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Brief Communication

Does surgery help in reducing stigma associated with drug refractory epilepsy in children?

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ABSTRACT

Introduction: Epilepsy has several comorbidities and associated stigma. Stigma associated with epilepsy is well known and prevalent worldwide. Surgical treatment is an established treatment for drug refractory epilepsy. Following surgery in children, it is possible that the stigma may reduce, but such an effect has not been studied earlier.

Materials and methods: Analysis of prospectively collected data was performed for pediatric patients at a single tertiary center for treating epilepsy. Child stigma scale, as described by Austin et al., was used to evaluate stigma both pre- and postoperatively. Analysis was done using Paired *t* test.

Results: In this study, following surgery, there was significant reduction of stigma ($P < 0.001$). This was proportional to the reduction in seizures, though there were 9 (30%) patients, who due to persistent neurodisability did not have any reduction of stigma despite having good seizure outcome.

Conclusion: Surgery in drug-resistant epilepsy helps in reducing stigma. Seizure reduction is probably not the only factor responsible for a change in stigma outcome.

1. Introduction

Stigma is a well-associated factor in epilepsy which increases disability and impairs quality of life [1–3]. Surgery has been proven to be effective for achieving seizure freedom in drug-refractory pediatric epilepsy [4]. Though, there are studies which have shown lesser stigma scores in adult patients undergoing surgical treatment compared with medical treatment [5–7], there are no studies for pediatric age group.

Stigma associated with epilepsy depends upon many factors including reduction in seizures, sociodemographic and psychosocial outcomes, and is inversely proportional to the quality of life [8–10]. Surgery for drug-resistant epilepsy (DRE) definitively improves the seizure outcomes, decreases mortality and unemployment rates [11]. However, there are limited studies available in demonstrating stigma score alteration following epilepsy surgery. Fletcher et al. [5] observed stigma and quality of life in 19 adult patients that have drug-resistant temporal lobe epilepsy, and found that stigma was less in surgical arm compared with medical arm ($P = 0.04$), which was directly proportional to the difference in seizures ($P = 0.032$). However, they did not have any pediatric patients and had not compared stigma scores pre- and postoperatively.

The main objective of the current paper was to study the stigma scores in pediatric patients undergoing epilepsy surgery and to note if the stigma scores correlated with seizure outcome.

2. Material & methods

The study was done at a tertiary health center, with significant experience in surgery for DRE. Ethical approval was taken from the institutional review board, and informed consent was taken from each caregiver and patient. Analysis of prospectively collected data, and interviews were done to document preoperative and postoperative stigma scores in children based on the scale described by Austin et al. [12], given in supplementary file. This scale comprises of a parent- and a child-related questionnaire with five and eight questions, respectively, to be rated on a Likert scale (1–5). To derive the results, they have to be summed and divided by their number of variables, separately

Abbreviations: DRE, Drug-resistant epilepsy; ILAE, International League Against Epilepsy; IQ, Intelligence quotient; QOL, Quality of life; SD, Standard deviation; WHO, World Health Organisation.

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Table 1
Demographic data for the patients.

