent guidelines of the American Academy of Neurology⁶ (AAN), there is average delay of 20 years from the onset of epilepsy to epilepsy surgery.⁷ In developing countries like India, where there are very few specialized epilepsy surgery centers, situation may be worse. Such delays may in part be attributed to the difficulties in identifying refractory patients, inaccessibility of epilepsy surgery centers or reluctance of neurologists to consider epilepsy surgery early in the course of the disease. To our knowledge only few studies addressing this issue published in literature till date, and none from developing countries where factors governing referral pattern for epilepsy surgery are likely to be different than developed countries. The aim of this study was to identify the factors contributing to the delay in referring patients for epilepsy surgery.

METHODS

DATA COLLECTION

Data were collected from neurologists gathered to attend a national level neurology conference in India in July 2016. A survey questionnaire⁸ was distributed to neurologists came from different

parts of country and collected back next day in person.

Survey design

The survey questionnaire consisted of three parts: (1) Demographic data (2) Their perception of medically refractory epilepsy and important factors deciding referral for pre-surgical evaluation (3) Knowledge and experience of epilepsy surgery.

Statistical analysis

All data was tabulated in Microsoft Excel® format and was analyzed through the statistical software SPSS version 16. The statistical analysis was based on basic descriptive statistics. In addition, Chi square tests were done to assess whether demographics (years in practice, number of patients with epilepsy treated each month, and distance from the nearest comprehensive epilepsy surgery center) had an effect on respondents' definition of refractory epilepsy, factors influencing surgical referral, knowledge of surgery outcome, and experience following referral. A p value of < 0.05 was considered significant.

RESULTS

In total, 114 responses were received, which included 100 neurologists, 10 physicians, 3 neurosurgeons and 1 pediatrician. We included only neurologists in the study to maintain the homogeneity of respondents.

All neurologists were active practitioners treating epilepsy patients regularly. 78% neurologist involved in survey treated >20 patients per month. 57% were young neurologists with less than 10 years of practice. 50% said that nearest Epilepsy center with facility of pre surgical evaluation (at least VEEG and MRI) is >100 km away from their clinic or hospital (Table 1).

Perception of drug resistant epilepsy was different among neurologists, 56% responder neurologists consider monotherapy failure after failure of three or more drugs trials. 52% of young neurologists (<10 year of practice) consider monotherapy failure after failure of 2 drug trials whereas 75% of older neurologists reported monotherapy failure after 3 or more drug trials, though this difference

was not statistically significant. 88% defined refractory epilepsy as failure of at least two drug combination therapy trials, including 36% who consider failure of polytherapy only after 3 or more polytherapy trials. 9% responders consider VNS (Vagal Nerve Stimulation) before referring patient for presurgical evaluation, 26% not sure about it's exact role (Table 2).

Most neurologists agreed that frequency of seizures (92%), knowledge of epileptogenic foci (91%), type of seizure (82%), desire of the patient to undergo surgery (81%), duration of epilepsy (80%) and age of patient (60%) were among the most important factors to consider before referral to pre surgical evaluation (table 3).

82% would refer drug resistant Temporal lobe if MRI shows hippocampal sclerosis and only 17% if MRI is normal. Whereas 52% would consider referral in ETLE with MRI lesion positive whereas only 14% if MRI is normal. 83% neurologists consider at least 2 yr duration of epilepsy before referring for surgery. Almost 88% neurologists consider seizure frequency one or more per month as minimum before considering surgery.

Survey revealed poor communication with patient, 5% neurologists have never discussed epilepsy surgery as an option, 13% don't discuss outcome of surgery and 15% neurologists do not discuss complications of surgery. 82% who discuss epilepsy surgery outcome, reported variable chances of seizure freedom, 61 +/- 19% (Range 5-85%), median 70% in temporal lobe epilepsy and 50 +/- 18% (Range 10-90%), median 50% in extra temporal lobe epilepsy. 48% neurologists who discussed chances of seizure free outcome after VNS, communicated 10% or less chances of seizure freedom. 69% responders discuss epilepsy surgery complications (permanent neurological deficits), out of which 54% reports 5-10% complication rate whereas 25% reported complication rate >10%. Overall median complication rate reported is 10% (Range 0-50). Although 85% responders agree that epilepsy surgery is under recommended, 25% have never referred a patient for epilepsy surgery.

Variable experience reported by neurologists who have referred patients for epilepsy surgery. 55% have not seen seizure free outcome, 25% have seen serious neurological complication, 47% reports poor communication from epilepsy center and 58% reported loss of follow up of the patient referred for surgery.

Various factors considered important or very important by Neurologists who have referred patients for epilepsy surgery, included serious complications after surgery (90%), seizure free outcome (82%), communication from referral center (84%), and follow up of patient after surgery (82%).

DISCUSSION

In this survey, important factors identified for delay in referrals for epilepsy surgery were lack of clarity about when to consider epilepsy as drug refractory epilepsy, reservation for patients with very high frequency of seizures, reluctance to consider epilepsy surgery early, relatively higher post-surgery complications, poor feedback communication from epilepsy centres and fear of loss of follow up of the patient referred for surgery.