S.No.	Age (yrs)	Gender	Age at onset (mths)	Area (R-Rural, SU- Semiurban, U-Urban)	Etiology	Seizure type	Frequency	Duration of epilepsy (yrs)	Preop neurologic impairment (IQ-Intellingence quotient), MR-Mental retardation	Procedure done	Preop stigma score (parent questionnaire)
1.	9	M	6	SU	Lt temporal DNET	FS	3/wk	8.5	Severe MR	Lt CAH	3.8
2.	15.5	M	0.1	U	Rt frontal and occipital gliosis–post perinatal insult	FS	5/day	15.5	Moderate MR	Multilobar resection	2.8
3.	1	F	1	R	Rt HM	FS	3/day	1	Hemiparesis	Endoscopic hemispherotomy	2.75
4.	5	M	18	U	Rt MTS	FS	2/wk	3.5		Rt CAH	4.6
5.	8	M	60	U	LGS with Rt MTS	DA, FS	2/day	3	Moderate MR	TPO disconnection	4.6
6.	10	M	84	U	FCD left frontal type II B	FS	4/day	3		Cortical resection	2.8
7.	11	F	96	R	Rt MTS	FS	1/wk	3		Rt CAH	4.2
8.	21	M	156	R	FCD Lt temporal lobe	FS	1/mth	8	Aphasia	Lt CAH	2.4
9.	10.5	F	42	U	Ischemic encephalomalacia Rt cerebral hemisphere	FS	2/day	7	Hemiparesis, Mild MR	Rt EH	3.4
10.	1	M	0.1	U	Rt HM	FS	6/day	1	Hemiparesis	Rt EH	2
11.	16	M	84	U	Left PO Gliosis	FS	3/day	9	Low IQ	ECOG guided resection	3
12.	5.5	M	3	R	Tuberous sclerosis- Rt frontal and temporal	FS	5/day	5.2	Profound MR	Rt frontal and temporal ECOG guided resection	3
13.	6	M	6	SU	Lt HM	FS + IA	5/day	5.5	Hemiparesis, severe MR	Lt OH	2
14.	0.5	M	4	SU	Rt HM	FS	7/day	0.2	Hemiparesis, profound MR	Rt OH	2
15.	5	F	54	R	Lt RE	FS, EPC	6/day	0.5	Hemiparesis	Lt OH	2.8
16.	9	M	36	U	LGS	DA, GTCS	50/day	6	Severe MR	CC	1.8
17.	4.5	M	42	SU	Rt Rasmussen's encephalitis	EPC	12/day	1	Hemiparesis	Rt OH	3.8
18.	8.75	M	60	SU	Lt temporal DNET	Focal to bilateral tonic clonic	5/wk	3.75		Lt CAH	5
19.	17	F	108	U	Lt MTS	FS + IA	2/day	8	Mild MR	Lt CAH	3.4
20.	13	F	72	U	Post-central gyral cortical dysplasia- Rt sided	FS	2/day	7	Mild MR	ECOG guided resection	4.6
21.	12	F	42	U	Left temporal, parietal and occipital encephalomalacia	FS	7/day	8.5	Mild MR	Multilobar ECOG guided resection-temporal, parietal, occipital	2.2
22.	8	F	4	U	Lt HM	FS	7/day	7.67	Hemiparesis, moderate MR	Lt OH	3
23.	4	F	3	R	Hypothalamic hamartoma	GS, Focal to bilateral tonic clonic	15/day	3.67	Severe MR	Transcallosal interforniceal disconnection	1.8
24.	13	M	0.1	U	Periventricular leucomalacia-bilateral	DA	70/day	12.9	Profound MR	CC	3.2
25.	12	M	6	U	Rt Mesial temporal FCD-type Ia	FS	3/mth	11.5	Moderate MR	Rt CAH	1.8
26.	9	M	18	U	Rt Mesio temporo-occipital FCD type Ia	FS	1/day	7.5	Mild MR	Rt CAH with posterolateral occipital lobectomy	1.8
27.	5	M	7	R	Bilateral frontal and left parietal cavernous hemangioma	FS	5/day	4.5		Excision	4.2
28.	2.5	F	0.1	U	West syndrome	DA	15/day	2.4	Profound MR	CC	3.25
29.	12	M	1	SU	Rt cerberal hemiatrophy with frontal encephalomalacia due to perinatal insult	FS	10/day	11.9	Moderate MR	Rt EH	5
30.	12	F	96	SU	Lt MTS	Focal to bilateral tonic clonic	3/wk	4		Lt CAH	2

CAH: Corticoamygdalohippocampectomy; CC: Corpus Callosotomy; DA: Drop attacks; DNET: Dysembryoplastic neuroepithelial tumor; EH: Endoscopic Hemispherotomy; EPC: Epilepsia partialis continua; FCD: Focal cortical dysplasia; FS: Focal seizures; GS: Gelastic seizures; GTCS: Generalized tonic clonic seizures; HM: Hemimegalencephaly; IA: Impaired awareness; LGS: Lennox–Gastaut syndrome; LT; Left; MR: Mental retardation; MTS: Mesial temporal sclerosis; OH: Open Hemispherotomy; RE: Rasmussen's encephalitis; Rt: Right; TPO: Temporoparieto-occipital disconnection.