Kwan and Brodie illustrated that once the first appropriate AED trial fails, the chance of seizure freedom is 14% with a second drug trial, and only 3% with a third or multiple drugs.⁹ However, in this survey, 56% respondents consider failure of 3 or more antiepileptic drug trials to be considered medically refractory. Furthermore, 88% defined refractory epilepsy as failure of at least two drug combination therapy trials, 36% requiring failure of 3 or more polytherapy trials before referral for epilepsy surgery. Many neurologists (9%) consider VNS (Vagal Nerve Stimulation) failure essential before considering epilepsy surgery, and 26% not clear about its status.

Seizure frequency was overwhelmingly important in the decision to refer a patient for epilepsy surgery (92% of respondents). 80% of respondent stated that patients should have at least one seizure every month for consideration of epilepsy surgery. However, it is known that even one seizure per year can negatively impact a patient's quality of life by restricting him or her from driving [10]. 83% neurologists consider at least 2 yr duration of epilepsy as minimum before referring for surgery, including 7% who would wait 10 years. One study showed that 14% of patients who had successfully undergone epilepsy surgery

were specifically advised by their neurologists not to consider surgery as a treatment option [11].

Epilepsy surgery complication rate reported in literature is <1% for death and 3% for permanent neurological deficit.^{3,4} However, in this survey neurologists reported higher complication rates for their patients, 57% stated the complication rate was above 5-10%, with 25% reporting >10%, median complication rate reported in this survey was 10%. In addition, 25% of respondents reported that they had had a serious complication with a patient who had undergone epilepsy surgery. These higher rates may be due to a true higher-than-expected complication rate, small sample size, or memory bias.

Survey revealed poor communication between epilepsy centers and referring neurologists and loss of follow up of the patient referred for surgery, which could have negatively impacted the referring physician's views on epilepsy surgery. Epileptologists should update the referring neurologist at every step of the evaluation process. Furthermore, patients should be returned to the care of the referring neurologist after the evaluation or the surgery has been completed.

Many researchers have emphasized the delay in referring patients for epilepsy surgery with similar findings [7,11,12]. The American Academy of Neurology Practice Parameter (2003) regarding epilepsy surgery indicates "it must be offered before absolute pharmacoresistance is proven in most patients." However, it does not make explicit recommendations on when to abandon further trials of pharmacotherapy and consider surgical intervention.⁶

Most neurologists attending conferences were practising in metropolitan cities like venue of conference. Therefore, the potential referral patterns in this study may not represent those in other regions.

This study focused on the views and decision-making processes of neurologists considering referral of patients to epilepsy centers. Delay in referrals may in part be explained by factors mentioned above.

However, the patients' lack of awareness about disease, unavailability of specialised centres, extended wait times for specialty clinic evaluations and inpatient monitoring beds and associated cost effectiveness were not taken into account. A national survey similar to this one would shed further light on the reasons underlying the delay between seizure onset and epilepsy surgery referral and lead to efforts to better educate referring physicians.

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Table 1. Demographic parameters of neurologists participated in survey.

1. Years in practice	<5	38%
	5-10	19%
	>10	43%
2. Epilepsy patient treated per month	<10	4%
	10-19	18%
	>20	78%
3. Distance from the nearest comprehensive epilepsy program	<50KM	48%
	50-100KM	2%
	100KM	50%

Table 2. Neurologist's opinion about when to consider epilepsy as medically refractory?

a) Monotherapy failure	1 AED*	4%
	2 AED	40%
	3 AED	40%
	4 AED	10%
	All the approved AEDs	6%
b) Polytherapy failure	No combination failure needed	3%
	1 combination	9%
	2 combination	52%
	≥3 combination	36%
c) Vagus nerve stimulation	Don't need to fail VNS treatment	65%
	Do need to fail VNS treatment	9%
	Not known	26%

*AED- anti epileptic drug

a. Duration of epilepsy	Yes	80 %
	No	20%
Y Minimum duration of epilepsy	<6mon	5 %
	<2yrs	12 %
	>2yrs	76 %
	>10yrs	7 %
b. Type of seizure	Yes	82%
	No	18%
Y Types	GTCS	32 %
	SPS sole seizure type	16%
	CPS	69 %
	SPS with other seizure types	25 %
c. Seizure frequency	Yes	92 %
	No	8 %
Y Seizure frequency (minimum)	Yearly	1
	Every 6monthly	4
	Every 3 month	7
	Monthly	46
	Weekly	28
	Daily	6
d. Presumed location of epileptogenic focus	Yes	91%
	No	9 %
Y Locations	Temporal without MRI lesion	17%
	Temporal with hippocampal sclerosis	82%
	Extratemporal without MRI lesion	14%
	Extratemporal with an MRI lesion	52%
e. Patient's desire to have surgery	Yes	81%
	No	19%
f. Age of the patient	Yes	60%
	No	40%
Y Age	<10yrs	20%
	10-29yrs	43%
	30-39yrs	37 %
	40-59yrs	17%
	>60yrs	4 %

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